
**MODULE 9:
JOINT OPENING STATEMENT
ON BEHALF OF
LONG COVID SOS AND LONG COVID SUPPORT**

I. INTRODUCTION

1. The Long Covid Groups (“**LCGs**”) in Module 9 are Long COVID Support and Long COVID SOS. Both are volunteer led patient advocacy and support groups for those who have Long COVID.
2. The Inquiry has heard evidence in previous modules about the devastating effect of Long COVID on our clients’ health. In this module, the LCGs give evidence about the corresponding impact of Long COVID on their members’ ability to work. Some members have lost their income entirely; others have seen it reduced significantly. Many have seen their careers damaged or destroyed. Many are unable to financially care for themselves or their families. Their illness had a wider impact on their family and friends whom they relied on to provide care and support.
3. A significant number of the UK population have been subject to such adverse financial impact. The ONS Winter COVID Infection Survey (“**CIS**”) found that in March 2024 in England and Scotland an estimated 2 million people (including 111,000 children) reported having Long COVID. Of those, 1.5 million people with Long COVID reported that their day-to-day activities were adversely affected, and 381,000 reported their daily activities were “*limited a lot.*”¹ The number of people affected across the United Kingdom are likely to be much higher. Long COVID continues to be a public health crisis with profound implications for the individuals and their families, but also for the UK economy and wider society.
4. The LCGs are grateful for the opportunity to engage with the Inquiry in Module 9. They ask the Inquiry to investigate why the economic impact on those who were affected was not a concern of the UK Government and why no steps were taken to mitigate the economic harm caused to people with Long COVID.

¹ [INQ000652457].

5. In this opening statement, the LCGs outline:
 - i. The economic impact of Long COVID;
 - ii. What should have been the UK Government's economic response to Long COVID;
 - iii. How the UK Government in fact responded to the economic impact of Long COVID;
 - iv. Emerging themes for further investigation in this module.
6. At the time of filing this opening statement, the LCGs have not yet received disclosure of all witness statements or all documents. The analysis below is therefore necessarily subject to any further disclosure received.

II. THE ECONOMIC IMPACT OF LONG COVID

7. The economic impacts of Long COVID can be sub-divided as follows: (i) the cost to individuals and their families who experienced extended periods of ill-health limiting their economic productivity; (ii) the increased demand for public services and social welfare support; and (iii) economic scarring from the curtailed economic productivity of Long COVID sufferers.

The individual costs

8. Many individuals with Long COVID took periods of time off work, reduced their working hours and/ or lost their jobs altogether.² They relied on savings, sold their homes or turned to social welfare support to support themselves. Family members became carers with a consequential effect on their income and economic productivity. The Every Story Matters Module 9 Report describes how one person who developed Long COVID after being hospitalised for Covid-19 stated that he lost his job and "*...when I got out of hospital, our life stopped completely....*"³
9. The LCGs' members echo that sentiment in their experiences:

AC: "Unable to work and still unable to work after almost 5 years. The first year was unimaginable and lucky that had savings to try and help with the situation."⁴ They

² [INQ000657079/13].

³ [INQ000588209/48-49].

⁴ [INQ000652535/25].

faced difficulties in accessing financial support as “*Long Covid was not recognised in lots of different ways from diagnosis to PIP, insurance companies and any other support network.*”⁵

A: “*Long COVID has taken me within the space of 3 years from doing a highly qualified, well-paid full-time job, to zero income and no resource to benefits at this time*”⁶

SB: “*... Not having full time wage has a big impact on our family finances, we had to cut down on many things, including food shopping, heating etc*”⁷

10. Studies carried out by the LCGs identified the following factors driving the economic impact on individuals: (a) employers’ lack of awareness or understanding of Long COVID leading to refusal of extended sick leave or adjustments facilitating return to work or staying in work, (b) a lack of awareness or understanding of Long COVID amongst DWP assessors, and (c) inflexible economic support programmes and statutory sick pay regime.⁸

Burden on public services

11. The individual experiences of people with Long COVID translated to a significant public cost in relation to healthcare services and demand for welfare support. In 2021, the OBR predicted that there would be “*greater-than-assumed*” spending as a result of Long COVID cases.⁹ The direct and indirect costs to healthcare alone have been significant. NHS England was forced to spend £128.5 million between October 2020 and June 2021 on Long COVID services and research in England alone.¹⁰ These figures, until 2021, did not include the costs for Long COVID services across the United Kingdom or for non-specialised healthcare for Long COVID (i.e. costs associated with GPs or referrals for healthcare related to Long COVID which were not provided by dedicated Long COVID services) before and after 2022. Long COVID has also contributed to increased UK Government spending on welfare support for people newly disabled by Long COVID.¹¹

⁵ [INQ000652535/27].

⁶ [INQ000652535/35].

⁷ [INQ000652535/48].

⁸ [INQ000657079/73]; [INQ000249073]; [INQ000272240]; [INQ000248884]; [INQ000377697].

⁹ [INQ000119291/65] see also November 2020 Report [INQ000114451/121]; March 2021 Report [INQ000114450].

¹⁰ £10 million was invested in five-part plan and a further £18.5 million was announced for research on 18 February 2021. In June 2021, NHSE announced a further £100 million investment into Long COVID Services.

¹¹ OBR reported in October 2024 that since 2019/20, “*incapacity benefits receipt rates have risen nearly-uniformly by around 2 percentage points...pushing up the caseload by 670,000.*” OBR, Welfare Trends Report – October

Macroeconomic costs

12. The number of people who have suffered from Long COVID has contributed to economic scarring of the UK economy. The available data confirms an increase in the number of people suffering from Long COVID,¹² and a corresponding increase in the number of people who are economically inactive or in employment with work-limiting conditions.¹³ The number of economically inactive people for health reasons increased by 40% or 800,000 between 2019 and March 2025. Between 2019 and 2024, the number of people in employment with work-limiting conditions increased by 31% (from 6.7 million to 8.7 million).¹⁴ The Labour Force Survey (“LFS”) which is the source of this data has not disaggregated the proportion of people with Long COVID who contribute to this overall figure. Nonetheless, the last ONS data from March 2024 – confirming that 1.5 million people’s daily activities are limited by Long COVID and 381,000 are limited a lot – suggests that the contribution due to Long COVID is significant.¹⁵ The results of the recent GP Patient survey makes clear that Long COVID remains a growing problem: as at March 2025, of 702,837 valid responses, 4.2% of people over 16 years in England self-reported Long COVID.¹⁶ A further 9.5% responded that they do not know if they have Long COVID. Even if only a small proportion suffer from Long COVID without formal diagnosis, this would further add to the overall number of people with Long COVID.
13. Further, initial studies such as LOCOMOTION (a £3.4 million research project funded by NIHR) estimated that from the point of infection to February 2023, the ONS’ 381,000 people “*impacted a lot*” by Long COVID lost £5.7 billion in income and had informal caregiving costs of £4.8 billion.¹⁷ The LOCOMOTION study evaluated the costs from lost income and the cost of informal care giving. Another study by the Economist Impact also concluded that Long COVID had a “*notable impact on the UK economy*.”¹⁸ Focusing on the workforce impact, the study estimated that Long COVID

2024. IFS has reported that there has been a large increase in spending on working age health-related benefits from £36 billion in 2019/20 to £48 billion in 2023/24. E. Latimer et al, Health-related benefit claims post-pandemic: UK trends and global context,” Institute for Fiscal Studies September 2024.

¹² The latest available data on prevalence and severity of Long COVID documents an overall increase in the number of people suffering from Long COVID: The Winter CIS 2023/2024 survey reported that by March 2024 in England and Scotland, 2 million people reported having Long COVID of which 1.5 million reported their daily activities were adversely affected by Long COVID and 381,000 reported their ability to undertake their daily activities were “*limited a lot*.” [INQ000652457].

¹³ [INQ000657079/23]; [INQ000652464].

¹⁴ Work limiting condition is defined in the Keep Britain Working Review as “*People who report a long-term health condition that affects the amount or type of work [they] can or could do.*” [INQ000652464/42].

¹⁵ [INQ000652457].

¹⁶ [INQ000652462].

¹⁷ [INQ000651341]; [INQ000657079/59].

¹⁸ [INQ000657077].

cost the UK GDP 0.5% (or USD 15.5 billion) in lost income from people directly affected by Long COVID. The study did not factor in the associated costs from caregiving, increased healthcare and demand for incapacity benefits.

14. The only study which has carried out a comprehensive assessment of all costs associated with Long COVID – “*personal, employer, medical and society losses*” - has been carried out in Germany.¹⁹ The authors found that “*between 2020 and 2024, Long COVID and ME/CFS cost Germany more than €250 billion. In 2024 alone, Long COVID and ME/CFS cost Germany €63.1 billion, equating to 1.5% of the nation's GDP.*”²⁰ The authors have explained that the report aims to fill “*the current evidence gap*” by modelling the latest data on infections, immunity and costs because “*Germany lacks sufficient direct surveillance data for this purpose, and while several government funded research projects are underway, they will not yield results for some years.*”²¹
15. The UK lacks surveillance data on Long COVID and its economic impact. There is a need to fill the evidence gap. As noted above, data from the March 2025 GP Patient survey provides that 4.2% of the population in England over 16 years have reported Long COVID.²² There is no data on the economic impact of Long COVID on that 4.2% nor on the 9.5% who do not know if they have Long COVID (a proportion of whom may well have Long COVID). The LCGs urge the UK Government to carry out a detailed study of the economic loss attributable to Long COVID in the UK equivalent to that carried out in Germany.

III. WHAT SHOULD HAVE BEEN THE UK GOVERNMENT’S ECONOMIC RESPONSE TO LONG COVID?

16. From the very start of the relevant period the LCGs highlighted the existence of, and the economic impact of, Long COVID and identified the steps the UK Government needed to take. On 3 July 2020, the LCGs wrote to the then Prime Minister, Boris Johnson, copied in all MPs and the CMO and GCSA calling for recognition of Long COVID and stating²³:

“Not only is this a calamity for each individual, but it is also a serious matter for an economy which is already facing an existential struggle: large numbers on

¹⁹ The rising cost of Long COVID and ME/CFS in Germany, Risklayer, May 2025, p. 18.

²⁰ The rising cost of Long COVID and ME/CFS in Germany, Risklayer, May 2025, p. 4.

²¹ The rising cost of Long COVID and ME/CFS in Germany, Risklayer, May 2025, p. 13.

²² [INQ000657079/15]; [INQ000652462].

²³ [INQ000238582].

long-term sick leave will significantly impact the workforce as it emerges from furlough...."

17. The LCGs identified the necessary steps to be taken, which included:
"(5) Consideration of the economic implications, including making provision for long-term sick leave, financial support and taking steps to ensure employers are made fully aware of this situation."
18. Throughout the relevant period the LCGs reminded the UK Government of the need to (i) factor in the economic consequences of Long COVID when making decisions in response to Covid-19 and (ii) develop economic interventions to mitigate the increasing burden of Long COVID.²⁴
19. More than 2 million people have been adversely affected by Long COVID,²⁵ which has resulted in a catastrophic financial impact. The UK Government ought to have developed a strategy to respond to the economic harm caused both to individuals and to the wider economy. That strategy could have identified and implemented a range of measures, including the following:
 - i. First, **data on the economic impact of Long COVID** should have been gathered. In order to respond to Long COVID, it is necessary to understand its scale and impact. In October 2020, the LCGs wrote to the ONS asking for Long COVID to be counted, observing that *"the condition seems to prevent so many from being able to work."*²⁶
 - ii. Second, **the risk of Long COVID should have been factored into policies** which had a bearing on the rate of transmission of Covid-19. The only way to prevent Long COVID is to prevent Covid-19. The causal relationship between policies which allowed for high rates of transmission and the high rates of Long COVID should have been modelled and monitored in all economic policies.
 - iii. Third, **information about Long COVID and how to respond to individuals with Long COVID should have been communicated to employers and benefits assessors.** The chair of the APPG on Long COVID, Jo Platt MP, said in relation to welfare benefits *"People with Long COVID are stuck with a double burden: a life changing illness and a system that doesn't believe them."*²⁷ Lack of

²⁴ [INQ000657079/25-48]; [INQ000656296/6-21].

²⁵ According to the ONS Winter Survey which ran from 6 February 2024 to 7 March 2024, in England and Scotland, 381,000 people reported their daily activities were impacted a lot and 1.5 million reported their daily activities being adversely affected. [INQ000657079/12]; [INQ000652457].

²⁶ [INQ000656296/13-14]; [INQ000272223].

²⁷ [INQ000657079/71].

understanding of Long COVID amongst employers and benefits assessors has been cited as a significant barrier to people with Long COVID remaining in work and accessing available benefits.²⁸

- iv. Fourth, **all frontline workers, including non-clinical staff, should have been eligible for Covid-19 sick pay as well as NHS workers.** The NHS Covid-19 sick pay provided an essential cushion for NHS healthcare workers who had risked their lives and health during the pandemic. Yet a whole cohort of keyworkers who provided other essential services (for example in transport, education and care services) lost their jobs or faced severe hardship when they developed Long COVID.
 - v. Fifth, **targeted economic interventions should have anticipated and prepared for mitigating the impacts of long-term sequelae of Covid-19** and should have been reviewed and adjusted as evidence emerged about Long COVID.
 - vi. Sixth, **DWP should have reviewed its available support** and ensured that assessments are able to reflect the relapsing and remitting nature of Long COVID.
20. Some of the evidence before the Inquiry suggests that specific steps to address the needs of those with Long COVID were considered unnecessary.²⁹ That evidence overlooked the following relevant considerations:
- i. Long COVID was a new condition, and unlike other long-term conditions (such as cancer or diabetes), there was a need for emerging scientific information to be shared with employers and benefits assessors so that they could understand the condition.
 - ii. Frontline workers exposed themselves to the risk of Long COVID to ensure that essential services could keep running for those who could isolate from the risk of Covid-19 and Long COVID at home. According to the ONS data from March 2023, self-reported prevalence of Long COVID was higher in those working in healthcare (4.41%) than in the general population (2.92%) regardless of whether they had a previous Covid-19 positive test.³⁰ Adequate financial support for those

²⁸ [INQ000657079/43]; [INQ000249013/4-5].

²⁹ See, for example, (i) the expert report of Dr Mike Brewer who states that that Long COVID is “*not especially relevant for the design*” of Labour Market Interventions; [INQ000588132/55] and (ii) the statements by Tim Leunig, economic adviser to the Chancellor, that it was “*odd for society to distinguish*” between people who have Long COVID or other long-term conditions “*if both conditions have the same consequence*” and that it was not clear why people with Long COVID should get “*more or less money*” because they could not work. [INQ000588231/231].

³⁰ M3 [INQ000249829/4]; Amani Al-Oraibi et al, “Prevalence of and factors associated with Long COVID among diverse healthcare workers in the UK: A cross-sectional analysis of a nationwide study (UK-REACH), 10 December 2024, BMJ Open.

who suffered long-term health consequences fairly recognises their sacrifice as well as providing reassurance to those who may serve on the frontline in a future pandemic.

- iii. There is practical benefit to targeting support towards this cohort of newly vulnerable people in a pandemic context. Targeted support through the introduction of policies, guidance and in some cases, extension of financial support, would prevent job loss and protect incomes of a statistically significant number of people made economically vulnerable within a relatively short period of time.
- iv. There are specific features of Long COVID that mean it requires a targeted approach. Long COVID can be a “*relapsing and remitting*” condition whereby its symptoms can fluctuate, sometimes unpredictably, so that an individual’s ability to carry out work (either at all or at full capacity) can be correspondingly variable.³¹ Eligibility for Statutory Sick Pay (“**SSP**”) and welfare benefits is currently premised on individuals suffering from long-term illnesses in a uniform way.
- v. Similarly, Long COVID (and its economic impacts) gives rise to particular equality issues that decision makers needed to understand to discharge their public sector equality duty, and to devise an effective policy response. Early assessments by the Covid-19 Taskforce reported that Long COVID “*disproportionately affects ethnic minorities and women*,”³² and that Long COVID prevalence rates were highest amongst those living in deprived areas which meant it had the potential to “*exacerbate pre-existing health and social inequalities in the long-term*.”³³ The paper also noted that as Long COVID had the potential to become a chronic condition affecting output and productivity due to absence from work it was likely to “*disproportionately impact those on lower wages and in low income groups...*”³⁴

21. The LCGs therefore ask the Inquiry to investigate the steps the UK Government should have taken to mitigate the economic impact of Long COVID.

IV. WHAT WAS THE UK GOVERNMENT’S ECONOMIC RESPONSE TO LONG COVID?

³¹ [INQ000280198/6, 14].

³² [INQ000292660/1].

³³ [INQ000292660/4].

³⁴ [INQ000292660/4].

22. The evidence to date discloses a complete failure across government to engage with the economic impact of Long COVID.

Consideration of Long COVID in development of economic policies

23. The available evidence suggests that despite the LCGs advocacy,³⁵ the UK Government first ignored, and then later minimised Long COVID, when developing policies which could increase the rates of transmission of Covid-19 in 2020.
24. The first response of the UK Government was to ignore early warnings of Long COVID. Sir James Harra, former Chief Executive and First Permanent Secretary of HMRC, states that Long COVID was “*not fully understood*” during the currency of Eat Out to Help Out (3 to 31 August 2020) which is why it was not considered.³⁶ This response overlooks: (i) the foreseeability of long-term health consequences from COVID-19, and (ii) the LCGs’ correspondence and advocacy campaigns from July 2020.³⁷ Further, there was an absence of consideration of Long COVID *at all*, as opposed to some consideration pending further evidence. There was no consideration of the risk Long COVID posed to the wider population in September to October 2020 as the UK Government rejected a circuit breaker and then delayed a second lockdown. Instead, the UK Government focused on economic recovery at the expense of public health.
25. When evidence relating to Long COVID could no longer be ignored, decision-makers diminished its impact. For example, in October 2020, HMT assessed the costs implications for the NHS from Long COVID as likely to have a “*Low/medium*” impact in 2020/2021 on the premise that people with Long COVID would not need NHS services.³⁸ HMT’s projection that people with Long COVID would recover at home without recourse to NHS Services directly contradicted the NHS announcement the same month of the development of Long COVID clinics.³⁹
26. The Covid-19 Taskforce prepared advice on the impact of Long COVID in February,⁴⁰ April,⁴¹ and July 2021,⁴² which included estimates of the impact of Long COVID on the workforce. In April 2021, the Covid-19 Taskforce estimated the cost of absenteeism

³⁵ [INQ000657079/25-48]; [INQ000656296/6-21].

³⁶ [INQ000614156/149].

³⁷ [INQ000656296/8].

³⁸ [INQ000609766/6].

³⁹ In October 2020, NHSE announced designated Long COVID clinics.

⁴⁰ [INQ000625664].

⁴¹ [INQ000292660].

⁴² [INQ000622771/4].

due to Long COVID was between £158-316 million for the period from March 2020 to March 2021, but recognised that other analyses estimated the cost to be over £2 billion.⁴³ In July 2021, the Covid-19 Taskforce revised the estimated costs following input from DHSC and advised that the estimated cost of absences was between £356-712 million in “(lost output; UK wide figure)” relying on data on Long COVID up until March 2021.⁴⁴ There was no attempt to forecast the economic impact from increasing numbers of people suffering from Long COVID after March 2021.

27. The UK Government went on to plan for high prevalence of Covid-19, acknowledging that this would lead to high rates of Long COVID. A Covid-19 Taskforce paper titled “Long Covid Risks to the Population and Health Service” dated 9 July 2021 stated: “*The next few months is likely to see a significant rise as higher case rates (with currently low vaccination rates in young people as a contributor), lead to an increased proportion of the public suffering from Long COVID.*” The paper recognised there would be an associated significant impact on the workforce.⁴⁵
28. This advice was communicated to the Chancellor and Cabinet Office but no steps appear to have been taken. A paper dated 21 July 2021 on “*High Prevalence Planning Summer Response*” identified issues and key questions for DHSC as including “*What is the proposed strategy to address the cumulative impact of long covid on public and private sector workforces, and what mitigations do DHSC/ DWP have on sickness absence?*”⁴⁶ No evidence has been disclosed as whether a strategy was developed or how DHSC/ DWP sought to mitigate the impact of Long COVID. HMT was not involved. Nor, notably, was the public warned about the trade-off between releasing from restrictions, the economy and Long COVID or indeed the financial implications that may result from developing Long COVID.
29. By 9 September 2021, the economic impact of Long COVID was recognised in the September Review Analysis Pack. Absenteeism was estimated to cost between £248-£476 million on the basis of 70,000 people in employment reporting symptoms that have a significant impact on day to day life (time period unspecified) without taking into account the indirect costs.⁴⁷ There was no reference to any strategy or plan to mitigate the economic impact of Long COVID.

⁴³ [INQ000292660/6].

⁴⁴ [INQ000622771/4].

⁴⁵ [INQ000622771].

⁴⁶ [INQ000092058/2].

⁴⁷ [INQ000067095/4].

30. The LCGs note that HMT continues to minimise the impact of Long COVID on the economy in evidence to the Inquiry. HMT cites studies on outdated data to suggest that Long COVID had a minimal contribution to economic inactivity (the February 2024 paper “Employment outcomes of people with Long COVID symptoms: community based cohort study” relied upon by Mr Sunak, for example, is based on assessments from 3 February 2021 to 30 September 2022 only).⁴⁸ HMT fails to acknowledge that no data are being gathered on Long COVID’s contribution to economic inactivity or on the increase in people who are working while limited by Long COVID. As set out above, the available estimates from the Economist Impact study estimated that USD 15.5 billion has been lost from the UK economy due to Long COVID workforce related absences. A comprehensive study in Germany which took into account wider associated costs concluded that the 2024 costs of Long COVID and ME/CFS are equivalent to €63.1 billion.⁴⁹
31. The LCGs invite the Inquiry to conclude that it is not open to HMT to minimise the impact of Long COVID on the economy without commissioning a detailed economic study.

Guidance/ Advice on Long COVID

32. In August 2020, the LCGs gave evidence to the APPG on Coronavirus and the HSC Committee that the lack of understanding of Long COVID amongst employers was forcing members to return to work before they were well enough. This caused lasting damage to employees’ health and productivity.⁵⁰ The LCGs also reported that after losing their jobs, people with Long COVID encountered disbelief and a lack of understanding from DWP when they tried to access social welfare support.⁵¹ The interim report from the APPG on Coronavirus published in December 2020 called for guidelines for employers on recognising and managing Long COVID.⁵²
33. No witness statement disclosed to date engages with this recommendation. No witness gives any consideration to how businesses could have been encouraged to support people with Long COVID to remain in employment. The absence of government guidance to employers remains unexplained despite decision makers

⁴⁸ [INQ000661483/313]; INQ000609924 /2].

⁴⁹ The rising cost of Long COVID and ME/CFS in Germany, Risklayer, May 2025, p. 4.

⁵⁰ [INQ000657079/27]; [INQ000248911].

⁵¹ [INQ000651255].

⁵² [INQ000249062]; [INQ000657079/32].

being aware that *“Employers are looking to HMG to give an indication of how Long COVID should be considered”* in relation to the Equality Act 2010.⁵³

34. Assessors for benefits claims were also not provided any guidance on how to approach claims from people with Long COVID. Instead, the Government’s agreed policy was to avoid reference to Long COVID for fear of increased claims in PIP: on 5 July 2021, Covid-19 Operations Committee minuted that the UK Government should not use the term Long COVID *“loosely”* because personal independence payments were at an all-time high.⁵⁴ This approach had a devastating impact on people with Long COVID. For example: one LCG member, “A,” reported that Long COVID was not recognised by assessors at DWP, nor employers. Their PIP claims were refused with the DWP representative advising them to make a fresh claim saying *“a lot of people with Long COVID get worse and have to make another claim.”*⁵⁵ Another LCG member, “J”, stated that they were refused PIP in 2024 as *“clearly the assessor thought Long COVID wasn’t real.”*⁵⁶

Data gathering on Long COVID

35. The collection of data was and remains an obstacle to understanding Covid-19 including its long-term sequelae. There was a delay in collecting any data on Long COVID until the LCGs wrote to the ONS on 16 October 2020 asking for Long COVID to be counted.⁵⁷ Even though the LCGs also highlighted the benefits of data to DWP as *“the condition seems to prevent so many from being able to work,”*⁵⁸ there remains to this day no concerted effort to gather data on the economic impact of Long COVID. Although canvassed by HMT in November 2020,⁵⁹ and the Long COVID Oversight Board at a meeting on 12 October 2021,⁶⁰ where both forums recognised the need for data on the economic consequences of Long COVID this issue was not resolved. The LCGs’ position is that the barriers to gathering data were not insurmountable. Simple mechanisms for data gathering such as recording Long COVID sick leave in NHS HR systems, or other HR systems recording sickness absences, have not been implemented.⁶¹

⁵³ See the Long COVID Oversight Board Minutes from 12 October 2021 [INQ000111897].

⁵⁴ [INQ000092025/7].

⁵⁵ [INQ000652535/36].

⁵⁶ [INQ000651217/3].

⁵⁷ [INQ000656296/13-14].

⁵⁸ [INQ000656296/13-14].

⁵⁹ [INQ000588226/137]; [INQ000610840].

⁶⁰ [INQ000111897/1].

⁶¹ [INQ000111897/1].

36. The LFS is the key source of data on labour participation. The LFS was amended in 2020 and 2021 to include new questions but no express questions were added about Long COVID and its impact on individuals' ability to work or claim benefits.⁶² The Director General for DWP Services & Fraud, Disability and Health, Neil Couling, suggests that agents of data collection – survey respondents and administrative systems – lacked the understanding and language to provide accurate and consistent data and refers to Long COVID as an example of this.⁶³ Yet he does not explain how the ONS could obtain reliable data on the prevalence and severity of Long COVID in the CIS survey but not on the employment outcomes of those individuals in the LFS. Nor does this explain why there remains a lack of data gathering on the impact of Long COVID on labour force participation in the present day.
37. The LCGs ask the Inquiry to explore why, despite the recognised gap in data on the economic impacts of Long COVID, no steps were taken to fill it.

Long COVID and key economic interventions

38. The UK Government relied heavily on economic interventions to stabilise and protect the economy but remarkably, the risk of long-term sequelae and the emerging evidence on Long COVID was not considered in any one of the key economic interventions at the time of their development nor during their operation.⁶⁴
39. Many of the witnesses justify the failure to consider Long COVID with reference to the lack of awareness of Long COVID in early 2020 when the economic interventions were designed. For example, Tim Leunig, former economic adviser to the Chancellor, states that the failure to consider Long COVID in the design of the Coronavirus Job Retention Scheme (“**CJRS**”) was “*self-evidently*” as Long COVID was “*not a concept in March 2020*.”⁶⁵ Baroness Thérèse Coffey, then Secretary of State for Work and Pensions, also states that Long COVID emerged as a challenge after DWP introduced temporary Covid-19 SSP and SSPR provisions.⁶⁶ Katie Farrington, Director for Universal Credit and Employment Policy stated that “*We did not know about the existence or prevalence of Long COVID in March 2020 and, as such, the Department’s design of the Universal Credit uplift policy could not take Long COVID into account*.”⁶⁷

⁶² [INQ000587400/22].

⁶³ [INQ000655668/147].

⁶⁴ [INQ000614156/149]. [INQ000588231/231]; [INQ000655668/161, 163]; [INQ000657741/17, 36]; [INQ000661480/22,59]; [INQ000653969/110].

⁶⁵ [INQ000588231/231].

⁶⁶ [INQ000588238/23].

⁶⁷ [INQ000657741/17].

40. None of the witnesses explain why they failed to take into account the risk of long-term sequelae when designing the relevant schemes or why they did not review and adapt the schemes to respond to the needs of the growing number of people suffering from Long COVID either in Summer 2020 or subsequently. That is despite:
- i. Professor Brightling and Dr Evans' evidence to the Inquiry in earlier modules that the risk of long-term sequelae was well known at the beginning of the pandemic.⁶⁸
 - ii. Matt Hancock, then Secretary of State for Health and Social Care was also advised about the risk post-viral conditions and persistent symptoms from Covid-19.⁶⁹
 - iii. Evidence of Long COVID became known relatively quickly to the extent that by Summer 2020, the LCGs had formed and were advocating government for recognition and a response to Long COVID.⁷⁰
41. **Mitigating the financial impact of Long COVID:** Baroness Coffey states that DWP “*continued to monitor and consider*” the UK government’s support provisions in line with “*emerging evidence*” on Long COVID. Baroness Coffey does not, however, exhibit any evidence of DWP monitoring Long COVID nor does she exhibit or describe any assessment or any strategy aimed at mitigating the impact of Long COVID on workforce absences. This is especially surprising given that a ministerial group meeting on 21 July 2021 identified the following issues for DHSC to address “*what mitigations do DHSC/ DWP have on sickness absence?*”⁷¹ Even when it was observed that ill health “*costs business x£100bn per annum,*”⁷² at a Long COVID Oversight Board meeting on 12 October 2021, DWP refused to change their approach to Long COVID unless DHSC pressed for it.⁷³
42. As set out above, the LCGs maintain that a number of simple economic interventions could have mitigated the severe financial impact of Long COVID, for example:
- i. **CJRS:** Beth Russell suggests that employees with Long COVID could have received financial support through CJRS if eligible but does not recognise that this was a matter of chance not choice.⁷⁴ The experience of the LCG’s members

⁶⁸ [INQ000280198/31]; Transcript 13 October 2023 [M2D9/90/10-91/23].

⁶⁹ [INQ000273833].

⁷⁰ [INQ000657079/5-6]; [INQ000656296/4].

⁷¹ [INQ000092058].

⁷² [INQ000111897/2].

⁷³ [INQ000111897].

⁷⁴ [INQ000588226/141].

was that CJRS, where used, was a positive measure but it relied on employer participation. For example, members of both LCGs report their employers refusing to participate in the furlough scheme after an employee with Long COVID ran out of sick leave.⁷⁵ Dr Brewer has recommended that HMT and HMRC consider amending the furlough scheme in a future pandemic to allow employees to request to be placed on furlough.⁷⁶ This could resolve the gap identified by the LCGs.

- ii. **SSP:** the extent to which SSP would cover people with Long COVID demanded assessment and review. There have been long standing concerns about eligibility for and level of SSP which affected many people with Long COVID.⁷⁷ For those who were eligible, SSP did not protect their jobs for the duration they needed. On 16 October 2020, Ministerial Advice to the Welsh Ministers considered potential enhancements to statutory sick pay for the social care sector.⁷⁸ The advice did not make any recommendations in relation to Long COVID even though the impact on care workers suffering from Long COVID following workplace acquired infections was acknowledged.⁷⁹ This reflects a failure to properly address the financial difficulties faced by workers who developed Long COVID from workplace acquired infections. Key workers risked their lives and their health to work during the pandemic only to lose their jobs when their sick leave ran out. The LCGs ask why, save for this one advice to the Welsh Ministers, decision makers did not consider extending SSP for people who contracted Covid-19 in the course of their work who went on to develop Long COVID.

43. The LCGs ask the Inquiry to explore why, knowing the economic benefit to keeping people in work, economic interventions targeted towards supporting people with Long COVID to remain in work were not developed.

44. **Alleviating economic hardship caused by Long COVID:** Many of the witnesses have sought to excuse the failure to consider Long COVID by pointing to the availability of benefits for people suffering from Long COVID.⁸⁰ The availability of benefits was not, and is not, a panacea for the financial challenges that people with Long COVID faced. As the LCGs and TUC noted in their report of 2023, “*universal*

⁷⁵ [INQ000656296/36]; [INQ000651217/5].

⁷⁶ [INQ000588132].

⁷⁷ [INQ000272240/12-13]; [INQ000587945/24].

⁷⁸ [INQ000493711].

⁷⁹ [INQ000493711/13].

⁸⁰ [INQ000588226/141] [INQ000655668/161]

*credit is not fit for purpose..*⁸¹ The LCGs strongly endorse the TUC's recommendations for reform to universal credit and the wider welfare system.⁸² In any event, there was a need for a Long COVID specific strategy to ensure the benefits system recognised and could respond to the needs of people with Long COVID. Yet none of the witnesses from DWP have exhibited any strategy or plan to address the increased demand for support from people with Long COVID.⁸³

45. Given that the DWP attended the Long COVID Oversight Board convened by the DHSC,⁸⁴ its failure to respond is surprising. The Board discussed issues including DHSC/ DWP Work and Health Unit's objective to support people with health conditions and/ or disabilities to enter, remain in or return to the workplace.⁸⁵ Further there were meetings between the DWP, DHSC and BEIS about policy response on Long COVID (disclosure of which has not been provided as yet).⁸⁶ DWP was well informed of the challenges facing people with Long COVID and yet failed to respond.

V. EMERGING THEMES FOR INVESTIGATION IN MODULE 9

46. The LCGs have identified three themes underpinning the failure to respond to Long COVID that warrant further investigation in Module 9: (i) the denial and minimisation of Long COVID by leading individuals, (ii) the shifting of responsibility for the economic impacts of Long COVID, and (iii) the prioritisation of the economy over public health.

The denial of and indifference towards Long COVID

47. Although the risk of long-term sequelae from a novel coronavirus was well-known,⁸⁷ there was indifference and, in some cases, outright disbelief, in response to the reports of long-term sequelae of Covid-19, Long COVID. Dr Helen Ward, Professor of Public Health, Imperial College London has said *"I think it's important to acknowledge that gaslighting is a real phenomenon. Many people, including physicians, are sceptical about its existence and believe it to be a psychosomatic condition. This undermines the experiences of those affected. This lack of recognition makes it challenging for people to find support..."*⁸⁸

⁸¹ [INQ000272240/14].

⁸² [INQ000587945/28-29].

⁸³ [INQ000588238/92-93].

⁸⁴ [INQ000067093]; [INQ000111897]; [INQ000067416]

⁸⁵ [INQ000112153/3] [INQ000111897/3]

⁸⁶ [INQ000283444] – 11 May 2021 meeting; [INQ000111897/1] – 21 October 2021 meeting. INQ000283476/2 *"no appetite to produce specific guidance around long COVID."*

⁸⁷ [INQ000280198/31]; Transcript 13 October 2023 [M2D9/90/10-91/23].

⁸⁸ [INQ000657077/68].

48. Mr Hancock was aware of Long COVID in May 2020,⁸⁹ as was Mr Johnson,⁹⁰ yet there was no known response to the risk of Long COVID. When the LCGs wrote to the then Prime Minister on 3 July 2020, copying in all MPs, and asking for recognition of the impact on the economy of large numbers of people on long-term sick leave, the only response came from Public Health England who stated that they did not have responsibility for economic considerations.⁹¹ Months later, in October 2020 when delaying calls for a second lockdown, Mr Johnson dismissed research on Long COVID as “*bollocks*”.⁹² He continued to minimise the debilitating symptoms of Long COVID asking in relation to the Spring Roadmap in March 2021 “*do we really believe in long covid? Why can’t we hedge it more? I bet it is complete gulf war syndrome stuff.*”⁹³
49. Just as Dr Tetlow observes in her report that Treasury officials may have interpreted a ministerial preference for analysis that emphasised the costs of restrictions following the Chancellor’s known scepticism about lockdowns,⁹⁴ it appears that the Prime Minister’s officials moderated the gravity of Long COVID. Examples of the wider minimisation of Long COVID include a delay until July 2021 in providing advice to Mr Johnson on the evidence underpinning Long COVID,⁹⁵ and the minimal, at best passing, references to Long COVID in advice on strategies that embraced high rates of transmission.⁹⁶
50. The disbelief and minimisation of Long COVID was shared by other ministers. Baroness Coffey, then Secretary of State for Work and Pensions, was indifferent to the impact of Long COVID expressing concern in a call with Lord Vallance that affected people would be “*making false claims for money from DWP.*”⁹⁷ Analogous sentiments were expressed at a Covid-O Meeting attended by Baroness Coffey on 5 July 2021 where it is minuted “*the term ‘long covid’ should not be used loosely as it described a number of syndromes, at a time when Personal Independence Payment claims had reached an all time high.*”⁹⁸ This approach to Long COVID is reflected in the frontline

⁸⁹ [INQ000273833].

⁹⁰ In May 2020, Mr Johnson shared an article on Long COVID with advisers [INQ000102087]; [INQ000102085].

⁹¹ [INQ000238582]; [INQ000656296/7]; [INQ000272236/1].

⁹² [INQ000251910/9].

⁹³ [INQ000214216/52].

⁹⁴ [INQ000588130].

⁹⁵ [INQ000252817].

⁹⁶ [INQ000657079/53-54]; [INQ000092058]; [INQ000055240].

⁹⁷ [INQ000273901_0274].

⁹⁸ [INQ000092025/7].

response: some of the LCGs' members were denied support because the assessor did not believe Long COVID was "real."⁹⁹

51. Other government departments appear to also have taken this approach. For example, the minutes of a DfE permanent secretary stakeholders meeting on 9 June 2021 recorded in regard to healthcare workers and teachers that *"it is becoming apparent that many of the symptoms attributed to long COVID may be due to burnout and exhaustion rather than infection with the virus."*¹⁰⁰
52. The LCGs ask the Inquiry to investigate whether and how the disbelief in Long COVID affected the lack of response to the economic impact of Long COVID.

The Abdication of Responsibility for Long COVID

53. As well as being a health issue, Long COVID had significant socio-economic consequences requiring a 'whole systems approach' i.e. a cross-governmental response which included perspectives from LCGs.¹⁰¹ DHSC led the response to Long COVID in relation to healthcare but no other government department substantively engaged with the consequences of Long COVID in their area of remit. Before this Inquiry, the relevant government departments appear to have all passed responsibility for Long COVID to others or back to DHSC.¹⁰² Notably, although HMT was warned in November 2020 that they would need to consider *"those who will be affected by Long COVID if we don't get the pandemic under control soon"*¹⁰³ HMT appeared to consider Long COVID was a health matter and any costs implications related to funding for the NHS or welfare support.¹⁰⁴ The documents reveal that HMT did not lead (or even contribute to) the development of any strategies to respond to the impact of workforce absences due to Long COVID.
54. DHSC established a short-lived attempt to discuss and co-ordinate *"whole of government activity"* on Long COVID through the Long COVID Oversight Board which ran from June to November 2021.¹⁰⁵ Yet the Board did not have a formal governance arrangement and did not deliver a programme of work. It is also unclear how actions agreed at the Board were followed through and if they had a substantive impact on

⁹⁹ [INQ000656296/38,41].

¹⁰⁰ [INQ000542824/4].

¹⁰¹ See further [INQ000657079/121].

¹⁰² [INQ000653220/22]; [INQ000588230/45]; [INQ000656295/27].

¹⁰³ [INQ000609516].

¹⁰⁴ [INQ000588226/137].

¹⁰⁵ M2 [INQ000273742/5].

each department's area of work. For example, on 12 October 2021, following an extensive discussion on the impact of Long COVID on employment, DWP agreed to explore the extent of new claims related to Long COVID.¹⁰⁶ Nothing is known to have come from this and it is not addressed in DWP witness statements. The LCGs also note that their voices were unrepresented in this forum which was kept separate from the Long COVID Ministerial Roundtables where they could share their members' current experiences.

55. The LCGs ask the Inquiry to investigate why each government department failed to engage with and take any action in response to the economic impact of Long COVID that fell within their remit. They also ask the Inquiry to explore why there was not a whole systems approach to Long COVID.

The False Economy: The prioritisation of the economy over public health

56. The UK Government's response to the pandemic has been characterised by a prioritisation of the health of the economy over the wellbeing of the public. This is plainly a false economy. As Ben Warner noted early in 2020, the workforce is one of the most important things for a "*functional economy*."¹⁰⁷ The LCGs observe that the UK Government did not recognise the threat posed to the economy by a significant increase in people whose health was damaged by Covid-19 in the long-term.
57. A partial explanation for the UK Government's approach can be found in Dr Tetlow's report where she points to systemic failings in the Government to "*integrate economic and public health evidence and analysis*."¹⁰⁸ Dr Tetlow also identifies a myopic focus on how the economy fared under restrictions. This led to a significant overestimation of the economic costs of the restrictions and underestimated the benefits including reducing the incidence of Long COVID.¹⁰⁹ The sparse references to Long COVID in advice to Ministers in this period is evidence of this approach.¹¹⁰
58. Long COVID was dismissed as a "*public health problem*" even as the economic impact on labour force participation was acknowledged.¹¹¹ As set out above, as the Government engaged in "*High prevalence Planning*" in July 2021, only DHSC/ DWP were identified to consider the impact of Long COVID on public and private sector

¹⁰⁶ [INQ000111897].

¹⁰⁷ [INQ000654339]; [INQ000657617/14].

¹⁰⁸ [INQ000588130/9].

¹⁰⁹ [INQ000588130/56].

¹¹⁰ [INQ000065143]; [INQ000113749]; [INQ000092058]; [INQ000113756/7].

¹¹¹ [INQ000217016/17].

workforces.¹¹² There was no input from BEIS, HMT and HMRC from an economic perspective. There is no known outcome from DWP/ DHSC being identified to develop a strategy to mitigate the impact of Long COVID on the workforce.

VI. CONCLUSIONS

59. Long COVID has '*long consequences.*' The LCGs want to know why the UK Government failed and continues to fail people with Long COVID. Long-term sequelae were foreseeable, and the emerging evidence of Long COVID was repeatedly highlighted by the LCGs since early Summer 2020. The LCGs' campaign in summer 2020 highlighted how thousands were feeling "*abandoned, conflicted, ignored...*"¹¹³ The LCGs ask the Inquiry to investigate why they were ignored and why the UK Government did not introduce early interventions which could have better supported people with Long COVID to remain in work if able, or access the support they were assured was available.
60. The LCGs ask that the Inquiry investigate why the UK Government failed to respond to the economic impact of Long COVID and in particular:
- i. Why did the UK Government not address Long COVID as a whole system problem?
 - ii. Why were there no steps taken to obtain data on the economic impacts of Long COVID? And why are there no efforts being made to obtain this data today?
 - iii. How did the disbelief and minimisation of Long COVID affect the response to the economic impact of Long COVID?
 - iv. Why was there no guidance developed for employers on how to recognise and respond to Long COVID? And why were DWP benefits assessors not provided with guidance in order to respond to Long COVID?
 - v. Did DHSC/ DWP develop a strategy to respond to the impact of Long COVID on the workforce and increased demand for welfare support? If not, why not?
 - vi. Why, knowing the economic benefit to keeping people in work, were there no economic interventions which were targeted towards supporting people with Long COVID to remain in work if able?
 - vii. Why did each respective government department fail to engage with and take any action in response to the economic impact of Long COVID within their remit.

SARAH HANNETT KC

¹¹² [INQ000092058].

¹¹³ [INQ000656296/10].

**SHANTHI SIVAKUMARAN
JANE RYAN
BHATT MURPHY SOLICITORS**

10 November 2025