

UK COVID-19 PUBLIC INQUIRY

MODULE 9 JOINT WRITTEN SUBMISSIONS ON BEHALF OF LONG COVID SOS AND LONG COVID SUPPORT

Hearing Date – 23 October 2024

I. INTRODUCTION

1. These submissions are made on behalf of Long Covid SOS and Long Covid Support (**‘the Long Covid Groups’** or **‘LCGs’**) in advance of Module 9’s first preliminary hearing.
2. The LCGs represent a significant cohort of the population whose health was profoundly impacted by Long Covid resulting in long-term financial consequences for them and their families. An estimated 2 million people, who represent 3.3% of the population in England and Scotland, experienced self-reported Long Covid as of March 2024.¹ 74.7 % of those with self-reported Long Covid – an estimated 1.5 million people – reported that Long Covid adversely affected their daily activities and 19.2% – 381,000 people - reported their ability to undertake daily activities had been *“limited a lot.”*²
3. In April 2021, the Cabinet Office Covid-19 Taskforce anticipated that Long Covid would impact on the economy.³ Later studies by the Institute for Fiscal Studies (**‘IFS’**) and Cambridge Econometrics have supported those predictions. The July 2022 IFS

¹<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/selfreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland>

²<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/selfreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland>

³ [INQ000292660].

Report on Long Covid and the Labour Market found that people with Long Covid “*have an increased risk of reducing their work hours to zero, with an associated fall in earnings....*”⁴ IFS assessed that there could be an impact at a macro level, “*in aggregate, this could represent a moderate impact on the labour market*”⁵ whilst on an individual level “*the impact of Long Covid on labour market activity can be reasonably long lasting...*”⁶ The IFS also found that in addition to established demographic characteristics of Long Covid, in 2021, Long Covid was “*disproportionately concentrated on more deprived groups.*”⁷ Cambridge Econometrics E3ME macroeconomic model suggests that Long Covid may have a macroeconomic cost of £1.5 billion of GDP each year.⁸ The ONS reported in November 2023 that Long Covid could be one of the influencing factors for a documented rise in long-term sickness being reported.⁹

4. These findings correlate with the experiences of people with Long Covid who have suffered loss of earnings, regression in career advancement, complete loss of livelihoods, financial instability and in some cases the loss of their homes due to the impact of Long Covid on their ability to work.
 - a. One LCG Member said that they did not “*receive any sick-leave payments*” because they were self-employed. They moved out of their home in order to rent it out to generate income to live on, and now rely on loans from friends and support from community charities. They are still effectively homeless.¹⁰
 - b. Another LCG Member reported that Long Covid meant they could no longer function as they had before. They said, “*it absolutely flattened me. So, I had to leave employment.*” Her husband became the sole breadwinner in the house.¹¹

⁴ IFS, “*Long Covid and the Labour Market*,” July 2022.

⁵ IFS, “*Long Covid and the Labour Market*,” July 2022.

⁶ IFS, “*Long Covid and the Labour Market*,” July 2022;

⁷ IFS, “*Long Covid and the Labour Market*,” July 2022.

⁸ See also the macro-economic impact of Long Covid on GDP analysed by Cambridge Econometrics: “*The Economic Burden of Long Covid in the UK*” March 2024 https://www.camecon.com/wp-content/uploads/2024/03/The-Economic-Burden-of-Long-Covid-in-the-UK_Cambridge-Econometrics_V1.1_March2024.pdf

⁹ LCGS M3 Witness Statement [INQ000370954] [8.2].

¹⁰ [INQ000356272] p.3.

¹¹ [INQ000356273] p.10.

5. The LCGs support the modular approach adopted by the Inquiry which has enabled the requisite focus on each of the core issues arising from the Covid-19 pandemic response. They anticipate that Module 9's focus will ensure that there is proper scrutiny of the Government's economic interventions in response to Covid-19, and specifically Long Covid, to inform the present and continuing response to Covid-19, in addition to the response to a future pandemic of a novel virus.
6. The LCGs address the following matters on the agenda.
 - a. Scope
 - b. Rule 9 Requests
 - c. Disclosure
 - d. Expert evidence
 - e. The KLOE for Every Story Matters.

II. SCOPE

7. The LCGs are keen to support the Inquiry's timely investigation into the economic interventions taken by the government across all four nations of the United Kingdom. Counsel to Inquiry's ('CTI') note for Module 9 has helpfully set out at [30]-[31] that the scope is provisional and is "*primarily an investigation into the response of government to the economic impact of the pandemic...*" It is understood that CTI will examine the broad overarching themes in the Scope concisely summarised at [32] through "*in depth analysis*" of **some** of the key economic interventions which will be identified through a process of evidence gathering and by engagement with Core Participants. The LCGs support CTI's inclusive approach through the invitation of proposals from CPs of areas for investigation in Module 9 at [36].
8. The LCGs offer the following key themes, drawn from their personal experiences, that they say call for in depth analysis:

- a. The provision of financial support for self-isolation, and other economic policies aimed to reduce transmission of the virus to facilitate workers' self-isolation during lockdowns and/ or when infected.
 - b. The provision of long-term sick pay, and other financial and occupational support for people whose ability to work was impacted by Long Covid, in particular the support provided to healthcare workers, teachers and other key workers. This must also include an assessment of the support provided to those who are no longer able to work, and who have lost their livelihoods entirely, because of Long Covid.
 - c. The provision of funding for public services to support people with Long Covid whose financial, social, and emotional wellbeing was affected in addition to the direct damage to their health.
 - d. The issuing of guidance and support for businesses and organisations on how to support workers and employees who suffer from Long Covid.
9. A particular area for focus which cuts across those themes is the provision of occupational support, including but not limited to long-term sick pay, for healthcare workers who suffer from Long Covid. Many LCGs members worked on the frontline as healthcare workers, and through workplace-acquired infections, now bear the long-term consequences on their health, financial, social and emotional wellbeing.¹² The disabling impact of Long Covid on their health has severely limited their ability to work, in some cases permanently. The Inquiry has heard compelling evidence in Module 3 to date about the difficult working conditions faced by healthcare workers and support staff in healthcare settings who were not provided with adequate protections. The Inquiry has, in Module 3 and earlier modules, stopped short of asking what occupational support **should** be in place for those whose health has been injured by the virus.¹³

¹² See for example the case studies in the LCGs Module 3 Witness statement at pp.10 – 11. The LCGs can provide the Inquiry with more detailed case studies on request.

¹³ See recommendations proposed by Long Covid Support and TUC in a Joint Report, *Long Covid at Work*, available at: <https://www.tuc.org.uk/sites/default/files/2023-03/Long%20Covid%20at%20Work%20report%20-%20FINAL%20COLOUR%202.pdf>.

10. The consequences of the absence of targeted economic intervention for healthcare workers with Long Covid, and the corresponding need for occupational interventions is a pressing current concern. It should also inform future pandemic planning: the economic interventions necessary to support those who risk their personal health to safeguard the health of the nation is a core element of any pandemic response. The UK cannot justifiably call upon its healthcare workers again in a future, as yet unknown, pandemic if it did not look after the healthcare workers who sacrificed their health and wellbeing in this present Covid-19 pandemic. The Inquiry is therefore asked to confirm that these matters will be properly investigated within Module 9, and if not, to confirm that this critical issue will not be overlooked by the Inquiry.
11. As members of the LCGs continue to suffer from the economic fallout of Long Covid, they are anxious that the Inquiry's recommendations draw on their very real and present experiences. They ask that the key themes set out at paragraph 8 above are subjected to in depth analysis and incorporated into the List of Issues for Module 9.

III. RULE 9 REQUESTS

12. The LCGs welcome the explanation given by the Inquiry Legal Team as to the progress of its work to date in Module 9. The Inquiry has already sent a significant number of 'questionnaires' to associations of businesses in key economic sectors. The LCGs would welcome confirmation on whether the Inquiry has issued any Rule 9 requests to date, and if so, the recipients of those requests
13. The LCGs make the following preliminary observations in relation to those requests:
- a. The predominance of requests to business networks risks generating an imbalance of perspectives in which the worker and employee experience will be lost.¹⁴

¹⁴ There are a very limited number of Trade Unions or representative organisations for employees identified for receipt of questionnaires.

- b. As the stated intention of Module 9 is to investigate the government's economic interventions, there is a surprising absence of questionnaires to the responsible government departments.
- c. If not already addressed, questionnaires should explicitly include questions to recipients regarding the impact of, and any response, to Long Covid.

14. These observations inform the following specific submissions.

i. Supplementary organisations

- 15. It is unclear whether any Rule 9 requests have been issued to the responsible government departments. For the avoidance of doubt, the LCGs anticipate that Rule 9 requests which specifically address Long Covid will need to be issued to the government departments who were granted core participant status and the responsible Secretary of State for each department.
- 16. Noting CTI's observation at [32] that "*evidence of individual or organisational impact will nonetheless be a core component*" as it may "*give context to the economic challenges,*" the LCGs are also willing to provide detailed evidence about the economic impact of Long Covid on their members.
- 17. The LCGs respectfully suggest that the Inquiry will be assisted by a Rule 9 statement from the following non-government organisations:
 - a. Long Covid Physio who can speak to impact of Long Covid on their members' ability to work and need for phased returns.
 - b. Professor Stavros Petrou, Academic Research Lead in Health Economics and Professor of Health Economics, Nuffield Department of Primary Care Health Sciences who can speak to the economic impact of Long Covid through his work in the LOCOMOTION Study.¹⁵
 - c. The Society of Occupational Medicine who can speak to the impact of Long Covid and the occupational adjustments necessary to facilitate a return to work.

¹⁵ Sivan et al. Long Covid Multidisciplinary consortium Optimising Treatments and services across the NHS (LOCOMOTION): protocol for a mixed methods study in the UK, 17 May 2022 <https://pubmed.ncbi.nlm.nih.gov/35580970/>; See also Kwon et al, "*Impact of Long Covid on productivity and informal caregiving,*" Eur J Health Econ, 2024 Sept 25. <https://pubmed.ncbi.nlm.nih.gov/38146040/>

- d. The Royal College of Occupational Therapists who can speak to the impact of Long Covid and the occupational adjustments necessary to facilitate a return to work.
- e. SCOPE who can speak to advice given, and support needed, for people with Long Covid and claims for disability benefits.
- f. Citizens Advice Bureau who can speak to advice given, and support, needed for people with Long Covid and claims for disability benefits and other financial support.
- g. Trade Union Congress, and occupation specific unions such as NASUWT and NUT, who can speak to the employment impacts of Long Covid and recommendations to support people with Long Covid.¹⁶
- h. The Health Foundation who has carried out research into economic, social and environmental factors sharing health and driving inequalities.¹⁷
- i. Joseph Rowntree Foundation who undertook modelling of the impact of Government decisions on benefits on people.¹⁸

ii. Rule 9 Requests related to Long Covid

18. At this early stage in the investigative process, the LCGs seek reassurance that the Rule 9 Requests being prepared and issued include substantive requests related to Long Covid. They outline below the lines of investigation that the Inquiry is invited to include in Rule 9 requests. They remain willing to meet with the ILT to assist in identifying further lines of enquiry relevant to Long Covid.

- a. Rule 9 requests to business networks and associations should include specific requests about i) the impact of Long Covid on their membership and/ or workforce including any data recorded about that impact, ii) financial and other occupational support provided to employees who suffer from Long Covid, and

¹⁶ Long Covid Support and TUC in a Joint Report, *Long Covid at Work*, available at: <https://www.tuc.org.uk/sites/default/files/2023-03/Long%20Covid%20at%20Work%20report%20-%20FINAL%20COLOUR%202.pdf>.

¹⁷ See for example M Suleman et al, *Unequal pandemic, fairer recovery: the Covid-19 Impact inquiry report*, July 2021 and the Interim Report of the Commission for Healthier working Lives, “Towards a healthier workforce,” October 2024 , <https://www.health.org.uk/publications/towards-a-healthier-workforce>

¹⁸ Joseph Rowntree Foundation modelling the impact of the Government decision to cut universal Credit in October 2021 <https://committees.parliament.uk/publications/7985/documents/82365/default/>.

- iii) any Government assistance or interventions that could have improved their response to support for people with Long Covid.
- b. Rule 9 requests to the responsible government departments should include specific requests related to i) assessments of the impact of Long Covid on the economy, ii) any advice or recommendations on actions to be taken in response, and iii) any decisions taken to support people with Long Covid.
- c. Rule 9 requests to representative organisations should include specific requests related to i) the financial and economic impact of Long Covid, and ii) recommendations for interventions needed to support people with Long Covid.

IV. DISCLOSURE

19. Through their engagement in earlier modules of this Inquiry, the LCGs have identified a number of categories of documents which may assist the Inquiry in their investigations in this module:

- a. Any advice, assessments or reports by Cabinet Office, the Covid-19 Taskforce or similar regarding the economic impact of Long Covid.¹⁹
- b. Any advice, policies, reports or related documents by DWP and BEIS on Long Covid.²⁰
- c. Minutes of meetings held between Department for Work and Pensions ('DWP') and Department for Health and Social Care ('DHSC') on Long Covid.²¹

¹⁹ An example of such a paper was disclosed in Module 2. Covid-19 Taskforce Paper, *In Depth: Long Covid* [INQ000292660].

²⁰ DHSC Long Covid Dashboards refer to BEIS/ DWP clarifying that their "policy position" is that Long Covid should be considered in the same way as other long term conditions. [INQ000283475]; [INQ000283476].

²¹ See for example reference to a meeting on 27 April 2021 that DHSC, DWP and Industrial Injuries Advisory Council (IIAC) met to continue discussions concerning the call to classify Long Covid as an occupational disease for key workers. [INQ000283440].

- d. Minutes of meetings between the Department for Business, Energy & Industrial Strategy ('BEIS')²² and DHSC on Long Covid.²³
 - e. Minutes, documents and reports from Long Covid Oversight Board relating to support for DWP, BEIS and related departments on economic impact of Long Covid.²⁴
 - f. Reports from the Office for Budget Responsibility which forecasted the impact of Long Covid on the economy.²⁵
 - g. Anonymised data on the number of people affected by Long Covid and support provided recorded by all material providers.
20. The LCGs appreciate that the ILT are at the nascent stages of the disclosure phase and anticipate that they can assist the ILT with further targeted requests for disclosure once the disclosure phase has begun.

V. EXPERT EVIDENCE

21. The thoughtful and comprehensive expert list identified in CTIs note at [54] is endorsed by the LCGs. They ask that the letters of instructions to the identified experts reference Long Covid and that the experts are requested to draw out the impact of Long Covid on their area of expertise. Specific issues related to Long Covid falling within the broad areas identified for expert evidence include:
- a. **Economic policy making** – assessment of any structures and processes used to design and deliver economic interventions in response to the anticipated burden of Long Covid

²² BEIS was replaced in 2023 with the Department for Business and Trade and the Department for Energy Security and Net Zero.

²³ See for example reference to a meeting on 11 May 2021 to discuss the challenges Long Covid poses to the workforce. [INQ000283444].

²⁴ For example see reference to work carried out by Long Covid Oversight Board for DWP on long term sick [INQ000092058].

²⁵ [INQ000114451/121]; [INQ000114450/136].

- b. **Public finances and macroeconomics** – analysis of whether any funding mechanisms available to government could have been and were used to support people with Long Covid, in particular to provide economic support for healthcare workers who were directly affected by Covid-19.
- c. **Devolved and local government finance** - consideration of whether there were any differential barriers to allocation of funding for support for Long Covid in the four nations and locally.
- d. **Labour market and inequality** – identification of the impact of Long Covid on the labour market and consideration of the disproportionate impact of Long Covid on different demographics.
- e. **Benefits** - explanation of how and when Covid-19 came to be included on the list of disability categories for Personal Independence Payments,²⁶ and the barriers faced by people with Long Covid in accessing benefits.²⁷

VI. KEY LINES OF ENQUIRY (‘KLOE’) FOR EVERY STORY MATTERS

22. The LCGs welcome the Inquiry’s identification of people who have Long Covid as a “*target group*” for the Module 9 themed reports by Every Story Matters. They ask that the Inquiry keep in mind the following matters in the course of the investigations for Every Story Matters:

- a. Long Covid has an ongoing impact on people and there is no definitive prognosis nor treatment. It is therefore inapposite to refer to people “*who had Long Covid*” applying the past tense.

²⁶ DWP, Dataset: Personal Independence Payments (Cases with Entitlement) https://stat-xplore.dwp.gov.uk/webapi/metadata/PIP_Monthly/Disability.html

²⁷ DWP Report “*Barriers to accessing Health Support for PIP, NS ESA, and UC Claimants*,” 7 October 2024 <https://www.gov.uk/government/publications/barriers-to-accessing-health-support-for-pip-ns-esa-and-uc-claimants/barriers-to-accessing-health-support-for-pip-ns-esa-and-uc-claimants>

- b. There is no singular experience of Long Covid; people with Long Covid include the self-employed, the employed, business owners and workers and those who were already clinically vulnerable from other conditions before developing Long Covid. The Inquiry is urged to ensure that their various and overlapping experiences are adequately represented through the Every Story Matters project and is complemented by formal evidence before the Inquiry through appropriate Rule 9 Requests to organisations and individuals including the LCGs.

VII. CONCLUSIONS

- 23. The LCGs remain willing to assist the Inquiry in their investigation in this important Module.

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11 October 2024