

UK COVID-19 INQUIRY

WITNESS STATEMENT OF LUCY MOORE

ON BEHALF OF LONG COVID SOS

1. Introduction

- 1.1. My name is Lucy Moore. I am the CEO of Long Covid SOS. Long Covid SOS is a registered charity (Charity Registration Charity No: 1199120 Registered address: 11A Westland Road Farringdon Oxfordshire SN7 7EX). I make this statement for the purposes of Module 9 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.
- 1.2. I became CEO in March 2025, taking over from our founder Ondine Sherwood who sadly passed away in March 2025. I have consulted with documents, evidence and statements and notes previously written by Ondine Sherwood, our volunteers and Board for this statement, as my own knowledge is limited to the start of my role from 2025. I have set out below our advocacy and wish to acknowledge the enormous contribution Ondine made to public health and awareness of Long COVID. Much of the work and issues referenced below arise from Ondine's advocacy. Further in accordance with the guidance provided by the Inquiry this statement amalgamates some of the relevant evidence to this Module from the previous statements provided by Long Covid SOS (Long Covid SOS has provided statements in Module 2, Module 3 and Module 7 of the Inquiry [INQ000280196, INQ000370954, INQ000587782]).
- 1.3. I make this statement in response to the Inquiry's request for evidence under Rule 9 of the Inquiry Rules 2006 dated 9 April 2025.

1.4. This statement is structured as follows:

Part A: Introduction to Long Covid SOS

1. **Overview**
2. **Who we are and what we do**

Part B: Long Covid SOS during the Relevant period (1 January 2020 – 28 June 2022)

3. **Long Covid SOS's engagement with and representations made to Government in relation to the UK economy**

Part C: Economic Impact

4. **The economic impact of Long Covid**
5. **The financial and economic impact of Long Covid on individuals**

Part D: Analysis and Reflections

6. **Analysis**
7. **Recommendations**

Part A: Introduction to Long Covid SOS

2. Overview

Case study S, 55

“Being pushed into ill-health retirement has ended many opportunities for career progression, that could have provided additional income or professional fulfilment and purpose...My employer did not provide sufficient support or specific guidelines for managing Long Covid. The 8-week phased return was too short, lacked flexibility, and contributed to my forced ill-health retirement. I was told that the policy on returning to work could not be changed just for me..”

2.1. Long COVID is a significant and growing public health problem with associated substantial financial and economic implications for individuals and the economy.

- 2.2. For those affected, Long COVID can lead to multiple detrimental financial impacts including diminished work capacity, lower or lost wages, reduction to pension pots, benefit claims and increased medical expenses. It is our experience that this financial strain can push people into debt, force reliance on family members or partners and exacerbate existing financial vulnerabilities. I have exhibited in this statement three illustrative case studies [LCSOS/01 - INQ000651217] from our organisation which set out the particular issues experienced.
- 2.3. On a macroeconomic level, there is extensive evidence of the impact of Long COVID on workforce participation and labour market [LCSOS/02 - INQ000272241, LCSOS/03 - INQ000292660]. Further, there are associated consequences for public spending on the healthcare system arising from this public health crisis. The Institute of Fiscal Studies, Long Covid and the labour market report, July 2022 states that based on the ONS 2022 estimate, 1.85 million people aged 17 and above have Long COVID which implies *“about 4.4 million lost working hours per week, and 110,000 workers off sick; the loss in earnings would aggregate up to almost £1.5 billion per year”* [LCSOS/04 - INQ000651220].¹ We note that to date the Government has not acknowledged the economic impact of Long COVID. To fully understand the economic impact, it would be prudent of the government to openly acknowledge Long COVID as a cause of working age people being unable to work, working reduced hours or being economically inactive.
- 2.4. I understand that the Inquiry is only considering the Relevant Period (January 2020 – June 2022) and is focussing solely on the financial support rather than non-financial occupational support in this module. The statement therefore does not address non-financial occupational support however, I would note that for people living with Long COVID it is difficult to draw a line between financial interventions and non-financial occupational interventions as they are necessarily bound up together in people’s lives, e.g. an absence of reasonable adjustments at work may lead to a need for other financial support such as reliance on benefits, as well as

¹ Estimates were made relying on May 2022 ONS statistics.

potentially worsening of symptoms and inability to work at all. This therefore reduces the person's ability to contribute economically.

3. Long Covid SOS: Who we are and what we do

- 3.1. 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 26,500 followers on X; 20,000 Instagram followers, and 6468 individuals have signed up to the website. Long Covid SOS became a registered charity in May 2022.
- 3.2. The 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 acknowledgment 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.
- 3.3. 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 symptoms, harm, and disability that people infected with Covid-19, continued to suffer from, and shared this information with decision-makers.
- 3.4. Long Covid SOS did the above on behalf of people living with Long COVID in the UK by:
 - Writing to the Prime Minister and relevant Government Ministers.

- Meeting with Government Ministers. For example, Long Covid SOS and Long Covid Support participated in the Long Covid Ministerial Roundtables chaired by Lord Bethell on 13 October 2020 and 16 November 2020.
- Participating in relevant Task Forces and expert panels relevant to Long Covid.
- Participating in the Long Covid Ministerial Roundtables and in NHS Long Covid Taskforce Meetings.
- Submitting evidence to a Health and Social Care Select Committee Inquiry.
- Collaborating with other relevant partners.
- Contributing to UK and international research.
- Conducting surveys into patient experience
- Contributing to publications.
- Undertaking wider advocacy.

3.5. Through our advocacy and work, as well as the personal experiences of our volunteers and supporters, we have identified a number of issues in relation to the economic impact of Long COVID, and the impact of the economic response on those with Long COVID. I should be clear that Long Covid SOS is not a membership organisation as such and therefore we do not provide direct peer support in the way that other Long Covid groups do.

What is Long Covid

3.6. We have had the opportunity to read the witness statement on behalf of Long Covid Support provided in this Module, in which Long COVID, its definition, symptoms, and prevalence have been explained. We agree with that explanation and did not repeat it here.

Part B: Long Covid SOS during the Relevant period (1 January 2020 – 28 June 2022)

4. Long Covid SOS's engagement with and representations made to Government in relation to the UK economy between 1 January 2020 and 28 June 2022

- 4.1. We have been asked to provide an overview of our work during the relevant period relating to the economic challenges faced by those affected by Long COVID; what our relationship was with the UK and Devolved Nations Government and whether we undertook any specific research on economic matters. Although Long Covid SOS did not commission any research, it did undertake an analysis and forecasting on economic matters. We advocated for, and raised the reality of, people's experiences with Long COVID, including the financial and economic consequences they faced, to the UK Government and others. I set this out below and exhibit a chronology of our advocacy [LCSOS/05 - INQ000651221].
- 4.2. Many of our volunteers contracted Covid-19 early in the pandemic. They report that they 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. 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 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. As we have stated above, a significant amount of our work was aimed at achieving the recognition of Long COVID, and an understanding of its symptoms and seriousness. We sought to raise awareness among the general public of the condition in the absence of any public health messaging on Long COVID.

- 4.3. There was an extensive delay in the formal recognition of Long COVID despite the risk of post-acute sequelae being well known from previous coronaviruses and from other viruses generally. In our view this is significant as it meant that there was a delayed policy response in relation to healthcare (which is addressed in Module 3), non-pharmaceutical interventions (“NPIs”) (considered in Module 2) and economic interventions and policies (addressed below).
- 4.4. On 3 July 2020, Long Covid SOS sent a letter to the then Prime Minister Boris Johnson, copied to all sitting members of Parliament, 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. [LCSOS/06 - INQ000238582]. The letter was signed by over 1000 people suffering Long COVID.
- 4.5. 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 stated:

“We are writing on behalf of thousands of forgotten victims of Covid-19 who have been sick since the early days of the outbreak... Throughout this period the general public has been assured by the Government and public health sources that most ‘mild’ or ‘moderate’ cases not requiring hospital admission, resolve within two weeks. However, it is becoming increasingly clear that for many this is far from the case...

There appears to be very little focus on the part of the Government on the ongoing very poor health of potentially hundreds of thousands of people. It is imperative that the needs of this group are addressed and sufferers are given the support they need. Not only is this a calamity for each individual it is a serious matter for an economy which is already facing an existential struggle: large numbers on long term sick leave will significantly impact the workforce as it emerges from furlough.” (Emphasis added).

4.6. We asked for:

- (1) the establishment of a working group to investigate “*long-term Covid-19*”
- (2) the commissioning of urgent research into Long Covid;
- (3) the development of protocols and care pathways;
- (4) the creation of multi-disciplinary clinics across the UK for testing, diagnosis and care of patients and
- (5) “*consideration of the economic implications, including making provision for long term sick leave, financial support and taking steps to ensure employers were made fully aware of this situation.*” (Emphasis added).

4.7. It is therefore evident that as early as 3 July 2020 in our first communication to decision makers we had highlighted the economic consequences to individuals and more broadly of Long COVID.

4.8. We were aware through our engagement with Long COVID patients that many were concerned about sick leave being limited e.g. being inadequate to provide support for people with chronic illnesses. We identified financial support was needed because people were struggling financially; people reported to us that they were unable to work, or working reduced hours or had lost employment opportunities. Lack of awareness about Long COVID by employers was experienced by our volunteers and the wider Long COVID community. It was our experience that there was a dearth of information or guidance. People were forced to try to explain, justify and advocate for themselves to employers.

4.9. I would note that, as we raised in our letter, our concerns were based on what we saw through our engagement with people with Long COVID, that is that they were struggling financially, were often unable to work and that we wanted specific support for sick leave and guidance to employers.

- 4.10. I should explain why bespoke guidance on Long COVID in the workplace was necessary. First, there was little recognition or understanding about Long COVID, and certainly no adequate government messaging about Long COVID during the relevant period. Unless you developed Long COVID, no-one knew what it was. This meant that there was no consistency in decision making or support; it was entirely subjective as to whether an employer was sympathetic and accepted Long COVID's persistent symptoms or did not. Second, the nature of Long COVID, as set out in our film (see below), showed that it was variable and can be episodic in nature. Therefore, the disabling symptoms can be up and down, as well as being aggravated by activities and further infections. Many employers did not understand this nor how to support employees suffering episodic symptoms to remain in work. Third, Long COVID has a specific virus causing a new disease so is distinct from other ME type conditions. Fourth, recovery from Long COVID is non-linear and it is not prescriptive. Fifth, the individual impact is varied as there are over 200 different symptoms that make up Long COVID. Sixth, Long COVID also includes those with organ damage from the covid virus, i.e., heart, lungs, brain. Seventh, there is evidence that there is an increased risk of blood clots for a year after covid infection and as per NICE and WHO new symptoms can develop months after infection and Long COVID itself can develop a few months after people have recovered from an acute Covid-19 infection. As such Long COVID is different from other long-term conditions and should have had bespoke guidance and consideration.
- 4.11. On 8 July 2020, Long Covid SOS published a film we created called "Message in a Bottle" [LCSOS/07 - INQ000272234 video; and LCSOS/08 - INQ000272235-screenshots] highlighting the stories of more than 100 people, most of whom had been unwell for around 3 months. 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.
- 4.12. These stories were captured on placards held up by individuals with Long COVID and illustrated by a voiceover stating: *"thousands and thousands of us have been struggling....we are feeling pressure to return to work, care for family... to return to normal... when we feel anything but...so we are sending out SOS...lots of us are*

feeling abandoned, conflicted, ignored... our numbers are growing and we need to be taken seriously..."

- 4.13. Examples of the persistent symptoms impacting on people included in the film:
- *"Was fit and healthy, now fatigue, no taste and smell, shortness of breath, sore throat".*
 - *"Day 131 and counting, alive but not 'living'".*
 - *"Day 146 and counting, debilitating fatigue, shortness of breath, bitter taste, chills, ear pain".*
 - *"104 days, can't think, can't breathe, can't walk".*
- 4.14. It is evident from this first-hand testimony that people suffering from Long COVID were feeling pressured to return to work in summer 2020 and that the impact on their capacity to work and/or return to work had financial implications which were a significant concern for many people. Despite this there was no government recognition of Long COVID other than a comment by Rt Hon Matt Hancock on 16 July 2020 that post viral fatigue was *"a significant problem for a minority of people who have had coronavirus"* [LCSOS/09 - INQ000086680]. There was no formal recognition at any press conferences, public health messaging, nor any guidance in economic or other policies. As far as we are aware, no adequate consideration was given to the self-evident problem of many working age people being sick for a long time.
- 4.15. On 21 July 2020, we received a response from Public Health England to our 3 July 2020 letter LCSOS/10 - [INQ000272236]. It stated that PHE did not commission research, develop care pathways or *"have jurisdiction over any economic interventions during Covid-19."* Professor Sir Stephen Powis NHSE replied on 3 August 2020 and invited us to a meeting which eventually led to the development of the NHS 5-point plan on Long COVID however, I do not detail this here as it has been covered in Module 3.

- 4.16. The letter was not answered by the UK Government ministers we wrote to. I am not aware of any specific financial or economic interventions by the UK Government to support people with Long COVID.
- 4.17. On 16 July 2020, we received a reply from Professor Chris Jones on behalf of the Welsh Government [LCSOS/10 - INQ000272236]. This referred to the debilitating symptoms of the virus and the impact this has on patients' quality of life. The response referred to research for potential treatments, the PHOSP (Post Hospitalisation COVID-19) study and stated that *"prevention of the virus is also a key concern."* On research the response referred to the National Institute for Health Research inviting applications to better understand and manage the *"health and social care consequences of the global Covid-19 pandemic beyond the acute phase."*
- 4.18. The response did not address economic implications specifically. I am not aware of any bespoke economic or financial interventions by the Welsh Government to support people with Long COVID.
- 4.19. On 4 August 2020, we received a reply from the Scottish Government, Strategic Planning and Clinical Priorities [LCSOS/10 - INQ000272236]. This did not address economic support but referred to the Scottish Government proposing to publish "The Recovery and Rehabilitation Framework" stating that this would provide *"clear principles, priorities and objectives to support planning to meet increasing demand."* It stated that it would *"prioritise understanding of how people have been affected by the virus while identifying and supporting interventions that aid recovery."*
- 4.20. I am not aware of whether the Scottish Government considered any economic interventions to support people with Long COVID, the response appeared to be directed towards clinical measures.
- 4.21. Our concerns were that the public health burden of Long COVID in terms of morbidity from disease and the associated economic and financial implications on

a macro and individual level were not being accounted for by the UK Government and other decision makers. The following note from Ondine Sherwood, drafted in preparation for the Ministerial Roundtable on Long COVID on 7 December 2021 [LCSOS/11 - INQ000067606] in which she spoke to Lord Bethell (then Parliamentary Under-Secretary of State for the Department of Health and Social Care), reflects these concerns:

"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?" [LCSOS/12 - INQ000238600]

4.22. The first Long COVID Ministerial Roundtable chaired by Lord Bethell was held on 13 October 2020. Ondine Sherwood was asked to present on behalf of Long Covid SOS. In her speech, she 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 her speech [LCSOS/12 - 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."

4.23. Long Covid SOS attended the subsequent DHSC Long COVID Roundtable meetings; we exhibit minutes of these meetings, dated between October 2020 to 3 November 2022. [LCSOS/12 - INQ000238600] The minutes record that concerns around the financial impact of loss of employment, benefits, sick pay, including sick pay and support for NHS staff living with Long COVID arose and were discussed at the Ministerial Roundtables on Long COVID.

4.24. 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, stating that it would be useful for the DWP as the condition seemed to prevent so many from being able to work. [LCSOS/13 - INQ000272223]. Ondine's email dated 16 October 2020 stated:

"You may remember me sending out a plea for the number of people with Long Covid to be counted so that we have a more accurate figure than "tens if not hundreds of thousands" (Quote from Simon Stevens BBC News)... Clearly it is in constant flux as people recover and more unfortunately get sick and

become new long haulers but I think it would benefit everybody, especially the NHS if we could have some proper data. It would also be useful for the DWP as the condition seems to prevent so many from being able to work.”

- 4.25. The ONS responded to Ondine [LCSOS/13 - INQ000272223] stating that it was working on a method to monitor national prevalence for Long COVID, which led to the preliminary data set in December 2020 [LCSOS/14 - INQ000272225] and subsequently regular publication from April 2021 [LCSOS2/15 - INQ000320261]. In the April 2021 release, it was estimated that 1.1 million people were experiencing Long COVID in the UK; as of April 2024, that number had risen to over 2 million in England and Scotland alone.
- 4.26. We are not aware of whether or how the DWP considered or utilised ONS data on Long COVID. As Ondine identified so clearly in that email, it was Long Covid SOS' concern that increased demand for long-term sick leave and the associated requirement for benefit support was a significant issue.
- 4.27.
- 4.28. Long Covid SOS had meetings with the ONS on 29 October 2020, 12 February 2021 and 17 September 2021; we do not have records of those meetings. My understanding from Ondine's previous statement in this Inquiry is that: *“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.”*
- 4.29. Ben Humberstone left the ONS in April 2021 and we continued the relationship with Dan Ayoubkhani. Dan Ayoubkhani introduced us to Logan Graham, who at the time was a Special Advisor at No. 10. He also helped put us in touch with Mina Mahmoudzadeh at the DHSC who was working on a paper for SAGE on Quality-Adjusted life Years (“QALY”) loss due to long Covid.

- 4.30. It remains the case today that having data on Long COVID is essential to good economic planning and interventions. It is highly regrettable that the ONS / UKHSA has now stopped monitoring Long COVID (the last statistics being published in April 2024). Currently in 2025 we are in the same position in terms of flying blind to the disease burden of Long COVID as the Government was in 2020, when we strongly advocated for the need to count Long COVID to inform decision making, including economic decision making. We have endorsed the resumption of national surveillance in our proposed recommendations with Long Covid Support.
- 4.31. On 12 January 2021, Long Covid SOS wrote to the then Prime Minister Boris Johnson following his announcement on 4 January 2021 regarding the vaccination programme and the lifting of restrictions. Rt Hon Matt Hancock, Rt Hon Jeremy Hunt, Professor Chris Whitty, and Lord Bethell of Romford were copied in [LCSOS/16 - INQ000238583]. In this letter, we set out economic concerns stemming from Long COVID:

“Unfortunately, we still don’t know exactly who is at risk from Long Covid and so cannot vaccinate this group prospectively. This cohort will be working age people who are contributors to the economy and who will develop a debilitating condition for which there is currently no effective treatment. Their transformation from taxpayers to consumers of NHS resources will be keenly felt. There are already very concerning numbers of previously healthy people with Long Covid who require sick pay and disability benefits. More are joining them in this wave of the pandemic and a further catastrophic increase must be avoided at all costs...It would be very short sighted indeed to ignore the potential for a huge increase in people with long term ill health on top of those already suffering.”

- 4.32. We did not receive a response or acknowledgement to this letter.
- 4.33. On 25 February 2021, Long Covid SOS sent a letter to the Secretary of State for Health and Social Care Matt Hancock regarding the lack of research and funding

for clinical trials, stating *“we find it troubling that there is no funded research currently being carried out within the NHSE assessment clinics themselves, given that this is where so many patients are being seen.”* [LCSOS/17 - [INQ000238601](#)]

- 4.34. We received a response to the above letter on 29 March 2021, affirming our position on the need for research into treatment options and explaining that the NIHR had announced a new funding call, with a focus on helping and supporting non-hospitalised individuals with Long COVID. [LCSOS/18 - [INQ000238602](#)].
- 4.35. 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 [LCSOS/19 - [INQ000238584](#)]. The letter was prompted by the Prime Minister’s 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-CoV-2 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. As well as putting considerable pressure on the NHS, their reduced capacity to work will further contribute to the impact Long Covid is already having on society and the economy through reduced output and tax revenues and increased sick pay and benefits claims.”

“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."

- 4.36. We did not receive a response or acknowledgement to this letter.
- 4.37. Long Covid SOS met with Logan Graham an advisor to the then Prime Minister, Boris Johnson, to discuss the economic impact of Long COVID and future plans to model the effects, and on 8 August 2021, we met with Mina Mahmoudzadheh, a DHSC researcher to discuss the economic cost of Long COVID and ongoing research by DHSC/SAGE. Unfortunately, no-one who is still within Long Covid SOS has direct knowledge of these meetings nor do we have any documents relating to them.
- 4.38. As stated, Long Covid SOS participated in the Long Covid National Taskforce as Patient and public voice partners ("PPVs"). The meetings on 4 August 2021 and 1 September 2021 flagged the economic impact of Long COVID and the indirect costs of Covid as important themes on emerging gaps in research, to be escalated to the Long Covid Programme Board [LCSOS/12 - INQ000238600].
- 4.39. At the NHS Long Covid Taskforce Research Subgroup on 2 September 2021, also attended by Long Covid SOS, it was noted that "*Work and employment is one of the biggest ways to minimise inequalities*". This reflected our concerns with the exacerbation of socioeconomic inequalities and disproportionate socioeconomic impact of Long COVID [LCSOS/12 - INQ000238600].
- 4.40. In September 2021, Long Covid SOS made written submissions to the Health and Social Care Select Committee into Clearing the Backlog [LCSOS/20 - INQ000238630] and Ondine gave oral evidence [LCSOS/21 - INQ000238558].

4.41. During this period, we raised various concerns about the economic impacts of Long COVID.

4.42. We were concerned about to what extent the financial investment received to date adequate to manage the backlog. Our concerns were as follows:

- There has been insufficient financial investment to date to cater for the needs of those with Long Covid: we hear of waiting times of six or more months before a patient can gain access to one of the assessment centres.
- The data from ONS on Long Covid prevalence is invaluable and widely cited. However, the epidemic of long-term morbidity following the COVID-19 pandemic must also be quantified in terms of economic, societal, and healthcare costs. As far as we are aware, there have been no studies published which aim to determine the likely cost to the nation of Long Covid.
- Our calculations at the time suggested that the minimum assessment and most basic diagnostics for those 643,000 people who have symptoms which impact their daily lives, could cost at least £520 million, based on the NHSE National Tariff. This is based on the assumption that assessment centres are operating as they should and following the standard set by UCLH. This estimate does not include referral to specialists or any advanced diagnostic tests, physiotherapy and other interventions. The healthcare burden is therefore likely to be significantly greater especially given the multi-system nature of Long Covid.
- The true cost of Long Covid is many times higher. Most people with Long Covid are of working age, and studies suggest that up to 67% are either unable to work or cannot return to previous working hours. This percentage correlates closely with the proportion ONS found reporting that their symptoms impact daily life.

- Loss of income tax revenue and national insurance payments could be around £2.4 billion per year based on average earnings and tax rates
- This cost to the exchequer does not take into account the productivity loss to the economy as a result of this very large group of people being unable to contribute to the workforce as well as other related opportunity costs
- Benefits claims for loss of income, disability benefit and sick pay could add another £1.25 billion in Universal Credit payments.
- Other areas of concern are hidden costs such as those relating to social care: the burden of caring for relatives is likely to be too onerous for those who find their symptoms disabling and alternative sources of care will need to be found.
- The social care needs of older people with Long Covid, or those with existing disabilities or chronic illnesses are bound to increase.
- We are aware that work is ongoing at the DHSC to calculate data for QALY loss and DALYs connected to post COVID illness. We anticipate that these data are likely to demonstrate the considerable burden that Long Covid places on people's lives and their ability to contribute to society.

4.43. In our view people with Long Covid need to be treated early to avoid the development of chronic illness and wider societal and economic damage. Those who have been suffering for months need to be assessed as a matter of urgency. Steps need to be taken to prevent more people developing this condition; there is some evidence that vaccination may reduce prevalence but avoiding infection is the best approach. Research into early prevention and treatment is still in its infancy, and we have much to learn about the long-term repercussions of COVID-19.

4.44. At the Long COVID National Taskforce Meeting on 4 November 2021, which was attended by Long Covid SOS, practical concerns related to Long COVID such as work, education, welfare, benefits, and finance were flagged. [LCSOS/12 - INQ000238600]

4.45. In response to Boris Johnson's announcement in February 2022 that remaining restrictions would be phased out, Long Covid SOS issued a statement to the press on 10 February 2022 [LCSOS/22 - INQ000238611] which urgently communicated that easing restrictions would increase the prevalence of Long COVID in previously economically active people:

"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."

4.46. On 21 February 2022, the Prime Minister announced the removal of all Covid measures. In response to this, on the same day, Long Covid SOS issued a joint statement with Long Covid Kids. As our member, Lyth Hishmeh, stated: *"It is not within the remit of politicians to declare the end of the pandemic and we are glad that Boris Johnson acknowledges that it is not over – it is in fact still raging worldwide. But abandoning all public health measures and putting the responsibility on to individuals will result in a complete loss of freedom for many and will ultimately come at a huge cost to society and the economy."* [LCSOS/23 - INQ000231928]

4.47. Slightly after the relevant period on 21 September 2022, Long Covid SOS wrote to Theresa Coffey, who was the then new Secretary of State for Health and Social Care:

“The Office for National Statistics estimates that two million people in the United Kingdom have long covid, of whom 384 000 are severely affected. One startling statistic is that more than 2% of 35-49 year olds in the UK have had long covid for more than a year: equivalent to around 266 000 people out of a total of nearly 900 000 in their prime working years with long covid.....With so many people of working age affected, this widespread health burden falls on both the NHS and the economy...

The impact on the economy is already being felt. The numbers of workers neither employed nor seeking work due to long term sickness have been rising throughout the pandemic and the Bank of England highlighted the contribution long covid has made towards an estimated 440 000 missing workers. More than 10 000 long term absences among NHS staff are covid related. The Institute for Fiscal Studies recently reported that 110 000 workers are on sick leave due to long covid—but these are the ones lucky enough not to have lost their jobs.

Numerous people with long covid find themselves in a catastrophic situation whereby they are unable to work and support their families, and some are being forced to sell their homes. Social care, healthcare, and education are the sectors most affected: in these cases the probability that covid-19 was contracted at work is high yet the condition has not been classified as an occupational disease and many are left with no compensation as a result.

We urge you to prioritise the needs of this group of people, many of whom are essential workers, carers, parents, and children. Long covid is the “pandemic after the pandemic” and cannot be ignored”

4.48. We did not receive a response. As is set out above, we repeatedly raised with the Government our concerns about the economic impact of Long COVID on the wider economy and the financial hardships faced by people with Long COVID.

Part C: Economic Impact

5. The Economic Impact of Long Covid

- 5.1. We have been asked whether Long Covid SOS commissioned any statistical analysis on the economic impact of the pandemic on those affected by Long COVID. Although we did not commission economic analysis, we did undertake our own analysis and provided it to the Health and Social Care Select Committee on Clearing the NHS back log, in September 2021 [LCSOS/20 - INQ000238630]. It is our evidence to this Inquiry that Long COVID has a profound impact on individuals and the wider economy.
- 5.2. Long COVID affects economically active people, with its debilitating effects leading to specific healthcare treatment needs, compelling them to leave the working population or to work significantly reduced hours. This in turn has created financial support needs.
- 5.3. This evidence is supported by independent analysis. For example, the ONS affirmed that the injury to health caused by Long COVID also came with an economic cost [LCSOS/2 - INQ000272241]. The Office for Budget Responsibility (“OBR”) warned of spending implications as a result of Long COVID first in November 2020 [LCSOS/24 - INQ000114451/121] and again in March 2021 [LCSOS/25 - INQ000114450], in their Economic Fiscal Outlook. This assessment reflected the concerns of those who asked the Government to ensure there was economic support and social safety nets for people affected by Long COVID.
- 5.4. We provided written evidence to the Health and Social Care Select Committee for their Inquiry into Clearing the NHS backlog caused by the pandemic in September 2021 [LCSOS/20 - INQ000238630].
- 5.5. At the time, we calculated the estimated costs of Long COVID. Our calculations suggested that the minimum assessment and most basic diagnostics, for at that time, based on ONS statistics, was the significantly lower number of 643,000 who

have symptoms which impact their daily lives, could cost at least £520 million based on NHS Tariffs. We found that the true cost of Long COVID would be higher because:

- The loss of income tax revenue and national insurance payments could be around £2.4 billion per year based on average earnings and tax rates.
- This cost to the exchequer does not take into account the productivity loss to the economy as a result of this very large group of people being unable to contribute to the workforce as well as other related opportunity costs.
- Benefits claims for loss of income; disability benefit and sick pay could add another £1.25 billion in Universal Credit payments.
- Other areas of concern are hidden costs such as those relating to social care: the burden of caring for relatives is likely to be too onerous for those who find their symptoms disabling and alternative sources of care will need to be found.

5.6. Our analysis of healthcare spending and our estimate did not include referral to specialists or any advanced diagnostic tests, physiotherapy and other interventions. Our analysis was based on the ONS statistics that by August 2021 643,000 people having symptoms that affected their daily lives. The healthcare burden is therefore likely to be significantly greater especially given the multi-system nature of Long COVID. [LCSOS/20 - INQ000238630]

Calculation for minimum Long Covid assessment based on service provided by UCLH using NHSE National Tariff

Intervention	Code/Description	No	Cost	Total
Outpatient appt	WF02B First Attendance - Multi Professional, respiratory medicine	1	£299.00	£299.00
Follow up	WF02A Follow-up Attendance - Multi Professional, respiratory medicine	1	£125.00	£125.00
	6 minute walk test - estimate	1	£50.00	£50.00

Stress test/ECG Holter	Electrocardiogram Monitoring or Stress Testing	1	£124.00	£124.00
Blood panel	Estimate from UCLH	1	£100.00	£100.00
X-ray		1	£26.00	£26.00
				£724.00
GP appointments		3	£30.00	£90.00
Estimated basic costs per patient				£814.00
Estimated total cost of all patients 'impacted' by Long Covid		643,000	Total:	£523,402,000.00

- 5.6. We undertook the following analysis to estimate the loss of tax and NI revenue. It was a rough calculation.

Calculations for loss of tax/NI revenue

Category of Income	Estimates	Average loss of income on tax and NI
Average salary	£29,900.00 p/a	(by reference to Census 2021 Data Average Household Income in the UK financial year)
Income tax	£3,464.20 p/a	(by reference to Gov.UK income tax calculator)
NI payments	£2,439.84 p/a	
Estimated number of people who are unable to work	188,000.00 pax	ONS reported in September 2021 that by August 2021 188,000 people reported that their ability to undertake their day to date activities had been "limited a lot."
Loss of tax		£651,269,600.00

Loss of NI		£458,689,920.00
Estimated number of people whose capacity to work is reduced by 50%	455,000.00 pax	
Loss of tax		£788,105,500.00
Loss of NI		£555,063,600.00
Total		£2,453,128,620.00

- 5.7. In July 2021, the following paper, titled “*Characterizing Long Covid in an international cohort 7 months of symptoms and their impact*” was published. This was a Long COVID study by UCL using data collected by November 2020 [LCSOS/26 - INQ000652469]. This was a survey of 3762 participants with suspected and confirmed Covid-19 via online support groups. It found that “1700 respondents (45.2%) required a reduced work schedule compared to pre-illness, and an additional 839 (22.3%) were not working at the time of survey due to illness.” This is consistent with the experience of our volunteers and engagements with people suffering Long COVID, that is that it has a significant impact on employment.
- 5.8. The effect of Long COVID on an otherwise economically active individual, can be estimated using QALYs. These are a tool to measure changes in the state of the health of either a person or a group, in terms of length of life. One lost QALY is equal to losing 1 year of life in perfect health. One gained QALY is equal to gaining 1 year of life in perfect health. This is explained in the paper by the Department of Health and Social Care, Office for National Statistics, and the Government Actuary’s Department and Home Office, titled “Direct and Indirect Impacts of COVID-19 on Excess Deaths and Morbidity” [LCSOS/27 - INQ000220213]

- 5.9. The DHSC published an update on 17 December 2020 which provides an estimate of QALYs lost for those who contract Long COVID, albeit this is limited by a lack of data on quality of life for those who are not hospitalised:

“Based on COVID-19 infections to September 2020, we estimate 53,000 lost QALYs; there may be a further 121,000 lost QALYs under the Winter Scenario between October 2020 and March 2021. There may also be additional health impacts for non-hospitalised patients, but it has not been possible to estimate this at this stage.”

- 5.10. In 2021, The Covid-19 Task Force (“CTF”), which was formed in Summer 2020 to prepare advice for the Prime Minister and Cabinet, produced advice warning of the impacts of Long COVID. [LCSOS/03 - INQ000292660] It warned:

“Based on the latest ONS survey on Long COVID symptoms and the ONS Labour market survey, 385,971 people in employment are reporting long COVID symptoms of varying duration and severity. In the survey, 16% of working age respondents report that long COVID symptoms reduce their ability to undertake day-to-day activities a lot. This means that around 61,755 people in employment, report symptoms that have a significant impact on their day to day life.”

- 5.11. The paper advised that:

- Long Covid risks impacting the economy through absenteeism
- The number of work days lost because of Long Covid symptoms is in the range of 1.4M – 2.8 M days in a year.
- The cost of absenteeism due to Long Covid is estimated at £158M to £316M (using the cost of wages lost being used as a proxy given the lack of data to calculate output which would most probably be higher).
- Other analyses examining total productivity loss estimate the cost to be over £2 billion.
- The total QALYs lost to Long Covid for the working age population [hospitalised] is 48,085.

- Long Covid risks adding pressures to both the secondary and primary care sectors, being likely to increase demand for healthcare services.
- Long Covid risks reducing workforce availability in the health and social care sector.

5.12. A further update of the DHSC [Direct and Indirect Impacts] paper was published on 17 September 2021. This modelled the considerable morbidity [Long COVID] QALY loss between April 2020 and April 2021 over a 1-year time horizon, for non-hospitalised as well as hospitalised survivors by region, age and sex. [LCSOS/28 - INQ000220215]. This estimated morbidity QALY loss per region over a one-year time horizon post infection for survivors who were infected between April 2020-April 2021: Estimated QALY loss by region due to COVID-19 morbidity, April 2020 – April 2021 Region Morbidity QALY loss:

- East of England 7,400
- East Midlands 8,500
- London 12,000
- North East 4,300
- North West 8,100
- South East 9,800
- South West 4,500
- West Midlands 8,500
- Yorkshire and the Humber 6,800

5.13. An additional, significant concern raised by the economic impact of Long COVID is its disproportionality. This is reaffirmed by research on the economic impact of Long COVID. As set out in the September 2021 update of the DHSC paper cited above:

“People in the most deprived socioeconomic groups have experienced greater adverse health impacts in almost all categories of harm for which we could consider deprivation... Recent estimates for “long COVID” (August 2021) also show that self-reported symptoms are 50% higher in

people in the most deprived quintile, compared to the least deprived (1.89% of people experiencing long COVID compared to 1.24%).”

- 5.14. It found the estimated morbidity QALY loss occurring in individuals that were infected with COVID-19 and survived between April 2020-April 2021 over 1-year time horizon post-infection is greater in females. Overall females have an estimated QALY loss of 43,000 compared to 38,000 in males.
- 5.15. Further research conducted on the prevalence of Long COVID in 2021 has found that those with Long COVID were more likely to be on benefits, and more likely to live in social housing. [LCSOS/04 - INQ000651220]
- 5.16. The Covid Task Force paper of April 2021 warned of this disproportionality, acknowledging that “*Long COVID disproportionately affects ethnic minorities and women.*” The CTF advised that:

“In addition to disproportionately higher case rates, ethnic minority groups face greater risk of experiencing post-discharge complications compared to white groups and may disproportionately experience Long COVID. Ethnic minority groups also have poorer access to healthcare services and commonly cite poor past experiences of care and medical treatment. It has the potential to exacerbate pre-existing health and societal inequalities in the long term.” [LCSOS/03 – INQ000292660]

- 5.17. The 2022 ONS Survey titled “Self-reported Long COVID and labour market outcomes, UK: 2022” [LCSOS/02 - INQ000272241] found that, 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. It found that employed people with self-reported Long COVID were more likely to experience long-term workplace absence 18 to 29 weeks after infection. It was shown that working-age people are less likely to participate in the labour market after

developing Long COVID symptoms than they were before being infected with coronavirus, that Long COVID may have contributed to the decreasing levels of participation seen in the UK labour market during the pandemic.

- 5.18. In the Institute of Fiscal Studies, Long COVID and the labour market report, July 2022 [LCSOS/04 - INQ000651220], the study found that people with Long COVID tended to opt to go on sick leave rather than lose their jobs however, this resulted in an average reduction of about 2 ½ hours worked per week, and earnings by £65 per month (6%) or £1,100 per person who leaves work. Their suggested estimate as of July 2022, was that the aggregate impact is equivalent to 110,000 workers being off sick.
- 5.19. More recent research continues to affirm the significant economic impact of Long COVID. Even where those with Long COVID are able to continue working, it often means reduced hours and/or reduced productivity. A cross-sectional study of employed adults who had a PCR-confirmed SARS-CoV-2 infection more than two years earlier, those reporting Long COVID reported greater total productivity loss than other Covid-19 survivors, amounting to approximately 44.9-167.5 hours per 3 months. As concluded in the study, therefore,

“Long COVID is associated with substantial work productivity loss. Given the large number of individuals affected by COVID, this has significant implications for healthcare systems, the workforce, and economies.”

[LCSOS/29 - INQ000651245]

- 5.20. We therefore consider that there remains an unequivocal need for the government to consider Long COVID, and crucially, its disproportionate impact on parts of the population.

6. Economic Impact on Individuals

Case study S

“While the financial support [sick pay and PIP] was helpful, it was insufficient to maintain my previous standard of living. Transitioning to a pension [due to medical ill health retirement] that is one-third of my salary drastically reduced my income and made me dependent on my partner’s earnings for mortgage payments, household bills, and other shared financial commitments. This loss of financial independence has significantly affected my confidence and self-esteem.”

6.1. We exhibit with this statement three case studies from our members [LCSOS/01 – INQ000651217]. These are illustrative examples which show that those with Long COVID have had to bear multiple financial pressures caused by their illness, including:

- (i) Ending employment
- (ii) Working reduced hours
- (iii) Pay for private healthcare
- (iv) Pay for occupational adjustments
- (v) Inadequate benefits
- (vi) Difficulties accessing benefits
- (vii) Reduced pensions and savings
- (viii) Carer support and associated consequences

6.2. We invite the Inquiry to consider these illustrative cases in full. Our organisation’s views of the available benefits and support schemes in the relevant period is set out below.

i. Statutory Sick Pay

Case study K

“I definitely would have taken longer on long-term sickness absence to try and get a bit better if my company had been willing to pay extended full sick pay or even to furlough me back in 2020 – even going back to work and using leave to shorten my working week and my boss sort of turning a blind eye was not enough as I was still having to spend the hours at a desk all day, and I feel it really ruined any chance I had of full recovery “

- 6.3. In our view statutory sick pay has been inadequate before and during the relevant period. However, the main issue we wish to highlight is that there was no consideration of specific statutory sick pay for those with Long COVID. We are concerned at the active disregard of Long COVID reflected in this decision.
- 6.4. The lack of sick pay support for those suffering continuing, long-term symptoms led to multiple financial challenges. For example, once sick pay eligibility ended employees faced pressure to keep working with or without reasonable adjustments or having to cut down to part-time work.
- 6.5. In our view the Government should have considered increasing the duration of statutory sick pay, as well as the level of support and provided guidance to employers to support occupational policies to facilitate those with chronic illness and disability to remain in work.
- ii. COVID-19 Sick Pay
- 6.6. Our member, Dr Susannah Thompson who fell ill with Covid in 2020, and developed Long COVID, was a GP and Medical Director. [LCSOS/30 - INQ000651246]. She remains unable to work due to Long COVID and is unable to practice as a doctor anymore. As a member of Long Covid SOS, she has steered us about the impact on healthcare workers and has provided these below comments about the operation of “COVID-19 Sick pay” (the sickness absence policy implemented for the NHS between 2020 to 2022 in relation to all Covid-19 related sickness absence).

- 6.7. COVID-19 Sick pay was important as a safeguard for healthcare workers who were at high occupational risk of exposure to SARS-CoV-2. In our view healthcare workers were at high occupational risk in part due to inadequate PPE.
- 6.8. However, there were failings in the system and gaps where healthcare workers did not receive the COVID-19 Sick pay. There was a wide variation in how it was applied across the UK. It was a good idea, and we endorse a similar approach for recommendations for a future pandemic. However, we wish to make some comments that set out in our view the issues and gaps in the scheme, and how it could be improved for the future.
- 6.9. First, NHS trusts were provided with “guidance” on COVID-19 Sick pay. This led to the guidance being applied differently in different trusts. For example, it was suggested in the guidance that bank staff should “receive full sick pay if they are required to self-isolate or become ill with Covid-19.” The guidance sets out how COVID-19 Sick pay should be calculated for bank staff, i.e., full pay should be based on sessions they have booked or looking back at previous bank earnings. For Bank staff that had irregular bank earnings, they should have been paid on the basis of what they would have been paid during self-isolation. [LCSOS/31 – INQ000409888] However, due to it only being guidance, in some trusts bank staff did not receive any sick pay. For example, a doctor who worked as a clinical lead in an emergency department (“ED”) on a bank contract, only received 10 days sick pay to cover their acute infection and no more support even though they had worked regularly in the same role for a few years.
- 6.10. We have heard from some of our members that COVID-19 Sick pay, was denied to multiple clinical staff, all on bank contracts but working significant hours at their trusts across the frontline on Covid wards, ICU and ED; they were told that it was “guidance and not compulsory”. They only received ten days paid sick leave, thereafter they received no further sick pay, despite their union getting involved and fighting for them. This highlights the problem with guidance, where it is not made compulsory and left as optional. Those at the frontline lose out and face significant

financial hardship due to their contractual arrangement with the hospital, even when the guidance says they should be covered.

- 6.11. Second, in order to be eligible to access COVID-19 Sick pay, the employee's sick note needed to have "Covid-19" written on it. We understand that this issue was explored in evidence in Module 3 but simply note that the requirement that sick notes needed to have "Covid-19" written on them provided lots of stress for people sadly due to lack of awareness. Many were required to return sick notes and request replacements that stated "Long Covid" or "persist covid" or similar, to qualify for the sick pay.
- 6.12. The lack of awareness amongst GPs was also a contributory issue. Our member Dr Thompson reports that even as a GP herself, she did not know Long COVID existed until February 2021. Despite remaining ill, she ignored her symptoms and pushed through, getting worse until she was bedbound. She reports that she discovered Long COVID via social media and patient advocacy groups. The delay in developing coding in GP medical records for Long COVID and poor consistency in use in primary care is arguably related to this lack of understanding of Long COVID.
- 6.13. Third, COVID-19 Sick pay did not apply to primary care. Funding was distributed via Clinical Commissioning Groups ("CCGs"). Initially there were promises that there would be additional funding, but the details were published on 4 August 2020 to retrospectively cover the period March 2020 to 31st July 2020 [LCSOS/32 - INQ000651248]. Because the GP payments were retrospective, they did not know how much money they would be receiving until the letter of 4th August 2020.
- 6.14. Fourth, GP's COVID-19 Sick pay was money that the practice had to apply for and justify, this resulted in some GPs not receiving any of the ongoing COVID-19 Sick pay, only their NHS contractual sick pay. During the initial roll out of COVID-19 Sick pay which aimed to cover March – 31 July 2020, the pay for covering salaried GPs was capped below the costs of locum cover, at £200 per session + NI and pension (as set out on the 4th August 2020 letter above). Further, the application process

was retrospective and backdated. In our view this meant at the time that GP practices did not know for sure that they would recover staffing costs. This increased the pressure, especially on GP partners with Long COVID who fall into the self-employed category. We understand that for CCGs the funding was not specifically ring fenced for COVID-19 Sick pay like hospitals. We are aware for example of one salaried GP who she was infected in early 2020 and has not fully recovered to date. She did not receive any additional COVID-19 Sick pay; she lost her locum pay (25% of her total pay) instantly, and then only received the standard NHS sick pay and no special COVID-19 Sick pay, meaning she was down to half of her base pay, and then her sick pay ended, when in theory she should have carried on with full pay for the whole period of COVID-19 Sick pay. She is now unable to work due to Long COVID and is receiving benefits.

- 6.15. Fifth, those employed as locums, self-employed, found themselves without sick pay, despite the heightened risk of contracting COVID-19 at work. For example, we are aware of a locum GP who received no sick pay at all, and a physio working for the NHS via a self-employed model who also received no sick pay from the NHS scheme, despite both of them contracting covid at work. Similarly, we know of a case of a physio who was working for a private hospital which was re-allocated as an NHS hospital during the covid pandemic, who was again likely exposed at work in April 2020. She only received 6 weeks COVID-19 Sick pay, then statutory sick pay, and then Employment and Support Allowance (“ESA”) and Personal Independence and Payment (“PIP”). She lost her job as a physio with over 20 years’ experience due to Long COVID. It is worth noting here that, economically speaking, she manages to work 1 or 2 hours a week, but that does not cover anywhere near the cost of managing her symptoms, health, and care. Without PIP and ESA funding, she would be completely unable to work.
- 6.16. Similarly, there was a gap for students in various different healthcare professions, physio, medical, nursing, who then caught COVID-19, most likely during placements, and developed Long COVID. For example, we are aware of a student physio who was not paid, as they were still a student, and therefore did not receive

any sick pay. The only support was a 60-day extension of the student finance. Because they had to leave halfway through the term, they now owe approximately £2,500 in a bursary repayment. So not only have they not received any pay for working during Covid, or sick pay, they have then been left with debt, no qualification and little support to finish their studies in any way that would adapt to the requirements of someone with Long COVID. [LCSOS/33 – INQ000393704]

- 6.17. All of this has resulted in healthcare professionals who contracted COVID-19, most likely at work, and are no longer contributing to the economy. In Dr Thompson's case, she will no longer qualify for a full state pension and has gone from a person who was economically active to one who is on benefits, and heartbroken at losing her career, which was her passion.
- 6.18. In July 2022 COVID-19 Sick pay ended (though for primary care funded via CCGs it had ended before then) and by September 2022 it had reverted to normal employment rules. In our view COVID-19 Sick pay ended far too soon. The decision to end COVID-19 Sick pay was criticised in the BMJ by the BMA [LCSOS/34 - INQ000651250]. Raymond Agius, BMA occupational medicine committee co-chair, said the decision was "*completely unacceptable*" and that: "*Healthcare workers are in harm's way, caring for patients who are infected, and this vital provision helped ensure that they faced no detriment if they needed to self-isolate or became unwell with covid,*" he said: "*The removal of this provision will not only force many staff to continue working if symptomatic but may have a significant impact on their livelihoods if they develop long covid.*"
- 6.19. For healthcare workers with Long COVID, when COVID-19 Sick pay ended they lost that financial support, and due to the financial consequences may have been forced to return to work when they were not recovered or without adequate adjustments, leading to potentially worsening symptoms and being the reason many have attributed to a deterioration in their condition leading to them no longer being able to work.

- 6.20. The BMA report, titled: “Over exposed and under protected the long-term impact of Covid-19 on doctors, dated 7 April 2023 [LCSOS/35 - INQ000373375] found that:

“Around 66% of respondents have worked despite not feeling well enough to perform their duties, as a consequence of post-acute COVID.”

“As many doctors with post-acute COVID are unable to work or have had to significantly reduce their hours or responsibilities, they are suffering a loss of income. Nearly one in every two (49%) doctors responding to our survey told us that they have experienced some form of loss of earnings as a result of post-acute COVID”

“Inconsistent access to COVID special leave provisions and the eventual ending of these schemes by NHS employers across the UK have caused many doctors with post-acute COVID to struggle financially. It also means many have now used up all their statutory sick leave entitlement or have had to use their annual leave entitlement. Some even had to take unpaid leave.”

- 6.21. The Royal Medical Benevolent Fund (“RMBF”), a charity providing support for doctors and families raised their concerns about their expectation to receive more requests for help following the end of NHS COVID-19 Sick pay. They emphasised that over 10% of doctors who approach them for help with financial struggles have Long COVID and this was before the changes to COVID-19 Sick pay came into force.

- 6.22. Chief Executive of RMBF Steve Crone states: *“We are very concerned what these changes in sick pay mean for doctors with Long COVID who are not able to work. Their mortgage and bills will still need to be paid, and we are faced with a cost of living crisis. While the RMBF will also ways be there for doctors in need, we shouldn’t be left to plug the gap for doctors who have provided care throughout the pandemic at the expense of their own health.”* [LCSOS/36 – INQ000651252]

6.23. Further, in our experience much depended on the individual employer in terms of return to work, phased reduction, mitigation measures in work such as being supported to wear properly protective masks and testing. Overall, there has been a widely inconsistent approach taken by Trusts in regard to support offered to healthcare workers with Long COVID following the end of COVID-19 Sick pay.

6.24. Further, healthcare workers are still getting infected with SARS-CoV-2 and developing Long COVID. This creates an ongoing situation where those at the highest occupational risk have no recourse to specialist financial support despite the known potential long term health impacts.

iii. The Coronavirus Job Retention Scheme (“CJRS” or “the Scheme”) / Furlough

Case study K

“I was on sick leave for nearly 5 months on and off as I tried to return unsuccessfully to working from home. I ran out of Company Sick Pay in July 2020 and my union rep managed to negotiate another month of pay. My company refused to participate in the furlough scheme and my line manager told me not to talk to HR. In August 2020, my manager suggested I return and do what I could, without much oversight, so that I could get paid. I felt under pressure from family and financially to return”

6.25. In our view the CJRS was a positive measure. It allowed employers to keep employing those sick and absent from work with Long COVID and maintain them up to full pay. The scheme allowed employees with Long COVID some relief – particularly when flexible furlough was introduced from July 2020, allowing furloughed workers to be brought back on a part-time basis.

6.26. However, not all employers participated in this scheme. One Long Covid SOS member, K, 42, was on sick leave for nearly five months on and off, as they tried to return unsuccessfully to working from home. They ran out of their company sick pay in July 2020. Their union representative managed to negotiate another month of pay. Their company refused to participate in the furlough scheme.

- 6.27. We raise the question whether an automatic furlough system or long-term statutory sick pay for people diagnosed with Long COVID could have been more universally helpful. Our view is that in a novel pandemic those who are impacted by the illness should be supported financially including being able to access long-term financial support for the duration of their illness or inability to work.
- 6.28. Moreover, the Scheme ended on 30 September 2021. In the absence of separate support or guidance, Long COVID sufferers faced with being removed from furlough, and unable to return to work full or part-time, would have to rely on other modes of support. The ending of this scheme could have been softened by government efforts encouraging employers to make reasonable adjustments or provide additional support for employees with Long COVID.

iv. Self-Employment Income Support Scheme

- 6.29. Whilst this scheme was welcome, there were gaps in the support it offered. The Resolution Foundation has published research recording that three in ten self-employed workers reported that they had lost profits due to the pandemic but had not been eligible for a grant under the Self-Employment Income Support Scheme (“SEISS”) [LCSOS/37 - INQ000651253]. Among other exceptions, when the scheme was introduced in 2020, those who were newly self-employed and hence did not have a tax return in the 2019-2020 financial year, were excluded. This impacted our volunteers that were self-employed but were not eligible for the scheme.

v. Employment and Support Allowance (“ESA”) and Personal Independence Payment (“PIP”)

Case study J

“I applied for PIP in October 2024 and was denied, given zero points even though I answered them in a manner which conveyed my eligibility. Clearly the assessor thought Long Covid wasn’t real.”

6.30. For those too sick with Long COVID and other health conditions to remain at work, ESA and PIP were essential safety nets. However, those with Long COVID struggled to access this support. Partly this was because there was (and remains) a lack of recognition about Long COVID. In an interview in May 2022 Ondine stated, *“If long Covid was [more] recognised as a disability, that will help with the [claiming of] benefits.”* [LCSOS/38 - INQ000651254]

6.31. For many with Long COVID, who suffer from fatigue and cognitive impairment, benefit schemes are difficult to navigate. One Long Covid SOS member states:

“I have not applied for PIP or any other benefits like a blue badge as the paperwork and system is punitive, cognitively, and emotionally draining, requires lots of forms to be filled in and I don’t have the energy for it.”

6.32. The above interview with Ondine confirms those experiences: [LCSOS/38 - INQ000651254]

“Most long-haulers are not successful in their application and are treated with suspicion,” Laura (who asked to keep her surname hidden), 30, who worked as a full-time civil servant prior to her infection in September 2020, says. “I couldn’t put myself through that – cognitively or emotionally.”

For Lucy, the financial impact of long Covid is something she’s unfortunately familiar with. After leaving her job, she struggled to find another role that’d accommodate her new normal. “I was terrified about the money,” she says. “I wasn’t sure how I’d cope financially. I put a lot of pressure on myself.” While she was successful in applying for financial help under the Employment and Support Allowance (ESA), her situation was still a

challenge. “[ESA] didn’t even cover my rent,” Lucy writes. “Disability benefits are not enough to live on... But that shouldn’t be news to anyone”.

- 6.33. We note further that reducing hours of work due to Long COVID potentially had an impact on eligibility for contribution-based ESA. For example, we aware of situations where someone has been working in full time employment for their career and then became sick with Long COVID. As a consequence of Long COVID they tried to continue working but with reduced hours. This accordingly reduced their national insurance (“NI”) contributions, and they were unable to qualify for ESA. This also applies to self-employed people who were sick, if they did not pay enough national insurance contributions to meet the threshold.
- 6.34. PIP is intended to provide support for people with long-term physical or mental health conditions or disabilities or people with difficulty doing certain everyday tasks because of their condition. Although highly relevant, they can be difficult to claim for persons with Long COVID. For example, a person who is able to walk for 5 minutes on an occasional ‘good day’ but can only do that once a week and the rest of the time they struggle to walk at all, using wheelchairs to get to hospital appointments and being bed bound, or stuck upstairs because they cannot manage the stairs. They are unable to work and really should qualify for the mobility element because they cannot walk 20 meters in a normal way. But the assessment process is not appropriate for episodic disability.
- 6.35. We have concerns about work capability assessments and co-signed Long Covid Support’s submission to the DWP about the specific problems faced by people with Long COVID in such assessments [LCSOS/39 - INQ000651255].
- 6.36. The submission set out that the current work capability assessment (“WCA”) is unfit for purpose, stating: [LCSOS/39 - INQ000651255].

“The 16 current WCA functional descriptors fail to accurately determine functional disability for a [person with Long Covid] and whether they are

unfit for work, fit for work or able to safely engage in work preparation activities.”

“... the WCA currently fails to consider a person’s function holistically. The 16 functional descriptors do not account for the fluctuating and episodic nature of Long Covid.” A person may be able to do an activity during an assessment and yet be unable to repeat the same activity later that day.

“there has been widespread and ongoing disbelief and disregard about the lived experiences of many [people with Long Covid] as revealed in the current COVID-19 Inquiry... Consequently [people with Long Covid] have experienced gaslighting and stigma by a range of stakeholders including healthcare professionals and people connected to the workplace.”

- 6.37. Government signposting for benefits for people with Long COVID was limited. It was not until 24 December 2021 that a page titled “Find help and support if you have Long COVID” was published on the gov.uk website [LCSOS/40 - INQ000283482]. Given the barriers faced by those with Long COVID suffering from cognitive difficulties or having trouble articulating their dynamic symptoms in benefit applications or assessments, targeted government communication and guidance was necessary and yet absent.
- 6.38. It is concerning that there remains a lack of guidance and understanding with DWP decision makers about Long COVID.
- 6.39. A furlough style PIP and/or ESA system to ensure frontline workers who had no access to sick pay, could have helped people significantly. They would not have had to get back to work too quickly either when they were still infectious or when they were developing symptoms of Long COVID. The application process would need to be easier than existing processes however, as we set out above and below it is very difficult to apply for benefits when unwell.

vi. Universal Credit

6.40. In our view the support offered by Universal Credit (“UC”) was inadequate. We note that the Institute for Government found *“In the UK, eligibility to Universal Credit was not changed, but the generosity was increased by a relatively modest (by international comparison) increase of £20 per week. This still left the UK system as one of the least generous, especially for those who previously had higher earnings. In the US and Australia, large temporary supplements to unemployment insurance were announced of \$600 per week (£440 per week) and AUS\$550 per fortnight (£150 per week) respectively.”* [LCSOS/41 - INQ000651257]

6.41. Adequate Universal Credit payments would have made a substantive difference for those with Long COVID, dealing with reduced or ceased income, and the additional costs of their illness.

vii. Ill health retirement.

6.42. Whilst some people have been successful in applying for ill health retirement, we are aware of significant numbers facing difficulty access ill-health retirement, because Long COVID is a novel condition, making the burden of proof that Long COVID sufferers face difficult to overcome. Those who have been successful usually have a proven damaged organ, for example heart damage or brain damage. Those declined for ill-health retirement tend to have the more “invisible” well documented but often difficult to quantify elements such as Long COVID fatigue, Dysautonomia and pain. That Long COVID is a novel condition and there is a lack of understanding about it also contributes to the refusals of ill-health retirement. For example, the reason one of our members was turned down was because the assessor disagreed with the Long COVID consultant and Occupational Health and thought that she may be able to return to work as the length of Long COVID illness is unknown. This person has been out of work for 5 years now, with significantly reduced economic activity, they would have been in a better financial position if their pensions had been granted, rather than having to rely on benefits. [LCSOS/42 - INQ000651258]

viii. Insurance

6.43. Our members have shared that they have also faced difficulties accessing insurance payouts because some insurance companies are unwilling to pay out insurance payments as a result of not knowing how long Long COVID will last, or whether someone will recover from Long COVID. As Long COVID is a novel condition, the burden of proof, in some cases can be impossible for a sufferer to satisfy; how long is long enough? The economic impact on those individuals unable to continue working but without the safety net of income protection, or critical illness cover they have paid for is devastating and takes them from being economically active to relying on benefits.

Other financial support

6.44. We note that as a new organisation we could not benefit from extra support for the voluntary sector, even though we were responding to a new health crisis brought about by the pandemic itself. This funding was targeted largely at established charities [LCSOS/43 - INQ000623618]. The omission of funding for emerging organisations particularly those addressing Long COVID further exacerbated health inequalities, indicating a need for a more inclusive and equitable approach to funding.

Part D: Analysis and Recommendations

7. Analysis: The Economic Response to the impact of Long Covid

Overall Economic response

7.1. We have been asked to provide our comments on the strengths and weaknesses of the overall response to the pandemic.

7.2. In our view economic response to the pandemic both overlooked and underestimated the impact of Long COVID. We note for example in Module 9 that none of the draft economic expert reports refer to Long COVID which indicates that

- there continues to be a failure to take account of the both the overarching economic and individual impacts of Long COVID.
- 7.3. It is our position that the government neither responded adequately to the macroeconomic nor the individual impacts of Long COVID. It prioritised protecting the economy from short-term harm (for example with Eat Out to Help Out) and neglected to account and plan for long-term economic risks and harm. In doing so, the response did not account for Long COVID, an illness which would foreseeably lead to lasting impacts on individuals and the economy.
- 7.4. This is despite the government having the resources and advice to foresee this impact of Long COVID. Claire Lombardelli (who was chief economic adviser at HM Treasury during the pandemic), gave evidence in Module 2 of this Inquiry and agreed that there was an economic effect for people suffering from Long COVID in terms of market activity, and said information on the economic impact of a significant number of people suffering from Long COVID would have been shared with the Treasury when they became aware of it [Module 2 on 6 November 2023, p.55 – 56 ll.21 – ll.10]. Yet, the economic costs of Long COVID did not feature in HM Treasury or Cabinet advice.
- 7.5. Instead of prioritising infection control within the population, decision-making prioritised short-term economic activity and did not take Long COVID adequately into account when considering decisions. As we set out in our letter to the UK Government on 3 July 2020 the economic impact of thousands of people with long term illness from Covid-19 appears not to have been adequately considered nor appropriate support policies implemented. There appears to have been little consideration of the creation of a new cohort of people suffering long term illness and/or disability from Covid-19.
- 7.6. In February 2022, Ondine was interviewed by the I-Paper and stated as follows [LCSOS/44 - INQ000238567]:

“We have twice written to the government to urge it to take long Covid into account when making policy decisions around protecting the population from Covid-19.

“Evidence is now starting to emerge showing how long Covid is impacting the workforce – this is inevitable when 1.3 million people in the UK are living with this condition, and many cannot return to their jobs.

“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.”

- 7.7. There was insufficient financial support for individuals who needed to self-isolate due to acute Covid-infection. People who had low incomes or were in insecure work were in a precarious financial position. As Mr Rotheram, Mayor of Liverpool City Region, explained in oral evidence in Module 2 on 27 November 2023: *“they were choosing whether to stay home and get no pounds, no pence or take the chance they didn’t have Covid and go to work.”* [Module 2 on 27 November 2023, p.188 ll.2 – ll.10]
- 7.8. These elements of the economic response – overemphasis on short-term economic stimulation, and inadequate support for self-isolation – undoubtedly led to the increased transmission of Covid, which in turn led to a higher incidence of Long COVID. This had a greater negative impact on individuals and the economy as a whole.
- 7.9. There is an economic impact from the continued circulation of SARS-CoV-2 virus in the community and lack of messaging to the wider public/improvement in air quality via air purifiers/ventilation etc. Our members are at risk of further Covid infections, so avoid social situations, eating out, theatre, shopping, etc. Those with Long COVID are proven to be at risk of harm from infection yet fall through many gaps including not being in the eligible group for vaccines and antivirals for acute

infection. We understand other groups will have represented about the impact on the clinically vulnerable. Those, like many of our members, who remain rationally scared of further SARS-CoV-2 infection, either because they have Long COVID and are worried about a further infection worsening their symptoms, or those who meet the guidance criteria of being clinically vulnerable to Long COVID. This is a segment of the population who continues to isolate as much as feasible and has reduced economic activity on many levels due to this. It should also be noted that benefits such as PIP and ESA are difficult to claim and provide a baseline of financial support, and no one with Long COVID wants or chooses to be on benefits but the nature of the condition, the difficulty to plan from one day to the next and the brain impairment as well as physical impairments add significant costs to living, and make it hard to find suitable, flexible employment. As one of our members says, “who would want to see a doctor who has memory problems and at times can’t remember her own name”.

- 7.10. As those with Long COVID were left with inadequate support for dealing with the costs of their illness and a reduction or cessation of income, there was a pressure to return to work which had a detrimental effect on their long-term health and their ability to engage in economic activity.
- 7.11. In the witness statement of Rishi Sunak, dated 6 September 2023, the Chancellor of the Exchequer from 13 February 2020 to 5 July 2022, acknowledged the risk posed by Long COVID to the labour market and economic scarring [LCSOS/45 - INQ000263374]. We have set out the wide-ranging impact of Long COVID on the economy – from cutting down the labour force, to its burden on healthcare and welfare support. Its impact on individuals’ finances has also been set out above.
- 7.12. There was a failure by the Government to offer policy or guidance to employers by recognising this new disease and associated impacts. Whilst we understand that the scope of Module 9 is not considering non-financial occupational impacts, we note that facilitating or enabling individuals’ return to work by offering support to accommodate symptoms of their illness, where possible, would mitigate the above

individual and macroeconomic impacts of Long COVID. It would increase economic activity, would enable incomes to be maintained and decrease reliance on benefits. Unfortunately, such support was scarce for those suffering from Long COVID in the relevant period. Instead, many felt “pushed out” of work. [LCSOS/46 - INQ000651262]

7.13. One of our members, Sarah Barley McMullen said to the Guardian: *“[I was told] that my team was being restructured and my job as a senior manager was being replaced with a higher-level role. I knew I wasn’t well enough to do that and asked whether my role could stay at the same level. I was told, ‘maybe you need to ask yourself whether you are well enough to stay’... I think it was the lack of understanding and lack of awareness of Long Covid. They didn’t know anything about it.”* [LCSOS/46 - INQ000651262]

7.14. Given the economic repercussions of Long COVID and its potentially debilitating effects on previously economically active people, the economic response to the pandemic should have included guidance and support for employers to carry out occupational assessments and to introduce adjustments and support measures to facilitate employees’ return to work. This should have included guidance raising awareness and understanding of Long COVID among employers.

Design and implementation of economic interventions

7.15. We have been asked to comment upon the strengths and weakness of economic interventions in the relevant period not addressed above. In our view any decision maker considering economic interventions in a pandemic must necessarily take account of morbidity and should be able to respond to emerging evidence. It was a considerable weakness that this did not happen. Therefore, whilst there were some good schemes which had positive impacts, those schemes did not take account of Long COVID.

- 7.16. As far as we are aware there was no specific or bespoke consideration to adapt the benefits system, to provide guidance or information to decision makers within the DWP or frontline staff on how to assist them with this new disease.
- 7.17. There needs to be financial provision for people who don't recover quickly from an infection, illness or condition contracted from a pandemic situation. Whether that is through employers or the current benefits system or signed off by GPs/secondary care, it needs to be automatic and easy to access. There also should be access to blue badges, occupational health visits at home for anyone housebound or struggling to attend appointments – for everything from shower stools to support getting a wheelchair or mobility scooter or transport to appointments, as well as help with paperwork, cleaning, or cooking.
- 7.18. Further, in our view a change to the benefits available and the benefits system could have been implemented to ensure frontline workers who had no access to sick pay had sufficient support for the duration of the illness. They would not have had to get back to work too quickly either when they were still infectious or when they were developing symptoms of Long COVID or exacerbation of symptoms.
- 7.19. We are aware of how much difference it can make to a person's economic activity and future financial situation to have a supportive approach. In one instance that we are aware of, a person with Long COVID had six months off work and was then able to return for one hour a week with other adjustments e.g. no emails. Very slowly over the course of 18 months she was able to increase back to full time work. Her financial situation is now secure; she is a contributing to the economy as she was previously. In contrast, another person with Long COVID after being on sick leave for six months was told that they could only have a six-week phased return. She tried and failed the six-week phased return three times, each time getting sicker, tried reducing hours culminating in significant health deterioration and loss of employment. She is now financially insecure and unable to work.

Engagement with Decision Makers

7.20. We have been asked to comment upon the strengths and weakness of the engagement of the UK Government with external parties. As we have set out above, we undertook considerable advocacy in various forms to engage with decision makers. It was our concern at the time that the Ministerial Roundtables on Long COVID could have been more effective and whilst they gave a space for patient advocates such as ourselves to speak there was no evidence to us that any decisions were actually changed or implemented due to the Roundtable. They appeared performative. Our direct advocacy through letters and videos did not appear to be taken seriously.

7.21. We would suggest in relation to the economic response specifically that it could have been useful to have patient advocates with Long COVID contributing to HM Treasury department, DWP or other relevant departments to help inform the development of policies with the lived experience of Long COVID.

8. Suggested lessons to be learned and recommendations for future pandemic

8.1. At this stage in Module 9 where we have not received all the evidence, we are not in a position to provide final recommendations. However, to assist the Chair we have set out below areas that we consider are necessary to make meaningful changes for the current situation caused by the decision making in the relevant period and future pandemics:

8.2. We have seen the suggested recommendation from LCS that the UK Government establishes an independent statutory body, focused on the current long-term stage of the COVID-19 pandemic. We understand that the idea is that the independent body would work with government stakeholders (national, devolved, local), business, and the 3rd sector to deploy whole-system interventions that mitigate or reduce the current and future impacts of COVID-19 and Long COVID. We agree with this proposal.

Immediate recommendations to change the current situation:

8.3. **Recognition:**

- The Government should **acknowledge the economic impact of Long COVID** and commission a **full and independent economic analysis of that impact**.
- The Government should **publicly acknowledge the ongoing impact of Long COVID on the labour market and the ‘economically inactive’**.
- **People with Long COVID should be consulted in the development of economic policies and advice** akin to Public Patient Involvement in the NHS.

8.4. **Economic support:** Long COVID causes workplace absenteeism, loss of earnings and labour market inactivity. A **package of economic support** (including increase to SSP) should be considered for individuals who have suffered economic losses due to Long COVID. A stakeholder panel should be convened to provide recommendations on packages of economic support to the Government for consideration.

8.5. **Data:**

- The ONS should immediately resume collection of national **data on the prevalence and impact of Long COVID** to assist the general public and decision makers with understanding it's risk.
- The ONS/UKHSA should be **directed to collect and analyse the impact of Long COVID on labour inactivity, productivity and ability to work** by reference to the evidence in M9 and Locomotion study.

8.6. **Review of Welfare benefits:**

- The DWP should commission a review of the impact of Long COVID and adequacy of welfare support for people with Long COVID which will consult with stakeholders.
- The DWP should review guidance to staff so that all frontline staff such as work coaches, disability employment advisers in the Jobcentre, and other

employment support providers are adequately informed, and confident to assess and support people with Long COVID, including through new support programmes and making use of permitted work options for people in receipt of ESA.

- 8.7. **Occupational support:** The Office for Equality and Opportunity and other stakeholders, such as Long Covid Groups, ME association, CPID etc., should review the evidence in the Inquiry and prepare bespoke guidance to employers about Long COVID (and long-term illnesses).
- 8.8. **Approach to Long COVID under equality law:** We endorse TUC's calls for strengthening of the Equality Act by recognising Long COVID as a disability. In our view formal recognition of Long COVID as a prescribed illness amounting to a disability under schedule 1 paragraph 6 of the Equality Act 2010 would enable employers to provide better job security. It would place a duty on employers to make reasonable adjustments that remove, reduce or prevent any disadvantages workers with Long COVID face, as for any other enduring condition or disability. **We invite the chair to request the Equality and Human Rights Commission ("EHRC") reviews the Code of Practice by reference to the evidence in the Inquiry.**
- 8.9. **Government should develop a new Disability Strategy co-produced with disabled people,** ensuring that any proposals to encourage workforce participation among disabled people are grounded in lived experience of structural barriers, such as limited access to NHS care and inflexible work arrangements, rather than the assumption that disabled people lack the motivation to work.
- 8.10. The UK Government should **publish public health messaging** on the ongoing risk of SARS-CoV-2 infection and risk of Long COVID.

9. Future recommendations for a future as yet unknown pandemic:

- 9.1. **Considering Long-term morbidity:** The long-term health consequences of a novel virus (including its socio-economic impact) must be factored into decisions made in response to the transmission of the virus and included in assessments of the necessity for NPIs and PIs
- 9.2. **Early public identification and assessment of the impact of disease on affected individuals' ability to work, care for themselves and be economically active.**
- 9.3. **Economic interventions:** Financial provision for those that do not recover quickly from acute infection should be bedded into any pandemic response. In a novel pandemic those who are impacted by the illness should be supported financially including being able to access long term financial support for the duration of their illness or inability to work.
- 9.4. **Surveillance systems** should be in place from the outset, for example in the form of sleeping studies and longitudinal studies. These should identify and monitor data on the impact of longer-term sequelae so that long-term health implications can be recognised early on. This data should feed into modelling for long-term sequelae to assist decision makers with a fuller picture of the severity of pandemic harm.
- 9.5. **Socio economic impacts:** There should be informed analyses by objective metrics such as QALYS and DALYs or other more comprehensive qualitative measures.
- 9.6. **Pandemic planning and response on long-term morbidity should involve all devolved nations:** Charities including our own have called for greater coordination, more inclusive policies and better support for all people with Long COVID, regardless of where they live in the UK.

Conclusion

10. We are grateful for the Inquiry’s consideration of the matters we have raised and are able to provide any further information available to us as requested.

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 in its truth.

Signed. PD.....

03/10/2025
Dated.....