

UK COVID-19 INQUIRY

WITNESS STATEMENT OF MIKE ORMEROD AND NATALIE ROGERS ON BEHALF OF LONG COVID SUPPORT

1. Introduction

- 1.1. Our names are Mike Ormerod and Natalie Rogers. We both have volunteer roles with Long Covid Support (“LCS”) which is a registered charity (Charity Registration No. 1198938). The charity’s registered address is 87 Standen Road, London, SW18 5TR.
- 1.2. Natalie is a founding trustee of Long Covid Support, joining the organisation from its beginning in summer 2020, becoming a director in May 2021 when LCS was registered as a charitable company limited by guarantee, and then a trustee upon its registration as a charity in May 2022.
- 1.3. Mike joined in October 2023 as a member of the Operations Committee and with a role focusing on the economic impact of Long COVID and generating actionable insight for decision makers in Government, NHS, Department of Work and Pensions (“DWP”) and other government bodies and agencies. He is also the Patient Public Involvement (PPI) Co-Chair for the Leeds Long COVID Rehabilitation Service and is the PPI Co-Chair of a £1 million+ research bid to the National Institute for Health Research to develop a national NHS framework for Long COVID and ME/CFS.
- 1.4. Both of us have Long COVID, Mike since September 2020 and Natalie since March 2020.
- 1.5. We make this statement on behalf of Long Covid Support and confirm that we are duly authorised to do so. We make this statement from our collective knowledge and from information that has been provided to us. We identify below the source of any information that is not from within our own knowledge.

1.6. We make this statement in response to the Inquiry's request for evidence under Rule 9 of the Inquiry Rules 2006 dated 9 April 2025. Long Covid Support has provided statements for Module 2; Module 3 of the Inquiry and Module 7 [INQ000280197; INQ000370954; INQ000587782] Natalie Rogers has provided a further impact statement in Module 3 [INQ000421868].

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PART A: Introduction to Long Covid Support (LCS)

2. Overview

- 2.1. Our experience of writing this statement has been physically, mentally and emotionally draining as we have documented matters which have been and continue to be our lived experience. We have both suffered neurological damage ("Brain Fog") which impacts our cognitive ability and the significant work involved has triggered Long COVID relapses.
- 2.2. Our evidence concerns the experiences of the members of LCS and the impact upon them of Government decision making and economic interventions. Later in the evidence we will discuss the costs of failure from economic interventions and we will discuss valuations of health-related quality of life, and of a year of life.
- 2.3. We know from experience that those costs of failure and valuations are measured by people dying and profound losses. Our members have become newly disabled, their lives have been radically altered, they have been unable to work, lost jobs, reduced hours or their symptoms have driven them to move to less demanding jobs. Their families have suffered, with financial insecurity and poverty. Their children's future lives have been changed due to disruptions to their education and to the impacts of insecurities in meeting basic needs such as food, housing, and heating.
- 2.4. We have relived our own experiences, the experiences of people we know, our members and the wider Long COVID community. We remember the people that we knew who have died either directly from COVID-19, from long term complications, or with Long COVID. We remember the people that we know who are living with Long COVID, and in too many cases just existing with Long COVID. We are reminded of the

collective grief at the loss of huge parts of our lives, both short-term and in far too many cases for the long-term.

3. Who we are and what we do

- 3.1. LCS was established on 2 May 2020. It began as a peer support Facebook group known as the 'Covid-19 Support Group.' Our organisation was established during the early days of the pandemic when there was a void in policy and medical information on the long-term effects of COVID-19.
- 3.2. Our organisation was created to share information and to provide support for people struggling to recover from COVID-19. We advocate on behalf of Long COVID sufferers, for appropriate recognition of the impacts of Long COVID on our lives and the economy more broadly. We engaged with the government and key decision makers seeking financial support, raising awareness of the wider economic impact of Long COVID, seeking UK policy changes regarding non-pharmaceutical interventions, employment, welfare, research, healthcare provision, and rehabilitation for sufferers of Long COVID.
- 3.3. In 2020, the group was renamed the 'Long Covid Support Group.' On 19 June 2020, LCS set up the Covid-19 Research Involvement Group. On 28 June 2020, LCS launched our website. On 26 May 2021 we registered as a charitable company and on 12 May 2022, LCS registered as a charity with the Charity Commission of England and Wales.
- 3.4. Our charity hosts one of the largest peer support groups of its type in the world, with members in over 100 countries and territories. Membership of the Facebook support group grew quickly, and at the time of signing this, there are now 67,800 members globally. We have over 24,700 UK members and 42,100 members internationally. The group has grown continuously since its creation and continues to grow, with membership increasing by around 500 a week to date.
- 3.5. Under the umbrella of LCS, there are other member groups that advocated for specific government and health policy in devolved nations – Long Covid Wales and Long Covid Scotland. They operate as separate organisations; however, we work closely together.

- 3.6. LCS is the Secretariat for the cross party All-Party Parliamentary Group (“APPG”) on Long COVID established in 2025 (chaired by Jo Platt MP, vice-chairs Lord Bethell, Lord Strasburger and Jodie Gosling MP).
- 3.7. A core aspect of our work arises from the economic impact of Long COVID. We have a designated multidisciplinary team, the LCS Employment Group, comprising of associate vocational rehabilitation professionals and people with lived experience. Within this, the Employment Advocacy Team has provided support to workers and employers concerning employees’ return to work. We have co-developed guidance with bodies including the UK’s Society of Occupational Medicine (“SOM”) and Chartered Institute of Personnel and Development (“CIPD”). The group have also worked extensively with unions and have collaborated with the Trades Union Congress (“TUC”) to run surveys into the impact of the condition on employment status and quality of life.
- 3.8. Through our advocacy and work supporting thousands of Long COVID sufferers, as well as our own personal experiences, we have identified several issues in relation to the financial and economic impact of Long COVID on people during the relevant period. The consequences of those decisions continue to be experienced by our members today.

4. Why did Long Covid Support emerge?

- 4.1. We should explain that LCS emerged due to the realities of people’s experiences suffering Long COVID. A key aspect of the experience of people living with Long COVID and the financial impacts upon them is the extent to which the Government failed to intervene to offer support and guidance to employers in the face of emerging evidence of a novel virus causing long term disease. Due to the disabling and fluctuating nature of Long COVID, many people with Long COVID needed non-financial occupational support, such as return-to-work adjustments, to remain in work.
- 4.2. We understand that Module 9 (and as far as we are aware, other Modules) will not investigate the non-financial occupational support provided to those that suffered long-term ill health/disability from COVID-19. Therefore, as requested, we do not address these issues in any detail in our statement; but the Inquiry will appreciate that in our advocacy and members’ lived experience, distinguishing between welfare benefits,

Statutory Sick Pay (“SSP”) or financial interventions by the Government and non-financial occupational support is artificial. The lack of *phased return to work* structures that dealt effectively with Long COVID symptoms and their fluctuating and variable severity, coupled with the lack of effective workplace adjustments has forced many of our members out of the workplace who would otherwise have been able to remain economically active.

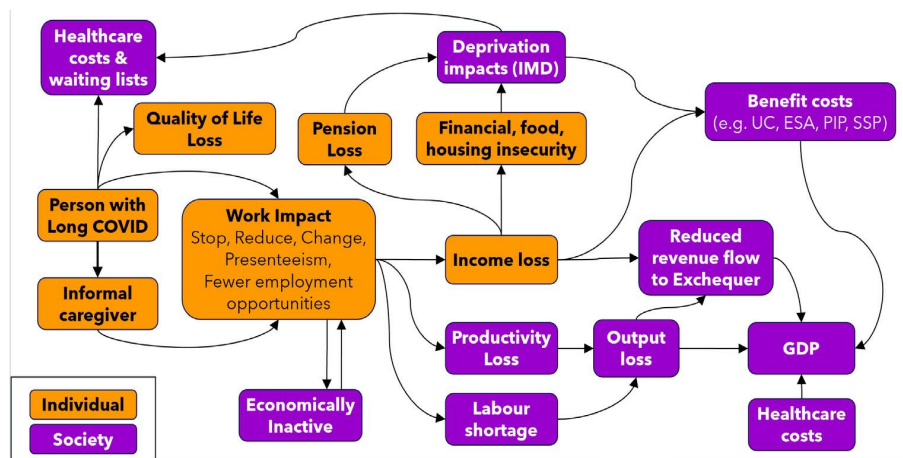
5. Long COVID is an ongoing public health crisis

- 5.1. The Inquiry is aware that many of our members and supporters contracted COVID-19 and developed Long COVID during the relevant period and continue to suffer the consequences today. The impacts felt by our members today and the growing numbers of people with Long COVID are driven by decisions taken around COVID-19 and Long COVID during the Inquiry’s relevant period, 1 January 2020 to 28 June 2022. Those decisions included denial and minimisation of Long COVID, unmitigated COVID-19 transmission leading to more Long COVID cases, wholly inadequate public health messaging about the risks from Long COVID and wholly inadequate economic impact assessments, to name just a few.
- 5.2. Long COVID is still an ongoing public health crisis. It’s a slow burn crisis. Long COVID is indiscriminate, it can affect anyone, regardless of age or prior health and fitness. Every COVID-19 infection carries a risk that an individual will develop Long COVID.
- 5.3. We invite the Inquiry to scrutinise in detail how the interventions, omissions and economic, fiscal and other policy decision making in the relevant period up to 2022 led to this ongoing public health crisis. It is essential that meaningful recommendations for change are made for future pandemics, and that these recommendations also influence what happens for people with Long COVID now, and for those who will develop Long COVID from the COVID-19 waves in the coming years.

6. Long Covid Support’s approach to economic impacts

- 6.1. During the relevant period (January 2020 to 28 June 2022) our capability was at the level of identifying gaps in economic impact assessments and raising those with government for further investigation (see section B and C for more detail). We also identified published research that covered economic impacts, both in the UK and globally, and highlighted these to government.

- 6.2. Our experience during the period highlighted the extremely limited economic impact assessments for Long COVID, and the lack of political will to undertake them. This lack of political will continues to the present day and drastically impacts government funding to investigate Long COVID's economic impact, provide effective financial support for people with Long COVID, and ultimately fund healthcare and research.
- 6.3. As a result, we have developed more in-house capability, using specific skills from our volunteers to produce actionable insight by analysing data from Freedom of Information requests, public domain data and online surveys of our membership. We also look for international comparators, as other countries do not have the same blind spot about Long COVID as the UK.
- 6.4. Due to the complex interactions, feedback loops/multipliers, dependencies and uncertainty between COVID-19, Long COVID, public health and economic interventions, we started using the whole-system approach in LCS at the end of 2023 – specifically, the Systems Thinking methodology, and making use of the skill sets of specific volunteers. We have also applied Systems Thinking to the analysis of the Inquiry's economic evidence and in our evidence presented in this witness statement. We note that there are ongoing initiatives in the Civil Service (championed by Sir Patrick Vallance when he was the Chief Scientific Advisor) on the adoption of System Thinking. [LCS/001 INQ000652441] and [LCS/002 INQ000652442]
- 6.5. LCS have developed a simple Systems Thinking model to describe these interactions from the perspective of a person with Long COVID. An earlier version of the model was presented to the Long COVID All Party Parliamentary Group. [LCS/003 - INQ000652443]



- 6.6. We take both a national view and a devolved nation view. We also look at economic impacts at the levels of local authorities, NHS Integrated care boards (“ICBs”), and even down to GP Primary Care Networks. We are just starting an initiative to look at MP’s constituencies to help them better represent their voters.
- 6.7. Equality is a core part of our approach.
- 6.8. The level we operate at is dependent on the issue we are investigating and the availability of data, both in the public domain and via Freedom of Information requests.
- 6.9. Our emphasis is on generating insight that triggers action from stakeholders, and not to provide a full business case valuation. Even if that action is simply a robust challenge to our insights, we see that as a good step as it increases both awareness and the evidence base for policy decisions. Our approach is to be compliant with government guidance, specifically the *Appraisal and evaluation in central government (HM Treasury Green Book)* [LCS/004 INQ000652444] and the *guidance on producing quality analysis (HM Treasury and Government Analysis Function’s Aqua Book)* [LCS/005 **INQ000625674** - addressed further below).

7. What is Long COVID

- 7.1. It may assist the Inquiry to have a summary of Long COVID, its prevalence, impact on daily lives, recognition, and the correlation to planning as regards economic decision making.

- 7.2. Long COVID is a patient derived term; patient advocacy was instrumental in the formal recognition of Long COVID as a clinical illness. We use the term 'Long COVID' as an umbrella term to encapsulate long-term illness caused by infection from COVID-19.
- 7.3. The fundamental approach to illness in the UK, of both benefits and employers, and also to a large extent of the NHS, can be described in our members' experience as 'You get sick with a known disease or condition, you get treatment or rehabilitation, you either die or recover to your best stable level, hopefully you re-enter the workforce, or in some cases you are no longer able to work'. Typically, return to work after an illness can be straight back to work full-time or done on a gradually increasing work commitment, usually over a period of up to 4 weeks. We call that fundamental approach "*Illness as Usual*" ("IAU").
- 7.4. Long COVID breaks that pattern. Long COVID is a complex, multisystem condition that significantly limits energy and can be profoundly disabling. It presents with a wide range of symptoms and varies greatly in terms of severity, duration, and recovery outcomes. Symptoms often fluctuate and tend to worsen with exertion—whether physical, cognitive, or emotional - essentially, any form of stress on the body. Recovery trajectories differ widely. Some individuals eventually return to their pre-illness level of health, while others experience only partial improvement. Unfortunately, some do not recover at all and risk getting worse and losing their baseline. Even those who show progress may face relapses, commonly triggered by overexertion or additional stressors, such as new infections or other illnesses. Because of its variability, individuals with Long COVID rarely encounter others whose experiences and symptoms mirror their own. Key relevant characteristics of Long COVID are:
- It did not exist until the pandemic.
 - It affects multiple organ systems – it is not just a respiratory illness.
 - Currently there are no agreed biomarkers or tests (e.g. blood tests) for diagnosis.
 - There is currently no cure.
 - Treatments are orientated around symptom management.

- Medical research has continually identified new symptoms – after five years there are over 200 identified symptoms across cognitive impairments, neurology including dysautonomia, immune system dysfunction, heart disease, gastrointestinal disorders, kidney disease, metabolic disorders, fibromyalgia and post-exertional malaise (a state of severe exhaustion that may happen after even minor activity — often leaving the patient unable to function for hours, days or weeks).
- Symptoms can fluctuate with varying severity up to the level of disability, they can change over time, they can be triggered by new events such as COVID-19 re-infection, other infections or illnesses, surgery and most importantly post exertional malaise.
- Long COVID has no standardised clinical pathway like the ones that exist for other diseases such as diabetes, cancer, cardiac disease, kidney disease etc.
- As the condition is only 5½ years old, long-term recovery is still an evolving picture.

7.5. Internationally, the medical knowledgebase continues to evolve rapidly. The US National Institute of Health database, PubMed, shows that by 28th June 2022, there were just under 11,300 scientific papers published globally on Long COVID and other long-term impacts of COVID-19. By 26th June 2025 this had risen to just under 28,500. This makes Long COVID one of the most researched conditions in a 5-year period. Long COVID research is now a torrent of water from a global fire hose. Yet, the UK government is continuing its failure to “drink from the fire hose” and use the research to support people with Long COVID.

7.6. The above aspects meant that people with Long COVID faced huge barriers in accessing health care, accessing benefits, getting a job or staying in work, social inclusion, family life, and in looking after their children or aging parents. All these barriers were made worse by the uncertainty about their future functional capability as it could vary significantly from day to day, week to week, month to month. [LCS/006 - INQ000652446]

8. Long COVID – Prevalence & Labour Impact Summary

- 8.1. We provided the following information to the All Party Parliamentary Group (“APPG”) on Long COVID [LCS/007 –INQ000272149]. This was based on the ONS Winter Covid Infection Surveys (CIS) in 2022/2023 and 2023/2024 [LCS/008 – **INQ000657075** and LCS/009 - INQ000652450], research from a NIHR study on Long COVID (LOCOMOTION) [LCS/010 - INQ000320289] and research into healthcare costs.

Prevalence

- 8.2. The ONS Winter CIS asked people *“Would you describe yourself as having 'long COVID'? That is you are still experiencing symptoms more than 4 weeks after you first had the coronavirus (COVID-19), that are not explained by something else?”*. Each Winter CIS survey was broken down into multiple Waves to give data on how both COVID-19 and Long COVID changed over the Winter period. Each Wave sent out surveys and reported the number of people with Long COVID who were still experiencing symptoms on the day they responded to the survey.
- 8.3. The Winter CIS 2023/2024 survey ran from 16th November 2023 to 7th March 2024 and covered England and Scotland only LCS/011 – INQ000652457 and LCS/012 - **INQ000652455**. The 4th and final Wave ran from 9th February 2024 to 7th March 2024 [LCS/011 - INQ000652457] and showed that:
- 2 million people (including over 111,000 children) reported having Long COVID.
 - 1.5 million people with Long COVID reported that their day-to-day activities were adversely affected by Long COVID, with 381,000 of those reporting that their ability to undertake their day-to-day activities had been “limited a lot”
 - 49% had caught Long COVID since March 2022.
 - 51% had Long COVID for over 2 years, and many over 4 years.
 - Long COVID was an ongoing risk, with 178,000 additional cases during the 16 weeks of the ONS CIS survey 2023/2024.

Labour Impact

- 8.4. At March 2023, across the UK, for just the 381,000 Long COVID whose daily activities are “limited a lot” [LCS/008 - INQ000657075] and [LC/027] - INQ000651341]:
- 16.7% were no longer in paid work and had no work income.
 - 11.5% were no longer in paid work but were receiving work income such as sick pay or permanent health insurance.
 - 23.5% had reduced paid work hours.
 - £5.7 billion lost income from infection to Feb 2023 - cumulative total.
 - £4.8 billion cost of informal caregiving from infection to Feb 2023 - cumulative total.
- 8.5. The number of people reported as being impacted “a lot” was 381,000 at March 2023 and March 2024. This is by chance, as March 2023 data covered the UK, and March 2024 data was for England and Scotland only. LCS extrapolated the March 2024 figure of 381,000 to the UK population which gave approximately 411,000 people impacted “a lot” – an increase of approximately 8% in 12 months
- 8.6. ONS data showed that UK-wide economic inactivity due to ill health had increased by 716,000 from the pre-pandemic baseline that is from Dec 2019 to Feb 2020 compared to Dec 2023 to Feb 2024. [LCS/013 - INQ000652454 and LCS/013a INQ000652453].
- 8.7. In May 2024, the ONS published data for the Working Age sub-group (aged 16-64 years) in England and Scotland, whose Long COVID impacted their daily activities “a lot” [LCS/012 - INQ000652455]. This showed that at 7th March 2024 there were 308,000 people in this sub-group. Combining the ONS CIS Working Age subgroup data with LOCOMOTION data showed that just these 308,000 people contributed at least 63,000 to 87,000 of that 716,000 UK-wide increase.
- 8.8. The ONS CIS data also showed that at 7 March 2024 [LCS/012 - INQ000652455], there were 844,000 people in England and Scotland only, aged 16-64 years, with Long

COVID whose daily activities were “impacted a little”. There is little data available to support an estimate of their impact on economic inactivity due to ill health or even reduced economic inactivity due to ill health.

Data from other sources

- 8.9. In December 2022, the ONS reported that approximately 23.3% of people with Long COVID aged between 16-64 years were inactive economically [LCS/014 – INQ000272241].
- 8.10. In April 2024 the ONS reported that people who weren't in education, were aged 16-64 years, and reported Long COVID were 19.5% less likely to be either employed or self-employed than people without Long COVID. [LCS/011 - INQ000652457]
- 8.11. In April 2024, the ONS reported that 56.4% of people with Long COVID said that symptoms worsen following "*mental and/or physical effort*". [LCS/011 - INQ000652457]
- 8.12. “Brain Fog” is common in people with Long COVID. It is better described as cognitive impairments across a range of brain functions. The UK Defence Medical Services studied serving personnel with Long COVID. The deficits found were comparable to intoxication at the UK drink driving limit or having aged 10 years. 47% of the people in this study had cognitive impairments [LCS/015 - INQ000652459]. In April 2024, the ONS reported that 39.4% of people with Long COVID reported difficulty concentrating. This frequency and severity of cognitive impairments (brain fog) has significant implications for people’s ability to work at their pre- Long COVID level across the dimensions of quality, productivity, and work hours.
- 8.13. The aggregated costs of Long COVID are significant:
- **£11.2 billion lost health related Quality of Life in one year just for the 381,000 impacted “a lot” population** (estimated from ONS Winter CIS 2023/2024 data and HM Treasury Green Book values at 20/21 prices).

- **Long COVID healthcare costs** are 2.5 times pre-pandemic costs at over £700 per person per year, and 1.5-2.0 times since the start of pandemic against matched patients without Long COVID. [LCS/016 - INQ000652513].

Key Evidence

- 8.14. Long COVID is a complex, multisystem condition that significantly limits energy and can be profoundly disabling. It is highly variable across symptoms, severity, recovery and duration and symptoms often fluctuate. There is a significant number of people who are unable to work, and whose lives have been and continue to be directly harmed by COVID-19. Long COVID has created a cohort of newly disabled people; many of whom have severe functional limitations i.e. are housebound and often bedbound. Some of whom have now been chronically ill for more than five years.
- 8.15. Yet the true scale of the impact of Long COVID is limited by a lack of national monitoring and surveillance. The UK has ceased all national surveillance of Long COVID and there is no ongoing monitoring of the continued prevalence or impact. The ONS Winter CIS Survey which provides almost all the UK Long COVID prevalence statistics is 1 year 7 months out of date as we submit our witness statement in October 2025. The UK is flying blind, yet it is clear that Long COVID remains a growing problem as at March 2025 GP Patient survey [LCS/017 - INQ000652462] data (which is said to be representative of the 16+ population in England) found that 4.2% self-reported Long COVID.
- 8.16. There is likely a larger group of people who can still work but at reduced capability and/or reduced hours. The 1.1 million people from England & Scotland who reported daily activities being impacted “a little” contribute to the group. The 0.5 million people from England and Scotland who reported activities impacted “not at all” may be in remission at the point in time they were surveyed, or they may have already made adjustments to their life and were reporting against that baseline rather than their pre-Long COVID baseline. Both these groups are little studied and the lack of information around them is a risk to a full understanding of the economic impact.
- 8.17. Many people have no knowledge of Long COVID due to the almost non-existent public health messaging. Many have heard of it but do not really know what it is. 9.5% of

people in England aged 16+ were unsure whether they had Long COVID when they responded to the March 2025 GP Patient Survey. This is an important distinction as the ONS Winter CIS survey specifically asks, *"Would you describe yourself as having 'long COVID'? That is, you are still experiencing symptoms more than 4 weeks after you first had the coronavirus (COVID-19), that are not explained by something else"*. Given the lack of testing, the lack of public knowledge about both COVID-19 and Long COVID symptoms this is another risk to a full understanding of the economic impact.

The financial impacts of Long COVID on the Individual

- 8.18. The following section covers key impacts, and we want to highlight some critical coping strategies at the family/household level. Many of our members have had to leave work; some have retrained for different jobs, some of them have become students, and have moved into "looking after the family and home". Many parents have redistributed parental responsibilities such as childcare. Often members have given up full or part-time jobs, reduced their hours or had to change jobs to cope with their symptoms. All these changes are due to ill health from Long COVID and are often accompanied by a drop in household income. However, these people would not fall into the ONS Labour Force Survey category of *"economically inactive due to ill health"*. They would instead fall into the currently non-existent category *"economically reduced activity due to ill health due to Long COVID"*.
- 8.19. The Labour Force Survey does track the number of people with work limiting conditions. The *Keep Britain Working Review: Discovery* [LCS/018 INQ000652464], using Labour Force Survey data, shows that the number of people with work limiting conditions has risen from 6.7 million in 2019 to 8.7 million in 2024, an increase of 31%. It is particularly striking that Long COVID is not mentioned once in the document.

Main financial and economic impacts raised by our members

- 8.20. The main financial and economic impacts raised by our members from their lived experience include:

- Income loss for individuals as they have to stop work or reduce work hours due to Long COVID, or the need to provide informal care-giving to someone with Long COVID.
- Income loss for individuals having to move to jobs lower on the career ladder as they are no longer able to perform at their pre-Long COVID levels.
- Loss of future benefits e.g. pension, salary increases from promotions, and reduced opportunities to move jobs.
- Loss of National Insurance contributions.
- Individuals losing employer pension contributions as they are no longer able to work, have reduced working hours or have had to switch to jobs with poorer pension benefits.
- Individuals being forced to reduce or even stop pension contributions to cover day-to-day expenses.
- All the pension losses above leading to increased levels of pension poverty in the future.
- Reduced spending by individuals and families as they increase their savings as a buffer against the uncertainty of Long COVID, both in terms of recovery and the fluctuating nature of the condition.
- Difficulty accessing a wide range of benefits – both in terms of the application process and the rate of success. This is caused by the lack of institutional knowledge on Long COVID driven by the denial and minimisation discussed previously. Benefits include Universal Credit, Employment and Support Allowance, Personal Independent Payment, Carer's Allowance, Attendance Allowance, Disability Living Allowance for children, Access to Work, ill health retirement and/or Industrial Injuries compensation.

- Repeated cycles of applying for benefits, then returning to work, then having to stop work or reduce hours - either voluntarily or by dismissal, then having to re-apply for the same benefits.
- Difficulty accessing and increased costs for insurance for private health care, travel, life, employment protection.
- Individuals burning through their savings to pay for day-to-day costs (e.g. mortgages, rent, food) ultimately resulting in people selling or even losing their home and having to downsize, move to cheaper rented accommodation, or move in with friends or family.
- Reduced spending and/or saving by parents and siblings as they provide financial support to people with Long COVID.
- Children with Long COVID who are missing substantial periods of education, leading to significant impact later in life.
- All the losses above driving individuals and families down the Index of Multiple Deprivation ("IMD") and triggering the known dis-benefits on health, employment and education.

Impacts of Long Covid on Employers

- 8.21. From an employer's perspective Long COVID generates multiple impacts and risks which they will seek to mitigate. Some of these risks have their severity and likelihood raised due to lack of knowledge on Long COVID. Some of these risks are not mitigated either partially or completely by state support.
- 8.22. Recruitment is an obvious area.
- If an individual has cognitive impairments from Long COVID then they are most likely going to perform poorly at interview.
 - An employer must choose between two candidates whose match to the job requirements is roughly even. However, one candidate is in good health, and one has Long COVID with a track record of intermittent absences due to their

symptoms and healthcare attendance. The least risk option for the employer is clearly the candidate with good health.

8.23. Other impacts from Long COVID include:

- Increases in both employers' sick pay costs from their employee benefits package, and Statutory Sick Pay for people on long term sick with Long COVID.
- Increase in labour costs to back fill people on short and long-term sick leave.
- Increases in labour costs as people reduce working hours due to Long COVID and either additional staff need to be recruited to cover the workload or overtime costs increase.
- The fluctuating and varying nature of Long COVID symptoms impacting delivery to deadlines.
- Decreases on service performance as people with Long COVID continue to work, but are no longer able to perform at the same output intensity and also generate higher error rates – which need to be identified and corrected.
- Impacts on service or product delivery performance due to increased demand on either the pre-pandemic baseline labour pool, or the reduced labour pool caused by Long COVID as well as the sickness absences due to COVID-19.
- Increases in spending on all services to support an increased population with complex needs caused by Long COVID – especially healthcare, housing, ill health and disability benefits [LCS/016 - INQ000652513]

9. Long COVID – Critical Failure Factors causing Economic Impacts

Overview

- 9.1. There was a perfect storm of critical failures. These factors, their interactions and their reinforcing feedback loops, drove up the number of avoidable cases of COVID-19, which in turn drove up the avoidable cases of Long COVID and the financial and

economic consequences. We will deal with these in more detail in Part C and Part D but they are briefly discussed here.

Long COVID – absence from pre-pandemic preparedness planning

- 9.2. The Inquiry Module 1 Findings laid bare the extensive failures of the UK's pre-pandemic preparedness. The absence of pre-pandemic preparedness planning for long-term sequelae meant that they were not factored into the discussions, decision making, planning and actions when the COVID-19 pandemic struck. It meant there were no plans or systems for sentinel/early warning/tripwire monitoring for the emergence of long-term sequelae such as Long COVID. It meant that there would be no data to identify the risk and impact of Long COVID to factor into decision making. It also meant that the increase in other diseases (e.g. diabetes, cardiac issues) resulting from a COVID-19 infection was not going to be picked up early enough.

Long COVID – minimisation and disbelief

- 9.3. The Inquiry has heard appalling evidence in other modules of the minimisation and disbelief in Long COVID emanating from the Prime Minister [INQ000251910/9]. We also learnt that there were similar attitudes reflected in comments by the Minister for the DWP [LCS/019 [INQ000273901_0274]] about concerns of "*false claims*" and that "*the term 'long covid' should not be used loosely as it described a number of syndromes at a time when Personal Independent Payment Claims had reached an all time high*" [5.7.21] [LCS/020 - INQ000092025]. We have also seen minutes from a Permanent Secretary for Education meeting dated 9 June 2021 in which it is asserted that "many of the symptoms attributed to Long COVID may be due to burnout and exhaustion rather than [sic] infection with the virus." [INQ000542824]
- 9.4. We are concerned that this reveals an attitude underlying decision making which both deliberately minimised Long COVID and disparaged recipients of welfare support - aggravating the huge barriers faced by people with Long COVID.
- 9.5. We are concerned that the failures of pre-pandemic preparedness allowed disbelief and minimisation to flourish and become institutionally entrenched in government thinking.

- 9.6. Disbelief and minimisation meant that when the risk of long-term sequelae was raised, it was effectively ignored, most notably in Boris Johnson's response to the first NIHR review in October 2020. [INQ000251910/9]
- 9.7. In our view that disbelief and minimisation meant that no steps were taken to gather data on the prevalence of Long COVID until the introduction of questions about persistent symptoms were regularly asked in the ONS Covid Infection Survey from April 2021 (following a preliminary survey in December 2020) [INQ000272260] and [INQ000320261]. Absence of evidence is not evidence of absence.
- 9.8. In our view disbelief and minimisation meant that even as the evidence accumulated it was not factored into decisions and policies.
- 9.9. There was no effective public health messaging on the risks of Long COVID except for one DHSC video in October 2020 which had very little impact – it was not seen by most of our members [INQ000280197/74] and [INQ000272244]. The government key slogans "Stay home, Protect the NHS, Save lives" and later "Stay Alert, Control the virus, Save Lives" were clearly focused on mortality. If the risk of Long COVID had been accounted for in government decision making, then the slogans would have included the risk. For example, "Stay Alert, Control the virus, Save lives, Protect your long-term health". We are sure the government public messaging experts can come up with better phrasing, but the critical point is "protect **your** long-term health". For the vast majority of the UK population there was and is a greater risk from Long COVID than of dying – even before the vaccination rollout. "Save lives" was about other people's lives. "Protect your long-term health" is about the impact on you.
- 9.10. Further, we have concerns about the impact the central government's minimisation of Long COVID had on external organisations. If Long COVID does not appear in government documents, discussions, scope definitions, risk registers, mitigation strategies, data and terms of reference then external organisations will likely not consider it.
- 9.11. An example of this is *The Keep Britain Working Review: Discovery* [LCS/018 - INQ000652464] published 20 March 2025. It shows the number of people with work limiting conditions has risen from 6.7 million in 2019, 7.0 million in 2020, 7.3 million in

2021, and 8.7 million in 2024, an increase of 31% since 2019. As stated above, it is particularly striking that Long COVID is not mentioned once in the document. Contrasted with the overwhelming evidence of the impact of Long COVID on economic inactivity and Long COVID generally it appears that the minimisation of Long COVID continues to this day.

- 9.12. We also note that disbelief and minimisation that is institutionally entrenched means that organisations do not take actions to change. Impacts from disbelief and minimisation are detailed below.

Long COVID was foreseeable - Long-term sequelae from viral infections were known before COVID-19

- 9.13. It is important to us that the Inquiry considers why there was an apparent failure to prepare for the economic impact of morbidity from disease in terms of interventions to support individuals, employers and the wider economic impacts of extended inactivity from disease on the labour market.
- 9.14. The Inquiry has heard extensive evidence that risk of long-term sequelae of COVID-19 was foreseeable. There was a body of evidence that survivors of SARS and MERS suffered from a constellation of persistent symptoms similar to Long COVID, yet despite this, the Government was completely unprepared for the long-term morbidity caused by infection from COVID-19. Professor Brightling and Dr Evans opined that Long COVID *“was foreseeable to us before the pandemic, because we were aware of what had happened with SARS-CoV-1 and it was even more apparent early on in the pandemic that this would be a potential problem”*.

Delayed recognition

- 9.15. From our own members it was clear that by Summer 2020, there was sufficient information and awareness that a significant number of people infected with COVID-19 were developing Long COVID. Despite this, as far as we are aware, there was no specific consideration of economic interventions to support people with Long COVID or weigh up that impact when considering policies to support compliance with NPIs.

- 9.16. Through our advocacy we shared our experiences of the debilitating and devastating nature of Long COVID in the hopes of the Government taking preventative measures to reduce transmission, as well as measures to raise awareness and support those who suffer from Long COVID (see further below). However, Long COVID continued to be overlooked, our pleas for employment and financial support were ignored and our experiences ignored in pursuit of a quick and temporary recovery of the economy.
- 9.17. In our view the Government's delay in recognising Long COVID left people with little financial support or guidance from employers or others whilst they managed the impact of debilitating long-term ill health. The delay in recognising Long COVID had implications for what was provided in terms of benefits, fiscal policies and interventions. There were also differences in how employers implemented employment rights as well as how they supported and allocated resources to respond to the needs of people with Long COVID albeit we understand that the Inquiry does not seek evidence on this.

Long COVID – impact of unmitigated transmission

- 9.18. The minimisation and denial of Long COVID meant that it was not accounted for in policy decisions within the Inquiry's timeline scope. The ONS Winter CIS 2023/2024 data shows the direct consequences of unmitigated COVID-19 transmission. It is our view that as a direct consequence of the failures under investigation in this Inquiry, more people have developed Long COVID and suffered avoidable harm.

Long COVID Data on Economic inactivity due to ill health, reduced economic inactivity due to ill health, and work limiting conditions.

- 9.19. There is a direct correlation between the start of the pandemic in 2020 and the rise in numbers of people unable to work full time – an increase of over 400,000 by March 2023. The ONS comments that “*nearly two-fifths (38%) reported having five or more health conditions (up from 34% in 2019), suggesting that many have interlinked and complex health issues.*” [LCS/021 – INQ000652468]. Further the ONS has said that rising inactivity may be due to Long COVID [LCS/022 - INQ000609922]. We are aware that the ONS is reviewing data from the Labour Force Survey but have relied on their existing data which documents trends which are unlikely to be affected by the review.

- 9.20. A Long COVID study by UCL using data collected by November 2020 [LCS/023 - INQ000652469], identified that over the course of their illness they experienced an average of 55.9 symptoms across an average of 9.1 organ systems. In our view this shows the profoundly disabling and unique impact Long Covid can have on a person. Our members case studies show the extensive impacts these wide symptoms have.
- 9.21. In March 2025 *The Keep Britain Working Review: Discovery* [LCS/018 - INQ000652464] found that 800,000 more people were economically inactive for health reasons than in 2019. This reflects the experiences of our members and supporters who were infected during the relevant period and thereafter, who continue to suffer with Long COVID. We are concerned however that the Keep Britain Working review did not explicitly ask questions about the role of Long COVID in contributing to this increase. This seems to be an obvious critical omission. Further, the survey groups the number of work limiting conditions people had into either 1 or 2+ symptoms clusters which massively under-represents the widespread symptoms experienced by people with Long COVID.

Long COVID – a profound, mass disabling impact on the population.

- 9.22. It is a mistake for any government to ignore the profound, mass disabling impact of Long COVID on the population. The facts speak for themselves. Long COVID clearly creates economic hardship for families and individuals, and long-term economic scarring. It may also act as a multiplier effect for a prolonged downturn.
- 9.23. Independent evidence establishes the profound impact Long COVID is having on the UK economy and labour market at a macro level (see for example “Begin Again? Assessing the permanent implications of Covid-19 for the UK’s Labour Market November 2021 [LCS/024 - INQ000652470]; IFS Long COVID and the Labour Market July 2022 [LCS/025 - INQ000651220]; Long Covid and Financial Outcomes: evidence from four longitudinal population studies, 2024 [LCS/026 - INQ000620510]; LOCOMOTION Impact of Long COVID on Productivity and Informal Care giving, 2023, [LCS/027 - INQ000651341]; Impacts of Long COVID on workers: A longitudinal study of employment exit, work hours and mental health in the UK 2024) [LCS/028 - INQ000652474]

PART B: Long Covid Support during the relevant period 1 January to 28 June 2022

10. Our engagement with government and decision makers in relation to the UK economy

10.1. LCS has advocated to the highest level of government, from the very early days of the pandemic, for morbidity and specifically the risk of Long COVID, to be factored into considerations by decision makers.

10.2. In summary, LCS advocated on behalf of people living with Long COVID in the UK by:

- a. Writing to the Prime Minister and relevant Government Ministers
- b. Meeting with Government Ministers
- c. Participating in relevant Ministerial Roundtables, NHS Task Force and other expert panels relevant to Long COVID
- d. Submitting evidence to the All Party Parliamentary Group ("APPG") and Select Committee Inquiries
- e. Collaborating with other relevant partners
- f. Contributing to UK and international research
- g. Conducting surveys into patient experience, co-creating and publishing original research
- h. Undertaking wider advocacy

10.3. We annex with this statement at [LCS/029 - INQ000652476], a chronology detailing all our engagement with Government, other organisations, and our collaboration with various bodies, but some of our key submissions are also included throughout this statement. Our engagement with the media and publications that our members have authored or contributed to can be found at [LCS/030 -INQ000652477]

10.4. We sought to bring attention to the inequitable impact of Long COVID. Our main concerns and reasons for advocating government on these issues were:

- To support people with Long COVID to stay in, return to or leave work well (that is to leave on fair terms with adequate financial support).

- To ensure that people with Long COVID are supported to stay in or return to work through the use of appropriate sickness management procedures, phased returns, and flexible working arrangements.
- To ensure that people with Long COVID, who have been rendered unable to work are recognised by the DWP and able to access appropriate support.
- To provide guidance to employers on supporting people with Long COVID in the workplace thus enabling inclusion, improving productivity and retaining skills.
- For appropriate health and safety measures to be put in place to protect employees from contracting COVID-19 in the workplace.
- For Long COVID to be recognised as an occupational disease - particularly in the case of frontline healthcare workers - enabling those too disabled to work to access long-term sickness benefit.
- To enable economic recovery through sustainable, healthy workplace practices and culture.

10.5. From our engagements with Government representatives, it is not clear that the Government took into account the reality of huge numbers of people suffering from Long COVID. It did not take steps to prevent Long COVID either by raising public awareness, adequately warning the public (beyond one film in October 2020) or providing any bespoke fiscal interventions.

10.6. We should say at the outset that we were not invited to or involved in any direct meetings with HM Treasury, DWP or other relevant departments. We attended the Ministerial Roundtables on Long COVID facilitated by the DHSC and whilst we consistently raised the economic and financial problems faced by our members as well as the wider impacts in relation to the labour market and NHS spending, we were never invited to participate or provide any specific information or evidence to economic or fiscal decision makers in the UK Government.

Spring – Summer 2020

- 10.7. In Spring 2020, calls for Long COVID to be recognised began, and gathered momentum through social media. LCS started campaigns on Twitter and other social media in May and July 2020 [LCS/031 - INQ000280197/5-6]. On 18 May 2020, two founding members of LCS started a placard campaign on Twitter listing symptoms and the number of days they had been ill for. On 17 June 2020, LCS members met with Shadow Public Health minister Alex Norris.
- 10.8. By July 2020, the long-term consequences of COVID-19 were formally recognised as a Category A direct health impact [LCS/032 - INQ000220213] and in December 2020, the Department of Health and Social Care, ONS, Government Actuary's Department and Home Office identified Long COVID as a Category A direct harm from COVID-19 [LCS/033 - INQ000074959].
- 10.9. On 5 August 2020, LCS gave evidence to MPs and members of the House of Lords at the second hearing of the UK's newly formed All Party Parliamentary Group ("APPG") on Coronavirus, which was covered in all major media outlets, including on the front page of the Telegraph and on Channel 4 News. Members of LCS went on to give further evidence to several APPG hearings on Long COVID. Witnesses testified that they felt pressured to return to work before they were well enough because their employer did not understand Long COVID. [LCS/031 – INQ000280197] [LCS/034 – INQ000249062]. Many of our members continue to report feeling pressured to return to work.
- 10.10. On 28 August 2020, LCS and partners sent a letter to Jeremy Hunt, Chair of the Health & Social Care Committee which was forwarded to Matt Hancock, Secretary of State for Health and Social Care [LCS/035 – INQ000248911]. In our letter, we explained that many of our members had been front line workers who were struggling to return to work, they were receiving inadequate economic support, they required more time to recuperate and recover from Long COVID [LCS/035 – INQ000248911]. We stated:

"We are grateful to the Health and Social Care committee for shining a light on the failures in the UK's response to COVID-19 and pressing for better responses by our government. Many of us bear witness to those failures having become ill

because the right action was not taken at the right time; we were poorly informed and poorly supported.”

10.11. We further stated:

“However, it is likely that many people with Long COVID are already experiencing economic challenges and these social and economic disparities will create additional burden and challenges for recovery for people living with this long-term intermittent condition which complicates our ability to work

...

all employers need to make reasonable accommodation for staff who are facing Long COVID - and we hope that the government will assist them to do just that for the increasing numbers of us. Given that Long COVID is an occupationally acquired condition for many of us, we expect the NHS and social care providers to act as a beacon of good practice in developing flexible and compassionate employment practices, engaging the Health and Safety Executive, RIDDOR in reporting occupationally acquired cases, as well as NHS occupational health Departments to assist staff to return to work. Sadly, few people living with long COVID report that experience from their employer - distressing not only on a personal level, but also because it prevents them from playing an active role in society.”

10.12. In the letter, we highlighted that the systems for accessing benefits were failing us, we were experiencing challenges when we sought support from our employers, and there was insufficient attention being paid to the disproportionate impact of Long COVID on socially and economically marginalised communities.

10.13. We called for the Department of Health and Social Care (“DHSC”) to:

- Provide better economic support and safety nets;
- Assist employers in understanding what support people with Long COVID required;
- Fund more and better research;

- Provide quality psychosocial and mental health services;
- Implement better public health programmes, including improved public health messaging;
- Help NHS and social care workers to return to work safely (many had been infected on the frontline of the pandemic response);
- Provide funding for patient-led support groups.

10.14. It is our members' experience that many acquired Long COVID in the workplace. Many of our members are healthcare workers and were employed at NHS Trusts. As we explained to the DHSC, we expected the NHS and Social Care providers to set the gold standard and good practice in developing flexible and compassionate employment practices.

Autumn – Winter 2020

10.15. On 10 September 2020, Matt Hancock gave evidence to the Health and Social Care Committee ("HSCC"). Jeremy Hunt, the Chair of the HSCC asked Matt Hancock to provide a response to the issues raised in our letter of 28 August 2020 [LCS/035 - INQ000248911]. Matt Hancock confirmed that he had seen the letter the previous night and would provide a response for the committee, which he did on 14 September 2020 although we have not had sight of that reply.

10.16. On 12 October 2020, Jeremy Hunt wrote to Matt Hancock about the concerns of the Long COVID patient advocacy groups, reiterating key points from our letter dated 28 August 2020, which he felt had not been adequately addressed in Matt Hancock's response letter. [LCS/036 - INQ000249042] He stressed our concern about the loss of talented and highly skilled staff who developed Long COVID after becoming exposed to COVID-19 in the course of their work.

10.17. At the time, we were concerned that there was a risk that the healthcare profession would lose many more highly trained individuals without better focused employment support. Our concerns persist to this day.

10.18. From the outset we sought guidance for line managers on how to:

- Manage absences and phased returns and called for employees to receive full pay, and
- Provide support and advice for handling relapses and have the flexibility to respond to the lived experience of those with complex and evolving conditions to avoid healthcare workers having to leave the profession.

10.19. During Summer 2020, Boris Johnson and Rishi Sunak strongly resisted imposing a further lockdown due to perceived further damage to the economy [INQ000088301]; [INQ000089917]. The Government needed to prepare for a resurgence in transmission of COVID-19 yet they were reluctant to implement the necessary measures which would effectively control transmission of COVID-19. It appeared to us that the Johnson government was intent on pursuing strategies which would allow business as usual to continue and avoid further lockdowns.

10.20. In October 2020, we were invited to attend the Ministerial Roundtables on Long COVID, initially chaired by Lord Bethell of Romford. Claire Hastie, a founding member of LCS was invited to speak at the first ministerial Roundtable that we attended on 13 October 2020 [LCS/037 - INQ000058536]. Claire Hastie emphasised the need for research and data on non-hospitalised Long COVID sufferers and Long COVID sufferers generally. LCS continued to attend the Ministerial Roundtables until they were stopped in February 2022. LCS attended with other patient advocates from Long Covid SOS and others, and raised concerns about the prevalence of COVID-19 and the risk this presented in terms of widespread Long COVID, including the economic impacts of this growing and significant public health problem.

10.21. By December 2020, the UK Government departments specifically recognised Long COVID as a Category A direct health impact [LCS/033 – INQ000074959]. This stated: *“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.”*

- 10.22. Around the same time, in November 2020, the Office of Budget Responsibility (“OBR”) in their Economic and Fiscal Outlooks warned of spending implications as a result of Long COVID for the first time [LCS/038 - INQ000114451/121]. They repeated these warnings in March 2021 [LCS/039 - INQ000114450/136] (discussed further below).
- 10.23. Despite these references to the potential impact of LongCOVID, in our meetings with Ministers there was no indication that such matters were being considered in the pandemic response by decision makers.
- 10.24. On 11 November 2020, we attended the Ministerial Roundtable on Long COVID, and we again raised concerns related to the recognition of Long COVID [LCS/040 - INQ000058981]. Our concerns were that the Government’s published COVID-19 symptoms list was restrictive such that many symptoms of acute Covid were not listed. We were concerned that Long COVID remained focused on hospital cases rather than what we saw in our membership group which was many community only patients suffering long term disease. We raised that symptoms and prevalence data (including geographical data) collection on Long COVID and research was urgently needed, and that the impact of Long COVID on schools, healthcare systems and staff and employees more generally needed to be factored into decision making.
- 10.25. On 16 December 2020, the ONS released an initial data set on prevalence of Long COVID. [LCS/041 - INQ000272260]
- 10.26. In an article for the Lancet on 18 December 2020, members of LCS identified shortcomings in the NICE guidelines on COVID-19 [LCS/042 -INQ000320251]. We noted that it failed to fully identify the symptoms and severity of COVID-19 as well as the disabling and fluctuating nature of Long COVID which may lead to the premature dismissal of COVID-19 patients.
- 10.27. On 18 December 2020, NICE issued the ‘Covid rapid guideline: managing the long-term effects of COVID-19’ which contained the UK’s first clinical definition ofLong COVID [LCS/043 – INQ000283459].
- 10.28. In December 2020, the APPG on Coronavirus published an interim report on COVID-19. In their report they concluded: *“The UK government is not counting the number of*

individuals who are left with long-lasting effects of COVID-19 as a measure of the severity and impact of the pandemic; As a medical condition, Long COVID has not yet received full recognition, sufficient research funding or adequate rehabilitation support. There are very few guidelines for employers or for GPs on recognising and managing Long COVID.” [INQ000249062]

- 10.29. The APPG had also concluded that there were insufficient guidelines for employers and GPs on recognising and managing Long COVID; Long COVID had not yet received adequate rehabilitation support; and the UK government was not counting those with long lasting effects of COVID-19 as a measure of severity and impact of the pandemic.
- 10.30. Most senior decision-makers in Government ignored early signs and advice on prolonged symptoms of COVID-19 and failed to commission timely advice on Long COVID to ensure that decision making considered the long-term health impacts of COVID-19 on the population. Long COVID was inexplicably ignored by decision-makers. Dr Simon Case, Cabinet Secretary from September 2020 to December 2024, was responsible for co-ordinating a response to the COVID-19 pandemic; however, when asked in oral evidence to explain why the Covid Taskforce did not factor in the long-term health consequences of COVID-19 into their advice on the response to the pandemic in 2020, until April 2021, he was unable to provide an explanation. [Module 2, 23.5.2024, p.178, l.21 – p.181, l.14]

2021

- 10.31. In 2021, we collaborated with the Society of Occupational Medicine to produce guidance for Employers and Employees on Returning to Work with Long COVID [INQ000249029] and [INQ000249030]. This guidance emphasised the importance of managers supporting returning workers. The guidance also recognised that people struggling with Long COVID may be returning to work for financial reasons despite struggling with day-to-day activities. The guidance noted that the pandemic has been a difficult time for everyone, and employers have had to adapt through schemes like furlough, working arrangements like remote working, and adjusting working arrangements. The guidance noted the importance of balancing employees' health and wellbeing as well as the business needs.

10.32. In January 2021, LCS and Long Covid Kids gave evidence to the APPG on the Coronavirus which informed the report on Long COVID [LCS/044 - INQ000320252], [LCS/007 - INQ000272149]. The APPG published their report on Long COVID in March 2022, they estimated that the 215 NHS trusts lost around 1.8 million working days to Long COVID absences between March 2020 and September 2021. The APPG recommended:

- A legal definition of Long COVID classifying it as a disability;
- A compensation schemes for key workers with Long COVID;
- Called for the government to urgently produce guidance for Long COVID on managing the impact of Long COVID in the workforce.

10.33. On 9 January 2021, LCS founding member, Claire Hastie sent a letter by email to all MPs urging them to participate in the Commons debate on Long COVID scheduled for 14 January 2021, as well as the APPG on Coronavirus oral hearing about Long COVID among health professionals on 12 January 2021 [INQ000248900]. We asked the Government to recognise that Long COVID was impacting a significant number of people and preventing them from engaging in economic activity. We raised our early concerns about support for people returning to work and called for employers to be better informed about Long COVID.

10.34. The letter raised the following key points:

- Long COVID affects vast numbers of people and has a significant impact on people's lives and ability to work. Almost 70% of people with Long COVID who fell ill prior to June 2020 were not working or were working reduced hours on account of their health, even after 7 months.
- Members of our group have had life changing effects from Long COVID. They have lost their livelihoods, struggled to access benefits, and are experiencing significant mental health issues among their painful, disabling and frightening symptoms.
- More needed to be done to support people with Long COVID in returning to work, and employers need more information relating to Long COVID and the

debilitating effects it can have. Those no longer able to work need advice from the DWP and to be able to access disability benefits.

- More needed to be done to prevent more people getting Long COVID including preventative public health measures to raise awareness and early treatment interventions for those affected by COVID-19.
- More needed to be done to support people affected by Long COVID including better and more consistent access to Long COVID services, greater investment in research and support with returning to work.
- For support groups to be funded to continue the valuable work that they do as we had become a lifeline for our members. [INQ000272263].

10.35. We continued to advocate for our members and call for guidance for employers. During 2020 and 2021, we met with the four devolved nations' Chief Nursing Officers to discuss key issues related to financial support for healthcare workers with Long COVID.

10.36. On 29 January 2021, we attended another Ministerial Roundtable. At the meeting it was noted that if the infection rates for COVID-19 remained high then it was likely that Long COVID would become more prevalent among younger people. At this meeting the ONS discussed the Covid Infection Survey from November 2020 which found that 10% of people were still symptomatic at 12 weeks. ONS stated that a new question of Long COVID would be included in the survey to directly report on the impact of and prevalence of Long COVID [INQ000272260].

10.37. On 7 February 2021, we contacted ONS and again on 12 February 2021 following a presentation from the ONS at the Long COVID Ministerial Roundtable on 29 January 2021 [LCS/045 – INQ000249020], [LCS/046 – INQ000248996]. In these emails, LCS raised concerns about the survey questions proposed by the ONS, stating that many people would not be aware of Long COVID, or consider themselves to be suffering from it. It was suggested that the survey questions should instead ask about the symptoms being experienced, and the length of time they were experienced. This led to a meeting with ONS on 16 February 2021.

- 10.38. This meeting was followed up with a further email from LCS to ONS on 22 February 2021, again raising concerns about the phrasing of the survey questions and providing suggested questions to gather data on prevalence of Long COVID [LCS/047 – INQ000249021].
- 10.39. On 23 February 2021, LCS attended a further Ministerial Roundtable chaired by the then Secretary of State for Health and Social Care, Matt Hancock, with Lord Bethell and Jennie Harries [LCS/048 - INQ000060080]. At this meeting, ONS representative Daniel Ayoubkhani, reported that the ONS would publish data updates monthly. At the meeting, LCS explained that there were barriers to people with Long COVID tracking symptoms through the Zoe App because they may be too unwell to engage. From the minutes, Matt Hancock concluded the meeting by noting that there was “lots left to do” and that there was a need for dynamic and collaborative decision making.
- 10.40. In March 2021, the LCS Employment Group provided evidence to the Health and Safety Executive in contribution to their Report on Return to work after Long COVID. [LCS/049 - INQ000249009]. The report noted that:
- “Ziauddeen et al. (27) recruited 2250 participants with a median duration of illness of 7.7 months through long COVID support groups and social media (Twitter and Facebook). 10% reported working reduced hours, 19% reported being unable to work (out of which 88% was reported to be solely due to COVID-19 illness (other reasons were other illness, COVID restrictions, combination), and 22% reported being made redundant or having taken early retirement. The most common reported reason for working reduced hours was COVID-19 illness (97%). 66% reported taking time off sick (median of 60 days). 38% reported a loss of income due to illness.”*
- 10.41. The National Institute for Health and Care Research invited one of the LCS members (Dr Jo House) to join the advisory group for the second NIHR review on Long COVID. LCS members helped to design the survey that informed the second review, including details of the impact on work, social and family life. On 16 March 2021, NIHR published the second themed review on Long COVID, the review reflected upon the importance of data on the prevalence of Long COVID. This review was intended to be of use for families as well as employers. This review identified that of the 3,286 respondents to the survey:

- 80% of the 3,286 said Long COVID affected their ability to work;
- 36% said it was affecting their finances [LCS/050 - INQ000248872]

10.42. The ONS published its first bulletin on Long COVID on 1 April 2021 [LCS/051 – INQ000320261]. In that release, it was estimated that 1.1 million people were experiencing Long COVID. As set out above, by 2024, this figure was approximately 2 million (in England and Scotland, so across the UK would likely be higher).

10.43. On 13 April 2021, the Cabinet Office produced a paper titled: “In depth: LONG COVID for the Long COVID Task force meeting” [LCS/052 - INQ000292660]. The paper identified that Long COVID disproportionately affects women, people from ethnic minority backgrounds and people in the health and social care sector and its ability to potentially exacerbate “pre-existing health and societal inequalities in the long term.” This paper is significant as it appears to be the first (and apparently only) analysis by the Covid Task Force, Analysis and Data Directorate on Long COVID.

10.44. Between May 2021 and 2022, our Employment Advocacy Team focused on supporting workers and employees with returning to work. We co-developed materials with organisations, including the UK’s Society of Occupational Medicine and Chartered Institute of Personnel and Development (“CIPD”). [LCS/053 - INQ000652499] [LCS/054 INQ000652500]

10.45. The team collaborated with the TUC to assess the impacts of Long COVID on employment. The first joint survey with us and the TUC received 3500 responses and our findings were published in June 2021 [LCS/055 - INQ000248884]. As well as co-producing research, the team participated in a webinar. An updated report was published in 2023 [LCS/056 - INQ000272240].

10.46. In June 2021, the LCS Employment Working Group submitted written evidence to the Work and Pensions Committee DES008 regarding employment Support [LCS/057 - INQ000249010]. In our evidence we detailed some of the challenges that people with Long COVID face, including people with Long COVID facing difficulties in remaining and returning to work, managing symptoms of Long COVID whilst trying to “keep a roof over our head” and difficulties applying for benefits. We explained:

“Furthermore, research shows many workers with Long COVID struggle to return to work and fulfil their usual hours or duties, remain in work or have lost their job. Anecdotal evidence gathered by Long Covid Support concurs with this research and reveals significant difficulties experienced by workers: relapses, exacerbation of symptoms, further sickness absence, a lack of employers support regarding reasonable adjustments, which a recent TUC survey identified as a significant issue. Consequently, occupational health stakeholders and vocational rehabilitation specialists are advising very gradual prolonged phased returns over extended period with consideration of reasonable adjustments. There is a key role for the DWP’s Access to Work scheme to support people to return to work too.”

- 10.47. We emphasised the potential number of people with Long COVID and therefore the inevitable increase in claims for benefits to the DWP and the necessity for support to allow people with Long COVID to rejoin the workforce and rebuild the economy:

“It is estimated one million people in the UK have Long COVID and one in ten people who contracted COVID-19 are estimated to develop ongoing symptoms most of whom are of working age. Therefore, it seems inevitable that the DWP will see increasing numbers of social security claims for Personal Independence Payment, Employment Support Allowance and Universal Credit over coming months and years.

We must therefore share a mission to help growing numbers of people with Long COVID recover sufficiently, be able to better manage everyday activities and make a sustainable return to work; rejoin the workforce and help rebuild our post-Covid economy.”

- 10.48. In our evidence to the Committee we put several questions to them regarding what support will be put in place for people with Long COVID, what actions will the DWP implement to ensure they are correctly and accurately assessing people with Long COVID; are DWP working with the NHS to ensure they are completing timely assessments; what health-related employment support will be made available for

people with Long COVID; whether DWP are considering new forms of employment support, schemes and benefits for people with Long COVID; and has DWP collaborated with employers to ensure there are good jobs available for people with Long COVID.

- 10.49. On 20 June 2021, we partnered with the TUC to work on a campaign on Long COVID [LCS/58a – INQ000249073]. We jointly called for Long COVID to be urgently recognised as a disability and COVID-19 as an occupational disease, to give workers access to legal protections and compensation. Contributors to a survey that informed the campaign noted that they were worried about their futures given the amount of sick leave they had been forced to take due to their Long COVID symptoms and some had experienced absence management or 'HR' processes being triggered because of the amount of sick leave they had taken.
- 10.50. By summer 2021, there was more than enough evidence of the harms of Long COVID for the Government to factor it into their decision making. We also made sure through our advocacy that they were aware of those harms. The Government clearly knew that high rates of transmission of COVID-19 would cause more cases of Long COVID and were aware of the associated economic burden of disease.
- 10.51. On 8 July 2021, LCS wrote to Rt Hon Sir Sajid Javid MP, the then Secretary of State for Health and Social Care urging that, when evaluating policy concerning removal from restrictions and widespread transmission, he considers the devastating and prolonged impact that Long COVID can have on people of all ages [LCS/058 - INQ000248931]. We raised concerns that many of our members have been unable to work, continue their education or their caring responsibilities for more than a year. We urged him to consider the devastating and prolonged impact that Long COVID can have on people of all ages, and the resulting impact on the country's productivity and economic prosperity when evaluating policy. We also raised concerns about the disproportionate impacts on children, young working age people and frontline healthcare workers.
- 10.52. We noted that many of our members have been unable to work and urged him to:

- *"Expand service provision to enable inclusion and equitable access to chances of recovery and resuming work, education and/or caring responsibilities. Currently Long COVID clinics are not available in the devolved nations, and our most recent survey indicates that only half of patients in England seeking referral are successful."*
- *"Support NHS staff with returning to work: Many caught COVID-19 and have gone on to develop Long COVID. A significant number are either unable to work at all or to their previous capacity, or are working, unsustainably, while still ill, reducing the health of an already stretched workforce. More and more of our members report losing their jobs with NHS Trusts due to Long COVID. Yet there are skills shortages; 35,000 unfilled nursing roles within NHS England alone. We assert that it is not only possible, but essential, to retain and rehabilitate staff, through appropriate occupational intervention, workplace adaptations and flexibility within the NHS. Greater access to effective measures such as extended phased returns, occupational health and vocational rehabilitation support would cost less than the significantly greater economic burden of chronic ill health, unemployment and the loss of skilled workforce. The government has devoted large amounts of money to keeping businesses afloat and to preserving viable jobs. Preserving the health of the workforce is of equal importance in limiting longer-term costs and contributing to economic growth."*
- *"Prevent further people being affected by Long COVID [...] In your own words you stated that Covid cases could soon rise to above 100,000 per day, which would suggest at least 30,000 new cases of Long COVID per day. It is likely that children and young working age people will be disproportionately affected, as will frontline workers. Long COVID already disproportionately impacts those of lower socio-economic status and inequality gaps are likely to widen. We are pleased that vaccines have currently weakened the link between hospitalisations and deaths, but they do not necessarily protect against Long COVID; Tim Spector of the Zoe Covid Symptom study, states that double vaccination reduces the chances of developing Long COVID by*

only 30%. Vaccinations may protect you from having severe acute disease but they do not necessarily prevent you from having Long COVID."

10.53. In our letter to Rt Hon Sir Sajid Javid MP, we made urgent recommendations, including:

- Count Long COVID to better plan health and social care support.
- Support NHS staff with returning to work.
- Prevent further people being affected by Long COVID by implementing measures that minimise the transmission of SARS-CoV-2
- Communicate an updated list of acute symptoms of COVID-19.¹
- Increase public awareness and messaging about the negative impact of Covid -19, i.e., that it can develop Long COVID.
- Continue to publish statistics on Covid and include reference to Long COVID.
- Provide grants for equipment to improve ventilation and air quality, including in workplace settings.
- Provide adequate and flexible financial and occupational support, in conjunction with employers to allow people with COVID-19 to self-isolate and then stay at home until they fully recover, to prevent progression to Long COVID through a premature return to work due to financial pressures.

10.54. As far as we are aware, at the time there was no adequate consideration given to the excessive numbers of people that would go on to suffer Long COVID following the removal of all restrictions on "Freedom Day" on 19 July 2021.

¹ The Inquiry will note that we have consistently raised this in our evidence to the Inquiry and note that the Inquiry has heard in Module 7 from Professor Timothy Spector about the "*stubborn*" response from the Government regarding the delay in updating the symptom list impacting transmission which "*led to excess Long Covid cases.*" M7 Inquiry 19.5.25.

- 10.55. In September 2021, members of the LCS Employment Group were part of an expert panel on the Chartered Institute of Personnel and Development webinar series 'Understanding the impact of Long COVID'.
- 10.56. On 2 September 2021, we received an email response from the Department of Health and Social Care ("DHSC") to our letter of 8 July 2021 [LCS/059 - INQ000249052]. The letter failed to respond to the substance of our letter. DHSC's response focused on research and diagnosis of Long COVID. The letter failed to refer to the Government giving any consideration to the prevalence of Long COVID caused by its decisions to facilitate high infections levels and end restrictions or our concerns about adequate financial support for those with Long COVID and supporting people to remain and return to work.
- 10.57. In October 2021, the LCS Employment Group submitted written evidence to the Work and Pensions Committee HAB0126 - Health assessments for benefits (published May 2022) [LCS/060 – INQ000249011] and final report [LCS/061 - INQ000652508]. We drew on evidence which raised concerns about the barriers, and poor experience and assessment outcomes when applying for benefits, including Personal Independence Payment ("PIP"), Employment and Support Allowance ("ESA") and Universal Credit ("UC"), and the delays and denials of these benefits thus impacting the recovery of people with Long COVID, and causing financial hardship. We set out the importance of recognising the at least 200 symptoms of Long COVID as it assists medical assessors to effectively identify the cumulative impact of these symptoms on a person with Long COVID's ability to undertake daily activities. We noted that the descriptors for ESA and PIP do not accurately assess a claimant's ability to work and therefore they were unfit for purpose. 79% of respondents to our Long COVID Survey in 2021 [LCS/062 - INQ000272247] stated that applying for benefits would be easier if the assessments reflected the relapsing nature of Long COVID and if decision-makers better understood Long COVID. We noted that we were beginning to see *"significant financial impact of Long COVID on peoples' daily lives including members reporting they are facing homelessness and bankruptcy."*
- 10.58. We also noted in our evidence that *"experiencing the realisation of the extent of their illness (e.g., this may be first time they have listed all their Long COVID symptoms and*

the impact on their daily life) may be traumatising and the fear of not being awarded a benefit is likely to be extremely stressful which again will have a substantial impact on a pwLC's [person with Long COVID] physical and mental health and wellbeing and recovery."

10.59. We identified that the length of time to process claims, which can take several months, and waiting times for medical assessments *"exposes pwLC to significant financial hardship which can impact on recovery, physical and mental health, and wellbeing."*

10.60. On 11 October 2021, the LCS Employment Group submitted a response to the DWP, Shaping Future Support: The Health and Disability Green Paper consultation. Much of our evidence focused on DWP support and possible solutions for people with Long COVID who receive benefits (ESA/PIP/UC) [LCS/063 - INQ000249013]. We gathered a wide range of lived experience from occupational therapists, our members and our affiliate groups Long Covid Physio and Long Covid Kids, which we gathered through a round table discussion and an online survey N-252 (An executive report of our LCS Survey, which ran from 25 September 2021 – October 2021) to formulate our response. We touched on challenges arising from the delay to recognise Long COVID and how that negatively impacted the DWP's ability to accurately assess an individual's entitlement to benefits. We also noted: *"the Department needs to set out how it will tackle the long-term effects of the pandemic on the jobs market, disabled people, and in particular those who suffer from Long COVID."*

10.61. We submitted:

"It is crucial for the Department to note that many people with Long COVID are facing significant financial challenges either as individuals and/or as parents with children with Long COVID. Some people are reliant on their partner's wage having run out of sick pay and are fearful or worried about claiming benefits. Therefore, timely and easy access to social security benefits is vital. We agree with the consultation response made by the DPO September 2021."

10.62. We submitted evidence on the impact of Long COVID on the labour market:

“Our Long Covid Support survey about returning to work or claiming benefits with Long COVID found that more than one in ten people have had no support at all from their employer to help them stay in work. 7% have resigned and 5% have been dismissed directly because of Long COVID, some terminated with immediate effect or having contracts ended with no recourse. Others reported being targeted for redundancy while still on sick leave. Our survey indicates that Long COVID has had a colossal and prolonged impact on the labour market. 86% have been living with Long COVID for over 9 months and the largest cohort of respondents (36%) for more than 18 months. In line with other surveys, the majority (88%) of respondents were female, and across genders the prevailing affected age groups were 45-54 (43%) and 35-44 (25%). These are people in the prime of their careers, at the height of their professional experience and earning potential. Yet 45% of people with Long COVID have been unable (many despite repeated attempts) to return to work and remain on long-term sick leave. This is a significant loss of skilled workforce. The prevalence of Long COVID in women has serious and potentially long-term negative implications for gender equality in the UK labour market. It may also impact child poverty.*

...

A key feedback from our survey is that respondents working in healthcare have been placed at the highest risk of COVID-19 infection in the workplace, but having become disabled by Long COVID, they often receive the least understanding, support and job security from their employers. Like most of our respondents with Long COVID, they also struggle to access disability benefits. Survey responses showed that healthcare workers find themselves pressured by employers, lack of income, lack of sick pay, or by their own strong work ethic to return to work while still ill — this enforced presenteeism is likely to result in a loss of productivity, delayed recovery and prolonged disability.

In NHS England alone, the RCN reports a shortage of around 40,000 nurses and the BMA a shortage of more than 50,000 doctors. Against this background a failure by employers and the government to provide healthcare professionals with Long COVID with adequate support in returning to work, and, where they remain in recovery, a failure to support their survival and wellbeing with appropriate

benefits has a disastrous impact on them, their families, their workplaces and colleagues, and on the health and wellbeing of our society, still in the midst of an ongoing pandemic.”

10.63. We highlighted the pitfalls with the PIP and ESA assessment process, for example, the assessment process for ESA and PIP does not consider the barriers faced by people with disabilities to participating in assessments or making an application.

10.64. We further highlighted that the people with Long COVID were failed not only by the Government but also their employers, we stated:

“We disagree with the phrase ‘falling out of work’, that is used in the Green Paper, because many people with Long COVID have not only been failed by the Government, but also their employers in terms of contracting COVID-19 in the workplace and subsequently receiving inadequate workplace support. Some people with Long COVID have either lost their job, or had good cause to leave it because they have been unsupported, made redundant, coerced or ‘pushed out’ by their employer.”

10.65. We made several recommendations, including:

- Long COVID be formally recognised as a disability under the Equality Act 2010, as it would allow for employers to better support and protect people with Long COVID.
- Redefining work so that it has a broader scope which would allow for the potential to regain skills for paid employment.

10.66. Factors that could have enabled people to return and stay in work included (percentages based on respondents to our survey):

- Having Long COVID recognised as a disability (70%)
- Having Long COVID recognised as an occupational disease (52%)
- Employer understanding of Long COVID (50%)

- Longer phased return (46%)
- Flexible/reduced hours (46%)
- Extended sick pay (41%)
- Occupational health support (35%)
- Having an advocate/representative help them (23%)

10.67. We understand that the strategy pursued by the Government in 2021 was to permit high rates of prevalence of COVID-19. Following the adoption of this strategy in 2021, there was no change in approach as far as we are aware as regards Long COVID in the Omicron Wave in Winter 2022 despite the correlation between high transmission and Long COVID.

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

- *"Support NHS staff returning to work. Providing greater access to effective measures such as extended phased returns, occupational health and vocational rehabilitation support, which would cost less than the significantly greater economic burden of chronic ill health, unemployment and the loss of skilled workforce."*
- *"Require the use of appropriate PPE for all health and care staff working with patients with confirmed or suspected COVID-19. Surgical masks provide inadequate protection."*

- *"Reinstate the advice for face coverings to be worn in schools, given the rapid increase in infection rates of the Delta variant and the disproportionate rise in cases among school-aged children."*
- *"Provide grants for equipment to improve ventilation and air quality in schools, healthcare settings, public transport, workplaces, and arts/leisure venues."*
- *"Expand service provision to enable inclusive and equitable access to assessment, treatment and rehabilitation at the earliest opportunity to maximise chances of recovery and resuming work, education and/or caring responsibilities."*
- *"Count Long COVID to better plan health and social care support by establishing a patient registry that would also serve to follow up any potential longer-term consequences of COVID-19."*
- *"Communicate an updated list of acute symptoms of COVID-19 in both adults and children to allow people to apply for PCR tests and to prevent unwitting spread, including taking account of the differing presentations of the Delta and new variants." [INQ000249053]*

10.69. On 1 December 2021, the LCS Employment Group submitted a written response to the Department for Business Energy and Industrial Strategy consultation on Flexible working [LCS/064 - INQ000249014]. We highlighted the advantages of flexible working as a reasonable adjustment that facilitates a successful return to work. We noted that flexible working could include a change in hours, longer breaks, remote working and the employers failing to provide flexible working and the government's failure to ensure its provision *"is resulting in losses of disabled people and women's jobs, experience and skills from the UK workforce – and this has accelerated during the pandemic. The exclusion is a significant cost, with no benefits, to employers and to the economy"*.

10.70. We highlighted that flexible working, and remote working adjustments are being denied to people with Long COVID and people with Long COVID are being singled out for redundancy.

2022

- 10.71. In February 2022, the LCS Employment Group submitted evidence to the Parliamentary Inquiry on Health Benefits [LCS/060 - INQ000249011].
- 10.72. Our concerns at that time are set out afresh here. Our members (comprised of people with Long COVID, their families and including children with Long COVID) report poor experience and assessment outcomes when applying for PIP, ESA and UC. Our members experienced barriers to accessing PIP and ESA, including not being informed by healthcare professionals that they may be entitled to PIP, ESA or UC; not understanding whether they would be eligible for these benefits; and being too unwell to complete applications to claim PIP, ESA and UC.
- 10.73. LCS is concerned about assessing functional impairments when applied to people with Long COVID. The descriptors used in assessments fail to consider the wide-ranging symptoms, fluctuating and energy limiting nature of Long COVID. As set out further below we invite the Inquiry to recommend a review of the PIP and Work Capability assessments to ensure that a holistic approach is taken. Assessments should consider how Long COVID symptoms impact a person's ability to carry out daily activities. There should be training and education for professionals who contribute to the assessment process; and to consider the roles of carers in the assessment process.
- 10.74. The case studies exhibited to this statement support that our members far from wanting to claim benefits while well, as newly disabled people they find the process traumatic, stigmatising and embarrassing.
- 10.75. On 31 March 2022, LCS and other organisations met with key staff from NHS England including Mark Radford and Tom Simons, Head of Human Resources, to share healthcare workers concerns about the inconsistencies related to COVID-19 sick pay across NHS England as well as the need to support staff with Long COVID to return to work safely.
- 10.76. On 17 April 2022, LCS contributed to PCS Union rep's seminar.

10.77. Between May 2022 and May 2023, much of the Long COVID Employment Group was focused on working with the TUC, educating unions on how to support members with Long COVID, and on the second joint LCS and TUC survey on 'Workers' Experience of Long COVID [LCS/056 – INQ000272240].

10.78. We understand that the Inquiry is concerned only with the relevant period, but we have provided a complete chronology of our advocacy in the appendix.

Part C: The Financial and Economic Impact of Long COVID

11. Overview

11.1. We address in this section the financial and economic impact of Long COVID, and the issues that we raised with the Government bearing upon the matters under consideration in Module 9.

12. Data gathering on Long COVID

12.1. Data is essential to understand the number of people with Long COVID and the degree of impact on their day-to-day activities. The socio-economic costs of a virus cannot be fully quantified and planned for if the long-term impact of the virus is not measured and factored into decision-making.

12.2. There was a significant delay in monitoring and gathering data on the long-term effects of COVID-19 and even when the ONS data was collected, data on Long COVID did not feed into the Coronavirus UK Preparedness: Commonly Recognised Information Pictures reports, Dashboards and other tools that decision-makers relied upon. Aside from early experimental data in December 2020, data on Long COVID was first published by the ONS in February 2021 and a monthly bulletin on Long COVID data was rolled out from April 2021. LCS and other patient advocates like Long Covid SOS played a role in advocating the ONS to start gathering data on Long COVID.

12.3. Further, there are very significant problems with clinical coding in healthcare records which was explored in Module 3. In short, there was and is huge inconsistencies and under reporting by primary care providers such that understanding prevalence, the associated healthcare costs and wider economic impacts is very difficult.

- 12.4. Walker et al analysed 58 million adults in English Primary Care Electronic Healthcare Records (EHR) between February 2020 and May 2021 [LCS/065-INQ000652511]. They found that the use of Long COVID clinical codes in primary care “*is very low, and variable between practices*”, for example more than 1 in 4 GP practices had never used them, the East of England coded 20.3 patients per 100 000 people compared to London at 55.6 patients per 100 000 people [LCS/065- INQ000652511].
- 12.5. Henderson et al analysed 19 million adults in English Primary Care electronic health records (“EHR”), from November 2020 - January 2023 [LCS/066 - - INQ000652512]. Their conclusion was that “*using EHR diagnostic or referral codes unfortunately has major limitations in identifying and ascertaining true cases and timing of Long COVID*” [LCS/066 - INQ000652512].
- 12.6. Due to the extremely poor clinical coding, which is not just confined to the UK, academic researchers globally have used big data approaches to identify Long COVID patients in clinical records using diagnosis codes, referral codes, symptoms and their onset dates. A good example of a big data approach was Yi Mu et al [LCS/016 - INQ000652513].
- 12.7. The research outlined above exemplifies a critical failing in pre-pandemic preparedness and in the Government response with regards to data gathering. This is just one example of many. The COVID-19 dashboard, was established by Public Health England (“PHE”) in April 2020, and overseen by a multi-agency steering group including the Department for Health and Social Care (DHSC), NHS England, NHS Digital and the devolved authorities. Crucially, it did not include Long COVID data or analysis. Even as the COVID-19 dashboard evolved to meet users’ needs for data, Long COVID was still not included.
- 12.8. In September 2023, UKHSA published its Data Strategy [LCS/067 - INQ000528385]. The strategy identified the COVID-19 dashboard as the flagship case study. Long COVID is again not mentioned. For the Long COVID community it is yet another example of not acknowledging the failures around Long COVID, and not planning to fix these for the future.

- 12.9. To our knowledge, central government did not give adequate consideration to Long COVID and its long-term economic costs. We consider data gathering on the prevalence and impact of Long COVID a critical step towards estimating those long-term economic costs. As we said above, data on Long COVID did not feed into the main data presentations that decision makers relied on to make decisions.
- 12.10. The failure to recognise the significance of data on Long COVID to public policy planning remains a pressing issue to this day as the UK has entirely stopped national surveillance of COVID-19 and Long COVID;. We note that the GP patient survey 2025 included questions on Long COVID but only covered England and age16+ .
- 12.11. The decision to end the ONS UK Coronavirus (COVID-19) Infection survey in March 2023, and COVID-19 and Respiratory Infections Survey in June 2023, means there was no longer any ongoing surveillance and published Government data on the prevalence of Long COVID.
- 12.12. The ONS Winter CIS 2023/24 was launched at the very last minute because of the risk from the winter COVID-19 wave. Mike Ormerod was involved with ongoing discussions with the ONS team just prior to its launch, while he was being onboarded into a new role in LCS. They were asked to review the questions and made some suggestions from a Patient Public Involvement ("PPI") perspective. Some of those suggestions were implemented. During November 2023 LCS offered to setup a Long COVID lived experience panel with the ONS to support the design of future Winter CIS questionnaires and analysis. However, as there were no future plans for Winter CIS the ONS did not take up the offer. Once Winter CIS 2023/24 data and analysis was released in March / April 2024 LCS raised a series of questions. As a result of these questions the ONS released a new dataset in October 2024 which contained a detailed breakdown by week of infection and activity limitation of people with Long COVID in England and Scotland [LCS/068 - INQ000652515]. This was the first time ONS had released such a detailed breakdown. We believe that this shows the values of transparency and working with advocacy groups.
- 12.13. Since March 2024 there has been no national Long COVID surveillance to measure prevalence or impact across the UK. This means that it will be difficult to predict and estimate the number of people with Long COVID and the resulting increase in people

who have reduced economic activity or are economically inactive. This to us appears to be a deliberate choice by the UK Government to avoid monitoring the ongoing impact of the pandemic and the continuing disease burden of Long COVID. At the same time, the UK government is greatly concerned about the increase in health and disability related benefits and the impact on public finances. We can only see this as the persisting consequences of the minimisation and denial of Long COVID that was so frequently displayed during the Inquiry's temporal period.

13. Economic policies which increased transmission of COVID-19

- 13.1. The policies pursued by the Government in response to the pandemic permitted high rates of COVID-19 infections. Mitigation measures were inadequate and there were wholly insufficient warnings to the public about the risk of developing Long COVID. This combination resulted in higher rates of Long COVID which could have been avoided and led to 2 million people in March 2024, and an unknown number in June 2025, suffering from Long COVID. Many of these people could have avoided Long COVID if the UK population had been given the right information and better mitigations were in place. Many of these individuals have experienced a significant impact on their financial health as well as their physical and emotional health. For too many it has been devastating. For the UK economy there is a significant and growing impact. Much of that individual and UK wide impact was avoidable.
- 13.2. By allowing high rates of transmission of COVID-19 without warning the public of the risk of Long COVID, the Government demonstrated a disregard for the financial damage Long COVID can wreak on an individual, the workforce and the wider economy. In our view the Treasury, in particular, was disproportionately focused on the costs of measures in response to COVID-19, rather than the costs of the virus itself including long-term impact. The Treasury's position undoubtedly influenced the Government's response to COVID-19.

Eat Out to Help Out

- 13.3. The obvious example is the Eat Out to Help Out scheme. The scheme contributed to rising rates of infections. This is shown in an HM Treasury submission dated 26 August 2020. This submission recommended that the scheme was not extended as it could

be criticised for encouraging people to go to higher risk areas. (§5 [INQ000088100]). By this time, it was too late as it had already contributed to higher rates of transmission. At the time LCS was utterly appalled by the scheme – referring to it as “*Eat Out to Catch COVID*”. We have also heard it called “*Eat Out to Die Out*”. From our perspective the scheme seemed aimed at convincing the public that it was safe again to eat out and mix in indoor spaces with little or no protection against transmission. If the scheme had been aimed at protecting the hospitality industry, then we believe it would have included takeaway / delivery food in the 50% discount to encourage extra orders.

- 13.4. We were concerned throughout the relevant period about policies that permitted widespread transmission and raised this with decision makers. We asked the Government to recognise that Long COVID was impacting a significant number of people and preventing them from engaging in economic activity. We raised as an issue support for people returning to work and called for employers to be better informed about Long COVID.
- 13.5. For example, as set out above, on 9 January 2021, LCS founding member, Claire Hastie sent a letter by email to all MPs urging them to participate in the Commons debate on Long COVID scheduled for 14 January 2021, as well as the APPG on Coronavirus oral hearing about Long COVID among health professionals on 12 January 2021 [LCS/069 - INQ000248900] and our letter dated 9 July 2021 to Sir Sajid Javid [LCS/058 - INQ000248931] raised our continuing concerns. We discussed high infection rates for COVID-19 leading to high rates of Long COVID among younger people and the impact on employment at the Ministerial Roundtable for Long COVID on 29 January 2021 [LCS/041 - INQ000272260].
- 13.6. We note that the COVID-19 Task Force provided a paper to the Prime Minister entitled “Long Covid Risks to the Population and Health Service” dated 9 July 2021 which states “*it is likely to see a significant rise as higher case rates.. lead to an increased proportion of the public suffering from Long COVID*” [INQ000622771]. We note that the Cabinet Office prepared a paper for Covid-O, and a meeting was held on 21 July 2021 entitled “High Prevalence Planning Summer Response Covid Task force” [LCS/070 - INQ000092058] considering “*a preliminary view of the major cross departmental risks of high prevalence....*” This stated as follows:

“Long COVID (i) 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 absences.”

13.7. LCS is not aware of any strategies being proposed, identified or implemented by Covid-O, or any other relevant department, concerning the cumulative impact of Long COVID on the labour force nor any mitigations implemented by DHSC or DWP. We had three possible concerns:

- It was known by the Government that Long COVID was a significant problem and that it wilfully disregarded this in pursuing a “High Prevalence” policy [LCS/070-INQ000092058].
- Given the *minimisation and denial behaviours* that we have already discussed, our concern is that the Government thought that the risk was small and worth mitigating, despite the mounting evidence against that view.
- The Government thought there was a significant risk, but the *minimisation and denial behaviours* meant that the risk went unmitigated.

13.8. In our view the Government accepted the high prevalence of COVID-19, knowing it would cause more people to suffer from Long COVID. We note that in oral evidence before this Inquiry, Sir Sajid Javid admitted that Long COVID was an accepted trade-off for releasing restrictions on social distancing². We were not told that this was a trade off at the time (certainly it was not referred to in the response to our July 2021 letter); in fact, there was no messaging on Long COVID whatsoever.

13.9. It is a concern to us that this apparent trade-off is explicitly recognised by decision makers and in advice (see for example Covid Operations Committee papers and Covid Task force papers referred to above concerning High Prevalence Planning [LCS/070 - INQ000092058, LCS/071 - INQ000092555, LCS/072 - INQ000622771 INQ000622771] at the time which recognised that high rates of transmission would result in increased incidence of Long COVID.

² Module 2, Day 28, 29.11.2023, p.142, ll13-p.143, ll.16

- 13.10. Sir Sajid Javid notes from a Long COVID Ministerial round table record *"Long COVID Dashboard 23/9...should focus on prevention/costs rising/how do we prevent/keep same where you can."* [INQ0000274058/21]. As far as we are aware there were no consequential policies either providing financial support to those with Long COVID, or offering advice to DWP decision makers, and employers. Further there was no substantive plan to prevent high rates of incidence of Long COVID through NPIs ("non-pharmaceutical intervention") to change the behaviour of those who mistakenly believed that Covid posed no significant risk to them, such as public health communications, ventilation, masks or other Covid-safe mitigation measures. We note that data from the ONS illustrates the sharp escalation of cases of Long COVID from June 2021 [LCS/073 - INQ000652520]

Financial support for self-isolation

- 13.11. We were concerned throughout that financial support for self-isolation was inadequate, did not take account of Long COVID and that there was insufficient public messaging about the support that was available. Financial support was essential to enable people to self-isolate to:
- Reduce transmission of COVID-19 and to avoid the risk of developing Long COVID.
 - Reduce transmission of COVID-19 to others who may be at risk of severe COVID-19 symptoms.
 - Allow people to rest and recover thus avoiding the worsening of Long COVID symptoms.
- 13.12. We should explain that it is necessary to rest and recuperate (often called pacing) to manage symptoms of Long COVID and that activity (physical, mental, emotional, social or otherwise) can aggravate symptoms and worsen functioning. Therefore, as we set out in our letters referenced above it was important that there was bespoke guidance relating to Long COVID, because it was a new disease but also because of the nature of the impact on work or other activities.

- 13.13. Further, in our view, during the acute phase of COVID-19 it is important to recover properly and not “push” through persistent symptoms. It is the experience of many of our members that they developed Long COVID having sought to get back to work or ‘pushed through’ whilst symptomatic and this worsened their health outcomes and led to Long COVID.
- 13.14. The Inquiry has heard in Modules 2 and 7 that the Government did not want to financially support people self-isolating:
- 13.15. Professor James Rubin, ex-committee member of SPI-B, gave evidence that SPI-B advised on financial support for self-isolation early in the pandemic, stating: *“one of the things we were immediately aware of was that the policies for self-isolation, because there wasn’t sort of financial support for it, would make it – if you were depending on an income, make it very, very difficult to do.”* He stated that SPI-B made a recommendation on this and received feedback from Sir Patrick Vallance saying: *“there was strong push-back from the government that they didn’t want to provide financial support”*. [Module 2, Day 12, 18.10.23, p.139 l.6 – l.18]
- 13.16. This accords with our experience as we raised self-isolation financial support in our advocacy with decision makers [LCS/058 - INQ000248931]. To our mind this calls into question, the Government’s commitment to reducing the transmission of SARS-COV-2 . In the absence of the Government’s commitment to financially support individuals, as Mr Rotheram, Mayor of Liverpool City Region, puts poignantly in his oral evidence, people: *“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, Day 26, 27.11.2023, p.188 l.2 – l.10]
- 13.17. The premature ceasing of support for self-isolation has also contributed to the ongoing spread of SARS-CoV-2 and in turn new cases of Long COVID. Whilst acute COVID-19 is no longer considered an immediate threat to health, this continues to contribute to the increasing number of people affected by Long COVID and other long-term health issues as a result of repeat infections. This continues to impact workplace absence and school attendance, contributing to an ongoing reduction to the health and wealth of the nation.

14. Macro-Economic and Fiscal assessments on the Impact of Long COVID

Long Covid Support's approach to economic analysis

- 14.1. We have set out above in paragraph 6 our broad approach to economic analysis and provide further details here by reference to our work.
- 14.2. We have been asked to address whether we have undertaken any economic analysis. During the pandemic period in-scope for the Inquiry our capability was at the level of identifying gaps in economic impact assessment and raising those with government for further investigation and sizing (see section B). We also identified published research that covered economic impacts, both in the UK and globally, and highlighted these to government.
- 14.3. Our experience during the period highlighted the extremely limited economic impact assessments for Long COVID, and the lack of political will to undertake them. This lack of political will continues to the present day and drastically impacts government funding to investigate Long COVID's economic impact, provide effective financial support for people with Long COVID and ultimately fund healthcare and research.

Compliance with UK government approaches.

- 14.4. Our approach to economic analysis is compliant with both the *HM Treasury Green Book: appraisal and evaluation in central government* [LCS/004-INQ000652444] and the *HM Treasury and Government Analysis Function's Aqua Book: guidance on producing quality analysis* [LCS/005-INQ000625674]

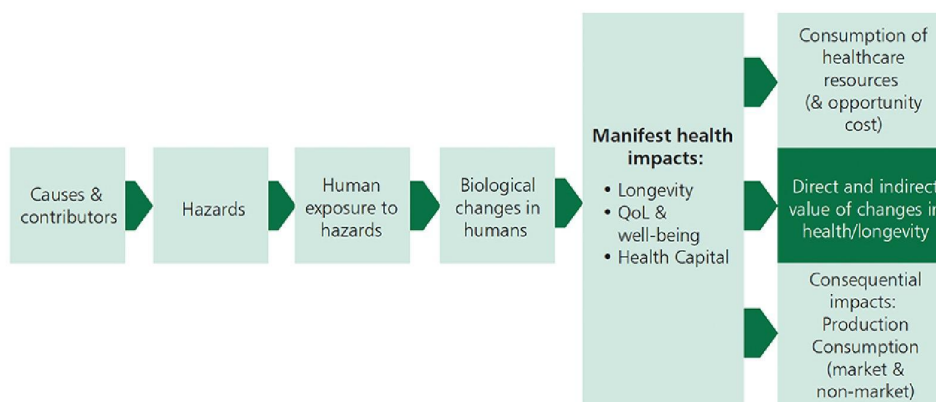
Valuing Life and Health - Quality Adjusted Life Years (QALYs) and Statistical Life Years (SLYs)

- 14.5. We would draw particular attention to the *HM Treasury Green Book* which includes valuations of the risk to Life and Health. This states: "*Changes in risks to life or health as a result of government interventions should be valued as part of appraisal and will usually require non-market valuation techniques.*"

- 14.6. We find it particularly striking that the valuations documented in the *Green Book* are almost never used in economic analysis even when discussing policies and interventions.
- 14.7. The *Green Book* states “QoL [Quality of Life] can be thought of as different dimensions of health (e.g. the capacities for mobility, self-care, usual activities, pain or discomfort and anxiety or depression).” The *Green Book* values perfect Health for one year (Quality Adjusted Life Year or QALY) at £70,000 at 2020/21 prices. The value of early mortality of one year (Statistical Life Year) is valued at £60,000.
- 14.8. The National Institute for Clinical Excellence (NICE) use a cost per QALY threshold of QALY (£20,000 - £30,000). This is often misinterpreted as the value of a QALY [LCS/074 - INQ000652523]. However, this is incorrect, NICE is solely concerned about the cost effectiveness of new treatment compared to current treatments and the calculation of Incremental Cost Effectiveness Ratios.

HM Treasury Green Book – Impact Pathway

- 14.9. Health affects the ability to produce and consume goods or services and the ability to derive welfare and well-being directly. The Impact Pathway approach is a way of structuring analysis of the effects of external factors from causes to consequences for health and life – see below.



Long Covid Support's focus on Impact Assessments

- 14.10. LCS focuses on two areas in the Impact Pathway – *Consumption of health care resources* and *Direct and indirect value of changes in health / longevity*. This focus is driven by the availability of knowledge and skills of our volunteers. We will make use of published research which looks at the Consequential Impacts
- 14.11. Our general approach is to make lower bound impact assessments to inform decision makers. For example, if the lower bound Quality of Life impact is £6 billion then this issue is worth investigating further as the other two manifest health impacts will only increase the impact value.
- 14.12. An example of this approach is from the Long COVID Status Report to the Long COVID All Party Parliamentary Group [LCS/003- INQ000652443]. We used data from the LOCOMOTION study, the ONS Winter CIS 2023/2024 and the Green Book valuation of a QALY, £70,000 at 2021/22 prices, to estimate the value of Quality of Life Lost in 1 year for the 381,000 people, in England and Scotland, whose day-to-day activities were “impacted a lot” by Long COVID.
- 14.13. The Quality of Life lost was estimated at £11.2 billion at 2020/21 prices = 381,000 people [ONS data] x (healthy population QALY score 0.92 - Long COVID QALY score 0.5) [LOCOMOTION data] x £70,000 [Green Book QALY valuation]. While this estimate uses data from outside the Inquiry temporal window it illustrates the principles behind our approach.

LOCOMOTION

- 14.14. The LOCOMOTION study [LCS/027- INQ000651341] (Kwon et Al)³ looked in depth at the financial and work impact for Long COVID Clinic patients from August 2022 to February 2023. The individuals in the study had Covid infections triggering Long COVID throughout the pandemic . The paper is one of the most detailed financial and economic impact assessments of the heavily impacted Long COVID population in the UK.

14.15. The Long COVID clinic population is believed to be representative of the ONS daily activities impacted “a lot” cohort (381,000 people in England and Scotland alone at March 2023). So, it does **NOT** include any analysis of the 1.1 million people who were impacted “a little” or the 392,000 people who were impacted “not at all” at the time of the ONS survey.

14.16. LCS members, Dr Clare Rayner and Prof. Ruairidh Milne were PPI Leads on the LOCOMOTION study and co-authored the paper “*Impact of Long COVID on productivity and informal caregiving*” (published in December 2023) [LCS/027 – INQ000651341].]. This paper was based on a survey of 366 patients attending Long COVID clinics that were part of the Locomotion Consortium (mean Long COVID duration 449.9 days). Outcomes were changes from the incident infection resulting in Long COVID to the month preceding the survey in paid work status, work income, work performance and informal care receipt.

14.17. The survey found that:

- 16.7% had stopped paid work and had no work income.
- 11.5% were no longer engaged in paid work but were still receiving paid work income (e.g. sick pay, permanent health insurance)
- 23.5% had reduced paid work hours.
- In total 51.7% had stopped paid work or reduced paid work hours relative to the pre-infection period.
- Only 27% had had returned to working their pre- Long COVID hours.

14.18. The study also investigated how income loss changed depending on the duration of people’s Long COVID. As the Long COVID duration increased so did the monthly income loss. The average monthly income lost hides the impact for individuals. Some will have dropped to no income (e.g. zero hours contracts, employer’s sick pay finishing). Some will have moved onto ill-health and disability benefits.

Long COVID Duration at February 2023	Average monthly income lost per person
< 1 year	£337 (18.5%)
1 - 2 years	£496 (24.1%)
> 2 years	£853 (41.5%)

14.19. At the point of the LOCOMOTION study in February 2023 there were many interacting factors making this a complex picture. Employers offered sick pay that varied from full pay, to partial pay, to just Statutory Sick Pay and the duration of sick pay was also very variable. The COVID-19 Furlough scheme and the Self-Employment Income Support Scheme (“SEISS”) were also in place for some of this which affected income people were receiving. Additionally, the NHS England COVID-19 absence exemption for COVID-19 related illness ended in September 2022. This meant that by February 2023 NHS staff with Long COVID would be entering into dismissal or half pay situations in the period January-February 2023 resulting in substantially greater income losses after February 2023.

14.20. The study data also allowed the evaluation of the income lost and cost of informal caregiving from first infection to February 2023. Informal caregiving by family used the 2023 market rate of £20 per hour as a proxy for the financial impact (e.g. reducing working hours to provide care). The study data was extrapolated to the 381,000 people in the ONS Winter CIS impacted “a lot” cohort at March 2023 (see table below).

Infection date to Feb 23	Total (Bn)	Monthly average (m)
Income Loss	£5.7Bn (95% CI ¹⁶ : £3.8Bn to £7.6Bn)	£277.7m (95% CI: £196.3m to £359.2m)
Informal Caregiving	£4.8Bn (95% CI: £2.6Bn to £7.0Bn)	£218.2m (95% CI: £122.4m to £314.2m)

14.21. The National Evaluation of Long COVID Clinics service outcomes measured the patient's Quality of Life using the gold-standard EQ-5D-5L [LCS/075 - INQ000652525] which scores best health as 1, and death as 0. The table below shows the index score for Long COVID and other diseases to give a comparison of quality-of-life impact. Long COVID clinic patients scored 0.5 on average. 68% of the patient scores were in the range 0.8 to 0.2.

Condition	EQ-5D Index (SD)
Healthy population	0.92 (0.17)
Diabetes mellitus (type 2)	0.79 (0.22)
COPD	0.68 (0.24)
Heart failure	0.60 (0.25)
Multiple sclerosis	0.59 (0.29)
Long Covid (this service evaluation study)	0.50 (0.30)

14.22. The study stated that Long COVID had a substantial impact on productivity, stating that:

"The substantial impact of LC on productivity has likewise been confirmed by numerous UK and non-UK studies of general or general working populations and specific professions including healthcare workers, teachers, and athletes [Productivity in employment not only increases national income, but is also a determinant of health and well-being. Productivity loss due to sickness begets further ill health via mediators including financial instability lack of cognitive stimulation, and loss of social identity Voluntary activities, particularly by retired older persons, likewise contributes to local and wider communities. It is therefore of national and individual interest that LC care strategies place adequate emphasis on vocational rehabilitation to help LC patients return to work or usual activities]" [LCS/027 - INQ0000651341]

Other assessments during the relevant period

14.23. In our view the macro-economic impact of Long COVID has not been properly assessed by the UK Government nor factored into decision making during the relevant

period. The limited assessments by the UK government significantly underestimated the actual impact of Long COVID.

Cabinet Office

14.24. For example, in April 2021 Cabinet Office received advice that Long COVID causes workplace absenteeism, loss of earnings and labour market inactivity [INQ000292660]. The report provided a conservative estimate, that between March 2020 and March 2021 the cost of workplace absenteeism because of Long COVID would be approximately £158 - £316 million.

14.25. The advice added that:

This cost is only indicative and should be refined as new evidence emerges.

...

Emerging evidence suggests long COVID is likely to have an important social and economic impact through its disproportionate effects on certain groups of people, its impact on output and productivity due to sickness and absence from work, and its mental health impact."

14.26. The report refers to an international survey [LCS/023 - INQ000652469] wherein the findings, include:

- Nearly half of the respondents have to work reduced hours
- Almost a quarter of respondents were not working
- Many had to take months of leave before returning to work and often required phased returns and/or other workplace arrangements, e.g. flexible hours and the ability to work from home

14.27. In light of the above, the report concludes: *"This is likely to disproportionately impact those on lower wages and in low income group who are less likely to be able to bargain for such arrangements, and for whom taking an extended period of leave or working fewer hours may make it more difficult to pay bills and other outgoings."*

- 14.28. This is the first advice to Cabinet Office on the macro-economic impact of Long COVID that we are aware of. Although the advice recognised that Long COVID was likely to have an important social and economic impact, we are concerned that Cabinet Office did not receive similar advice about the impact of Long COVID before April 2021 and then did not appear to take that advice into account in decision making as far as we are aware. We also note that we are not aware of Cabinet Office being advised on the socio-economic impact of Long COVID (aside from in very general terms) after this as more and more information became available.
- 14.29. LCS's view of this report is that it highlighted a number of critical points about the impact of Long COVID including the levels of uncertainty. However, this was seriously overshadowed by a number of critical failings.
- 14.30. On page 1 of [INQ000292660] it states *"Long COVID risks impacting the economy through absenteeism. We estimate that from around 390,000 working age adults who could have experienced long COVID, 61,755 (16%) of them had symptoms that significantly reduced their ability to perform day-to-day activities, leading to 1.4 - 2.8 million working days lost. The cost of absenteeism due to long COVID symptoms was estimated between £158 - £316 million for the period from March 2020 to March 2021. This cost is only indicative and should be refined as new evidence emerges."*
- 14.31. The authors made no estimate on workdays lost for the remaining 328,000 (84%) people of working age who were reporting symptoms of Long COVID of varying duration and severity.
- 14.32. The authors had assumed that the ONS impacted "a lot" cohort would lose between 15%-30% of their total workdays based on their duration of Long COVID. However, there is no explanation of the basis behind that critical assumption and no evidence of assumption reviews or red team reviews.
- 14.33. We struggle to see how the authors set this assumption when the international paper they refer to selected participants by illness onset in the period December 2019 to May 2020 and illness lasting over 28 days. This was to allow analysis of symptoms over 7 months duration.

“For the majority of respondents (>91%), the time to recovery exceeded 35 weeks. During their illness, participants experienced an average of 55.9+/- 25.5 (mean+/-STD) symptoms, across an average of 9.1 organ systems.”

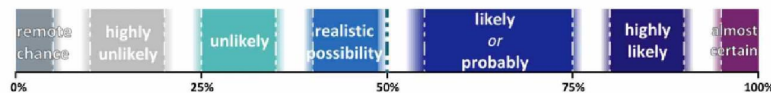
“A total of 2454 (65.2%) respondents experienced symptoms for at least six months. For this population, the top remaining symptoms after six months were primarily a combination of systemic and neurological symptoms (Fig. 11a), including fatigue (80.0%, 95% confidence interval 78.5% to 81.6%), post-exertional malaise (73.3%, 71.5% to 75.1%), cognitive dysfunction (58.4%, 56.5% to 60.2%), sensorimotor symptoms (55.7%, 53.7% to 57.6%), headaches (53.6%, 51.5% to 55.5%), and memory issues (51.0%, 49.1% to 53.0%).”

- 14.34. The authors also refer to the NIHR “Living with COVID” web post (15th October 2020) [LCS/076 - INQ000236442] which summarises the first NIHR review into Long COVID. Again, on reviewing the research listed in that post which included widespread disabling symptoms and explicitly raised economic inactivity as a matter for further investigation we struggle to see how they got to 15% - 30% workdays lost.
- 14.35. At paragraph 11 the authors calculated the working days lost to Long COVID just for the impacted “a lot” cohort: *“As a percentage of the total number of days worked in a year, this range of working days lost is estimated to be between 0.02% and 0.04% of all working days in England.”* This is not a helpful comparison as it fails to mention that this is from the period when tight public health restrictions were in place (e.g. lockdown) and should not be used as an estimate moving forward. In effect, it minimised the impact at the time and minimised any future impact. Comparing the average working days lost by the general population to that of the 61,755 from the ONS impacted “a lot” cohort would have been a much more meaningful comparison.
- 14.36. Paragraph 14 does include information on QALYs lost but fails to convert QALYs lost to a monetary value. Simply applying the Treasury Green Book values for QALYs lost, £70,000 per QALY at 2020/2021 prices, the 48,085 QALYs lost in just the hospitalised population with Long COVID gives a value of £3.6 billion (48,065 x £70,000). We struggle to understand why the authors failed to do this. For policy makers reading the detail in the report 48,085 QALYs lost is not a big number, unless they understand the

Treasury Green Book valuation for QALYS. 48,065 QALYs lost vs £3.6 billion cost of QALYs lost is a critical example of minimisation.

14.37. The final page of the document rates the Author's confidence as "Low". In the statement it explicitly mentions "... complications through discharge ..." meaning that it's referring to hospitalised patients and does not mention the people who were self- or GP managed through infection. Again, a very significant minimisation.

Probabilistic language



Confidence Statement

There remains much uncertainty around the clinical presentation of long COVID including the mechanism through which COVID-19 leads to complications following discharge and the frequency of severe post-COVID-19 complications. As such, it is too soon to determine the potential impact on health care. Similarly, whilst it is highly likely that long COVID will have economic impacts, the magnitude will remain uncertain until we have better data on the relationship between long COVID and time off work, and the effectiveness of therapeutics in treating symptoms. The estimate of human capital costs is based on experimental data which does not fully capture the severity of symptoms of long COVID and time taken off work as a result. Furthermore, we have not been able to disaggregate this estimate by sector, or disproportionately impacted groups, and the data does not shed light on co-morbidity and the associated costs.	Low
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14.38. We also note that there is no probabilistic language rating given for the author's view on how likely the paper is to be accurate.

14.39. We note at the time of publication of the paper in April 2021 there was extensive evidence from patients, patient advocates, ONS data and our advocacy to the Government and other decision makers on the devastating impact of Long COVID on people's health, jobs and financial security.

14.40. Mike Ormerod, one of the Authors of this witness statement has extensive experience of commercial risk management in their pre- Long COVID career. Given the Low confidence rating and the uncertain future including number of people who will develop Long COVID, how badly they would be affected, and how long they would take to recover, the Author would have expected to see in the advice at least four scenarios and the following mitigation actions:

- Setup monthly surveillance to identify new cases and to track recovery patterns
- Monthly reviews of research both pre-print and published
- Re-evaluate the scenarios monthly, update them to reflect the new information and create new scenarios if required
- Monthly reviews with decision makers

14.41. We would invite the Inquiry to investigate whether this advice was representative of risk management process in the Cabinet Office advice generally about the impact of Long COVID and indeed COVID, or whether it was an extreme outlier.

14.42. Aside from the April 2021 advice to Cabinet Office by the COVID-19 Task Force, we are not aware of any other advice to Cabinet Office or another relevant department about the financial and economic cost of Long COVID. Independent reports have shown that this cost was, and continues to be, considerable.

The Office for Budget Responsibility (“OBR”)

14.43. The OBR recognised there would be an economic cost associated with increased cases of Long COVID as early as October 2020. The OBR reported that an increase in spending on disability benefits *“could be directly related to the virus (e.g. 'long covid') or indirectly related (e.g., increased prevalence of mental health conditions due to economic conditions or lockdowns).”* LCS/038 – INQ000114451/121]

14.44. In their March 2021 report, the OBR concluded that *“The most direct virus-related costs that could persist longer than currently factored into the Government’s plans are the direct health costs of coronavirus.....There could also be greater-than-assumed medium-term implications for spending as a result of 'long Covid' cases and the consequences for mental health arising from the pandemic and lockdowns.”*

The Office for National Statistics (“ONS”)

14.45. The ONS undertook an analysis in 2022 of the impact of Long COVID on labour market outcomes [LCS/014 – INQ000272241]. This study 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.
- Among working-age people not in full-time education, the odds of inactivity (excluding retirement) for those reporting Long COVID 30 to 39 weeks or 40 to 51 weeks after a first test-confirmed COVID-19 infection were 45.5% and 34.3% higher, respectively, compared with before infection; this was after adjusting for background rates of inactivity in the labour market.
- The relationship between self-reported Long COVID and inactivity (excluding retirement) was strongest for people aged 50 to 64 years, where the higher odds of inactivity compared with pre-infection peaked at a 71.2% increase among people reporting Long COVID 30 to 39 weeks post-infection.
- Compared with before a first test-confirmed COVID-19 infection, employed people with self-reported Long COVID were more likely to experience long-term workplace absence (for example, through sickness) 18 to 29 weeks after infection.

14.46. Later studies by the ONS have found that the number of people not working in the UK due to long-term sickness has risen to new records. In November 2022 the ONS reported that *“the number of working-age adults who are out of the labour market (known as “economically inactive”) because of long-term sickness has been rising since 2019, from around 2.0 million people in spring 2019, to about 2.5 million in summer 2022. This rise in long-term sickness started before the coronavirus (COVID-19) pandemic, but since the pandemic hit the UK in early 2020, the number of people out of work because of long-term sickness has risen by 363,000. A range of factors could be influencing this recent increase. We introduce some of these in this article, but more understanding is needed about the impacts of National Health Service (NHS) waiting times, long COVID, and the ageing workforce.”* [INQ000272242]

14.47. The 2022 All-Party Parliamentary Group report on Long COVID also concluded that Long COVID had a significant impact on the workforce. They estimated that the NHS

trusts in England lost around 1.8 million working days to Long COVID absences between March 2020 and September 2021. The Nuffield Trust estimates that in 2019 - 2022, sickness absence days for NHS staff increased by 29% LCS/077 - INQ000652527. In 2022, NHS sickness absence equated to the loss of around 74,500 full-time equivalent staff. [LCS/007 - INQ000272149] Repeated COVID-19 infections and Long COVID are likely to be contributing factors. However, as NHS trusts could not record Long COVID using a specific absence code on HR systems it is difficult to monitor the impact of Long COVID on sickness absence.

HM Treasury

- 14.48. We are not aware of HM Treasury undertaking informed appropriate assessments of the impact of Long COVID or assessments on future impact. We are concerned that HM Treasury did not have the systems in place to adapt to a novel virus and respond in rapid time, did not plan for morbidity and numbers of people being long term sick or use the appropriate data to measure and estimate the impact of Long COVID. These assessments could have been important to inform any balancing exercise weighing up the direct and indirect costs of the virus with the costs of measures taken in response.
- 14.49. It is a concern to us that Long COVID was a fundamental blind spot in all aspects of policy making and consideration by central Government.

Other assessments after the relevant period

- 14.50. We set out here some of the key independent evidence showing the impact of the decision making in the relevant period.
- 14.51. Notably, the number of people economically inactive due to ill health numbers has increased. The ONS July 2023 update [LCS/078 - INQ000652528] stated: *“The number of people economically inactive because of long term sickness has risen to over 2.5 million people, an increase of over 400,000 since the start of the coronavirus (COVID-19) pandemic. For those economically inactive because of long-term sickness, nearly two-fifths (38%) reported having five or more health conditions (up from 34% in 2019), suggesting that many have interlinked and complex health issues.”*

14.52. The Economist Impact 2024 Long COVID report included the UK and other countries. For the UK, their modelling calculated the GDP impact as \$15.5Bn / £12.2Bn at April 2024 prices. The report understates the impact as costs for quality of life, health care and informal caregiving are excluded. They also assumed that people who reduce hours do so for only 6 months which is not supported by other data. [LCS/079 –

INQ000657077

14.53. A 2024 EU labour market and economic impact assessment estimated an output loss of 0.1-0.2% in 2021 and 0.2-0.3% in 2022. The paper estimated the prevalence of Long COVID cases at around 1.7% of the EU population in 2021 and 2.9% in 2022.

14.54. A study by researchers from the University College London (“UCL”) found that the societal costs related to Long COVID were £931 per month per individual at 6 months [LCS/080 – INQ000652529]. This was calculated using the national average hourly pay and average working hours per week. [LCS/081 - INQ000652530]

14.55. In the article ‘Work Productivity Loss in People Living with Long COVID Symptoms over 2 years from Infection’ by Naik, Hetan et al [LCS/082 - INQ000652531], they found that of the 906 Canadian participants, 165 (18.7%) reported having Long COVID. Compared to people with no Long COVID symptoms, people with Long COVID were:

- Over 3 times more likely to report productivity loss (absenteeism)
- Over 4 times more likely to report work performance impairment (presenteeism)
- Lost 99.2 hours more over 3 months – equivalent to 2.7 weeks of full-time work.
- the value of total productivity loss associated with long COVID among full-time workers was £2,006 over 3 months and £8,025 over a year - calculated using the average hourly wage in British Columbia, Canada (£20.22) and the exchange rate on 12th July 2023 (1 CAD = £0.5845).

Healthcare costs

14.56. Whilst the impact on the healthcare system was explored in Module 3 we do consider it relevant that in considering the economic and fiscal interventions and impacts of the

same during the relevant period that the healthcare costs of Long COVID are considered. Lin Ly et al [LCS/083 - INQ000652532] found that between in the 12 months after diagnosis between Nov 2020 and Jan 2023, Long COVID patients were 8 times more likely to use healthcare resource and cost over £1,000 more than the non-Long COVID control group.

- 14.57. Mu Y et al [LCS/016 - INQ000652513] used complex analysis of diagnostic codes and referral assessment codes to identify Long COVID patients as the clinical coding was insufficient. The data was from January 2018 to January 2023 to allow pre-pandemic comparison. Long COVID patients cost over £700 per person per year, 2.5 times pre-pandemic costs and 1.5-2.0 times pandemic costs of matched patients without Long COVID.
- 14.58. Most strikingly individuals with Long COVID had, when compared to all other control groups the:
- highest hospitalisation rates over two years
 - highest GP consultations per person per year
 - highest outpatient appointments
 - highest Emergency Department attendance
- 14.59. The only neutral result identified was the duration of In-Patient stay where there was no significant difference.
- 14.60. Every COVID wave will bring more Long COVID cases driving increased cost, increased load on GPs and other services and increases in waiting lists. During the 16 weeks of the ONS CIS survey 23/24 there were 178,000 additional cases of Long COVID with the associated healthcare costs.
- 14.61. We are not aware of decision makers conducting any detailed analysis of Long COVID healthcare costs when considering economic or fiscal interventions and impacts during the relevant period.

15. Economic and financial impact of Long COVID on individuals

KM, adult, states: *"I was subject to financial pressure to get back to work and there were barriers to getting sick pay. I had to drive to a COVID-19 testing centre because my employer did not accept home tests and was harassed for sick notes afterwards despite being bed-ridden."*

Economic impact

- 15.1. We have been asked to address any analysis or work we undertook in relation to the impact of Long COVID on individuals. As set out above our advocacy has often focused on the financial and economic impact of Long COVID on our members [LCS/035 - INQ000248911], [LCS/046-INQ000248996], [LCS/037-INQ000058536], [LCS/040-INQ000058981], [LCS/45]-INQ000249020], [LCS/048-INQ00060080].
- 15.2. Developing Long COVID is an extreme economic challenge since many had to reduce their hours or stop work altogether. Members' finances were significantly impacted with a number losing not only their jobs, but also their homes, and relationships. Once employees reached the end of their sick pay entitlements they faced multiple financial challenges. For those employed, the pressure to keep working, with or without reasonable adjustments often leads to employees becoming too exhausted to do any social, household or leisure activities. Some may be offered part time work but obviously this results in a lower income. Access to welfare benefits is impaired by health conditions. It is a difficult and complex system and as far as we are aware there was no guidance to the DWP as to how to either assist or identify a new cohort of people with chronic health impairments from COVID-19. Caregivers for those with Long COVID were also affected as many often forgo work, losing earnings, in order to care for their loved ones.
- 15.3. Rt Hon Jo Platt MP, chair of the APPG on Long COVID has recently said about the welfare benefits system *"People with Long COVID are stuck with a double burden: a life changing illness and a system that doesn't believe them."* We agree and hope that the Inquiry will draw on the case studies provided by our members. [LCS/085 INQ000652535]. They illustrate the range of problems people with Long COVID

experience when attempting to access support, the impact Long COVID had on them, their finances and occupation.

16. Research Long Covid Support has undertaken

Our work

- 16.1. We have been asked to address the research LCS did during the relevant period including work with other organisations about the impact of Long COVID on individuals. We felt compelled to carry out the research documented below, as our member's lived experience overwhelmingly highlighted that it was not being addressed. Long COVID was literally erasing people's lives and livelihoods, and nobody was measuring the extent of the problem. We hoped that by doing so, we could make the invisible visible to policy makers.

Workers Experience Survey

- 16.2. In June 2021, LCS and the TUC published their first joint report into 'Workers Experiences of Long COVID' based on a survey of more than 3,000 people with Long COVID [LCS/58a-INQ000249073]. The survey found that:

- Over half (52%) had experienced some form of discrimination or disadvantage due to their condition.
- Around a fifth (19%) said their employer had questioned the impact of their symptoms.
- One in eight (13%) faced questions from their employer about whether they had Long COVID at all.
- One in 20 respondents (5%) said they had been forced out of their jobs altogether because they had Long COVID.
- Around one in six respondents (18%) said the amount of sick leave they had taken had triggered absence management or HR processes.

- 16.3. This led to a call for people with Long COVID to have their rights under the Equality Act 2010 clarified. Section 6 of the Act defines a person as having a disability if that person has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities. Regrettably the Equality and Human Rights Commission ("EHRC") published an ill thought through tweet stating that Long COVID should not be *"treated as a disability"* in the absence of "case law or scientific consensus". This was incorrect as a matter of law as section 6 of the Act requires an individualised assessment to determine if a person is disabled.
- 16.4. By May 2022, there was a significant scientific consensus that people with Long COVID suffer substantial and long-term impairment. We were dismayed as the EHRC tweet fed into a dismissive narrative about Long COVID not being a 'real condition'. [LCS/086 - INQ000652536] Our solicitors on behalf of the Long Covid Groups wrote to the EHRC to say: *"The tweet of 7 May 2022 was poorly drafted, is misleading and feeds into a damaging and harmful narrative that Long COVID is not a serious medical condition. This is also the impression given by using inverted commas around 'long covid'. There are multiple bioindicators for Long COVID, most evidently having had COVID-19. The use of quote marks is inappropriate and dismissive to those that have been seriously harmed by COVID-19 infection."* [LCS/087 - INQ000652537] and received a response dated 31 May 2022 [LCS/088 - INQ000652538] which apologised for the original tweet and stated: *"clear that individuals experiencing symptoms that are both substantial and long-term are likely to meet the definition of disability under the Equality Act 2010."*
- 16.5. A further survey with the TUC was completed in 2022 and published as a joint report into workers' experience of Long COVID. This was a survey of 3,373 people completed between 14 September 2022 to 1 November 2022. [LCS/056- INQ000272240]. The report made findings on the impact of Long COVID on employed and self-employed persons:

The Employed

- 16.6. The survey found evidence of shockingly high levels of poor treatment by employers [LCS/056 – INQ000272240]. One in seven respondents (14%) had lost their job because of reasons connected to Long COVID. Given the high numbers of people experiencing Long COVID, this finding is extremely concerning and many people losing their jobs could be in key sector roles.
- 16.7. Two thirds of respondents (66%) said they had experienced one or more types of unfair treatment at work. This includes one in six (16%) who had been subject to bullying and/or harassment at work, one in 13 (8%) told us they had been threatened with disciplinary action and almost a quarter of respondents (23%) said their employer has questioned whether they have Long COVID and/or the impact of their symptoms. Around half of respondents (49%) said they had reason to believe they had contracted COVID-19 at work highlighting that many people are being continually failed by their employer, from a lack of health and safety measures, including ventilation, to poor treatment in response to Long COVID. 19% of respondents explained that they experienced disbelief and suspicion by employers who questioned the impact of symptoms and 13% of respondents faced questions about whether they had Long COVID.

Financial support

- 16.8. We asked respondents if they received any financial support (excluding benefits which we asked separately). The most common form of financial support reported by respondents was their own savings (50%), of which 38% had savings of less than £16,000 followed by four in ten respondents (41%) who relied on a significant others' funds (e.g., partner, parents, friends).
- 16.9. It is worrying that people with Long COVID are having to rely on savings to financially support themselves and even more concerningly are the percentage of people who reported taking out private loans or using a debt service e.g. pay day loans, loan sharks (6%), with a further (4%) having considered applying for a private loan or debt service. Additionally, one in sixteen (6%) told us that they were using food banks.

- 16.10. Some respondents reported receiving financial support on leaving their job which included: money received at the end of employment (5%); accrued payments for annual leave (5%); a redundancy payment (3%).
- 16.11. The comments provided by respondents revealed that some people felt they were just about surviving on their current level of income, but they no longer had a sustainable source of income:

“So far I am surviving on half pay as I now get PIP. My money runs out in December. Then I will have no income.”

Woman, 36–45 years, education.

“Renewed my mortgage to pay debt off.”

Woman, 46–55 years, health and social care.

“Overdraft and credit card.”

Woman, 65+ years, other sector.

- 16.12. Concerns and uncertainty about how any future income could be secured was evident especially when employment related sick pay was close to ending:

“Currently receiving full pay on NHS sick leave but will lose my job if unable to return in January so will likely have to sell my house.”

Woman, 46–55 years, health and social care.

“None so far but currently planning to downsize our house to manage financially.”

Woman, 36–45 years, charity/third sector.

Welfare benefits

“I was made to feel like a criminal rather than an ill person holding on by their fingernails they in the process have worsened my condition and I have not yet over a year later regained the already tiny baseline that I lost as a result of this.”

Woman, 36–45 years, other sector

16.13. In addition, we asked about welfare benefits:

- Most of the respondents (78%) reported they were not in receipt of state support and (19%) reported they were.
- Just over a third of respondents who stated they were in receipt of benefits (38%) stated they received employment support allowance (ESA) and three in ten received Universal Credit (30%).
- Almost six in ten of these respondents (58%) were in receipt of Personal Independence Payment (PIP).

16.14. There were two key issues which arose in the context of benefits (a) challenges with navigating the DWP processes and, (b) worsening health and well-being caused by the process itself.

16.15. Many respondents who had applied for one or more benefits reported the DWP's claims process to be "very lengthy," "confusing," "complicated," and "very hard work." Respondents talked about how hard it was to complete the required paperwork for a claim especially when they experienced cognitive dysfunction and or fatigue. As this respondent put it:

"Difficult and confusing form and process. Especially for someone with cognitive and fatigue issues. Took me two weeks to fill the form. If I hadn't got help from benefits and work website I wouldn't have got the benefit."
Woman, 46–55 years, other sector.

16.16. Respondents reported negative health impacts being caused by the application process, that is symptoms being worsened by the process itself. Respondents talked about the exacerbation of their ill-health and Long COVID symptoms, with some experiencing a significant "*crash*" that lasted for a prolonged period as well as Post-Exertional Malaise ("PEM") / Post Exertional Symptom Exacerbation ("PESE") after

making a claim. PEM/PESE is a delayed worsening of symptoms that occurs after minimal physical or mental activity.

"All of this process is incredibly stressful and exhausting and has a detrimental effect on long covid symptoms especially when only advice from GP is to rest."
Woman, 36–45, charity/third sector

- 16.17. Overall respondents described their experiences of claiming as *"demeaning," "dehumanising," "degrading," "humiliating,"* and talked about being left with a range of emotions and traumatic type feelings. Some respondents explained they were made to *"feel like you're lying" "made to feel like a cheat for trying to claim PIP" or "guilt."*

Unemployed

- 16.18. 7% of respondents were currently unemployed and had lost their job since March 2020 (survey completed 2022). Of them, almost nine in 10 (88%) believed they had lost their job due to Long COVID and half (53%) had reason to believe they had contracted COVID-19 at work.
- 16.19. When looking at the symptoms they experienced, the most common were, as with other respondents, fatigue (98% compared to 96% overall), cognitive dysfunction – difficulty with thinking and concentrating (95% compared to 844% overall) and shortness of breath or difficulty breathing (84% compared to 73% overall).
- 16.20. Of the respondents who had been become unemployed since March 2020, half (54%) said they were using a significant others' funds to financially support themselves, four in 10 (40%) said they were using savings of less than £16,000.
- 16.21. Some of the respondents out of work observed that acquiring COVID-19 through work had life changing consequences:

"I caught covid at work because my employer failed to adapt and take appropriate infection prevention measures. I was the only employee to be furloughed two weeks after I was signed off and they sent notice of redundancy by post without any conversation or consultation."

Woman, 36–45 years, legal.

“I caught COVID-19 at work in March 2020 after I was sent on a business trip that I believe should never have gone ahead [leading to a] life-changing and life-limiting disability as a result.”

Women, under 26 years, wholesale and retail.

“I gave everything, including my health to teaching. I wish I hadn't. My employers did everything to support me during my contract, knowing it would end and they could replace me. I blame lack of funding from the government forcing schools to make cutthroat decisions. My employer, in effect is the government. They should declare that front line workers who caught covid get a compensation payment.”

Woman, 46-55, education.

- 16.22. An important question for this Inquiry is the extent to which the Department for Business, Energy & Industrial Strategy (“BEIS”) and the Department for Work and Pensions (“DWP”) and DHSC considered the impact of Long COVID in relation to the mandates of their respective departments.
- 16.23. For example, minutes from a Long COVID Oversight Board meeting on 12 October 2021 record that an attendee said DWP was unlikely to adopt a new approach for Long COVID unless DHSC were to press for it [LCS/089 - -INQ000111897]. An action from the meeting was for Jean King to Liaise with DWP to explore DWP claims data on the extent of new claims related to Long COVID. We would like to know whether DWP did identify an uptake in new claims related to Long COVID and if so, why there was no change in policy or processes to accommodate the needs of people with Long COVID. We hope that this will be explored in this module of the Inquiry.
- 16.24. Our surveys revealed that there were profound and significant impacts upon people with Long COVID which led to many people having to apply for benefits for the first time. Despite Long COVID creating a significant uptake in demand for social support, there is no evidence of the benefits system flexing to this new cohort of people.

- 16.25. Access to benefits was a theme in our advocacy and in the roundtables yet there was no guidance to decision makers assessing benefits claims for example on how to assess people with fluctuating disability nor adjustments to processes given the worsening of symptoms applications can cause. There was no specific financial support for those that suffered Long COVID and it was a case of the system trying to accommodate new claimants for a new disease which had a rapidly evolving base of knowledge.

Other evidence of impacts on individuals

- 16.26. In our response to the Shaping Future Support: the Health and Disability Green Paper, dated October 2021, we emphasised several of our members personal experiences of how Long COVID had impacted them financially, including: *“Some people with Long COVID have either lost their job, or had good cause to leave it because they have been unsupported, made redundant, coerced or ‘pushed out’ by their employer”* [LCS/063 – INQ000249013]
- 16.27. Our members have personal experience of financial hardship because of Long COVID, including people who had to sell their homes and move into friends' homes. One member explains: *“Maxed out credit cards, overdraft, money from friends, selling possessions, food voucher from council, not buying food, limiting energy use”* [LCS/085 - INQ000652535].
- 16.28. In the case studies provided [LCS/085 - INQ000652535], one member notes that the only support they received was extended sick leave, another member noted that they were “lucky” they had an employer with a favourable sickness policy which allowed them to have an extended sick leave of 5-6 months therefore their pay was not reduced to half, after 18 weeks.
- 16.29. There is wider evidence of the financial implications on individuals. Early survey data (Ziauddeen et al., 2022; in November 2020) reported lost income by 37% of people with Long COVID [LCS/090 - INQ000652540]. A follow-up survey one year later (Ziauddeen et al., 2023; in November 2021) recorded 47% of people reporting lost income [LCS/091 - INQ000652541]. The later TUC and LCS (2023) survey covering September-October 2022 found that 14% of people said that they had lost their job

because of reasons connected to Long COVID and 50% were having to use savings to support themselves financially [INQ000272240].

- 16.30. Other studies have found that 21% of people had been able to maintain the roles they had prior to Long COVID however, a much larger proportion (62%) had been affected, either by having to take sick leave, reducing their hours, changing roles or quitting altogether [LCS/010 - INQ000320289]
- 16.31. Kwon et al. (2023) [LCS/027 - INQ000651341] estimated income losses from a sample of Long COVID patients referred to specialist Long COVID care clinics. Their estimates imply an average reduction in annual incomes of £10,764 for those who were in work pre-infection, with much variation by sector. People suffering with Long COVID for longer (more than two years) were more likely to see larger income losses. At individual/household level, these income impacts appear substantial, both immediately, but also have longer term implications with respect to economic security, standards of living and pension pots.
- 16.32. As always, an average income loss hides the impact on individuals, some would have lost most if not all of their income. For example, individuals on zero hours contracts, in precarious employment, self-employed if they did not meet the criteria for their scheme (e.g. SEISS). Individuals on higher salaries would experience greater losses than the average especially if they are not working, as ill-health benefits do not protect their current income. The loss of an even a small amount of income can have disproportionate impact on the poorer people in our society, forcing them to decide between “Eat or Heat” for example.
- 16.33. In our view no one should be in a position of losing their job due to a failure to accommodate Long COVID. There should be a duty on employers to make reasonable adjustments for people with Long COVID, taking into account that recovery from Long COVID is neither certain nor linear. These reasonable adjustments have to account for the unique nature of Long COVID being a fluctuating energy-limiting and multi-dimensional disability. That is, the symptoms often present in clusters, come and go in episodes and present differently and change over time. Unlike many other diseases, there is no one size fits all approach to reasonable adjustments that would work for an illness like Long COVID, and employers need to be mindful to accommodate the

diverse needs of their employees. The unpredictability of Long COVID is a challenge that many employers struggle to meet.

16.34. The lack of support and failure to recognise Long COVID as a disability affected people suffering from Long COVID during the pandemic. Future modelling and policy decisions need to recognise that this is an ongoing problem.

16.35. We note DHSC Long COVID policy officials met with colleagues in BEIS on Tuesday 11 May 2021 to discuss the challenges Long COVID poses to the workforce [LCS/092 - INQ000283444]. The position of BEIS officials was that Long COVID did not appear to require a new or substantially different response to other long-term conditions. In our view this is wrong. Long COVID requires a bespoke approach from other long-term conditions for two key reasons. First, it was a new disease from 2020. This meant that in the first instance there had to be recognition of it as a long-term disease, unlike other existing conditions that employers, DWP decision makers or others would have been aware of. Second, Long COVID can cause disability, symptoms are multisystemic, can be fluctuating, varying and aggravated by activity. For those worst affected, their baseline health is poor at all times, cycling through clusters of symptoms with only short periods of partial respite interspersed with worsening symptoms. The nature of the disease condition required a bespoke approach.

16.36. In June 2021, a DHSC weekly update on Long COVID suggested that it would be helpful to have bilateral discussions with ministerial counterparts in BEIS and DWP about Long COVID [LCS/093 - INQ000283455]. The minutes of these meetings, if they were held, have not been disclosed in the Inquiry.

17. Financial support for people with Long COVID

17.1. In our view, for both benefits and employers, the fundamental approach is the “*Illness as Usual*” (“IAU”) approach outlined below:

- (a) You get sick with a known disease or condition.
- (b) You get treatment or rehabilitation.
- (c) You either die or recover to your best stable level.

- (d) Hopefully you re-enter the workforce, or in some cases you are no longer able to work.
- 17.2. This is a very linear model which is appropriate for most illnesses. Almost all available financial support during the pandemic followed the *Illness as Usual* approach.
- 17.3. Long COVID does not fit the *Illness as Usual* model. It is a complex, multisystem condition that can be severely disabling and poses a growing public health and socio-economic challenge. It affects people of all ages, including those who experienced only mild or asymptomatic COVID-19 infections, and can result in long-term disability, loss of productivity, and increased healthcare utilisation. Symptoms vary widely between individuals, can fluctuate and may affect multiple organ systems. They often worsen with physical, cognitive, or emotional exertion, significantly impacting an individual's ability to work, study, or care for themselves and others. Recovery is highly variable - some individuals regain their prior health, while many experience only partial improvement or ongoing relapses. A substantial number do not recover at all. Most people with Long COVID do not find others with identical symptom patterns, contributing to isolation and under-recognition.
- 17.4. People can re-enter the workforce for an agreed number of days per week and then find that they are only able to work consistently for fewer days than agreed, and in some cases not at all. This can vary from week to week and month to month
- 17.5. Our lived experience shows that Long COVID requires something different as the unpredictable and individualised nature of Long COVID makes diagnosis and management difficult, leading to gaps in care and support. Without a coordinated response, Long COVID will continue to strain healthcare systems, reduce labour force participation, and exacerbate existing health and social inequities.
- 17.6. As far as we are aware there was no consideration to amending policy guidance to adapt to Long COVID

Statutory sick pay

E, case study 16, 32, functional assessor

"Initially I was off sick for an extended period of time (5 months) and after 2 months spent 3 months on SSP without a wage. I had to get a new job which wasn't physical and thus had to take a pay cut and then I was unable to work full time due to my symptoms and had to reduce my hours to part time hours. I had to move back in with my parents and they have had to provide a lot of financial assistance to supplement my reduction in wages."

17.7. LCS has the following concerns about the insufficiency of Statutory Sick Pay as it affected members:

- (a) It follows the Illness as Usual ("IAU") approach.
- (b) No adaption was made for a new complex, multisystemic disease that can be profoundly disabling, fluctuates, is energy limiting and varies greatly in terms of severity, duration and recovery outcomes.
- (c) Removal of Statutory Sick Pay for isolation led to increased transmission of COVID-19 and more people developing Long COVID.
- (d) People were driven to return to work while sick and/or infectious with COVID-19 increasing their chance of developing Long COVID, as well as leading to increased transmission of COVID-19 and more people developing Long COVID.
- (e) People who had been ill with COVID-19 and now had Long COVID symptoms were forced to return to work, often making their Long COVID symptoms worse and/or delaying their recovery.
- (f) Individuals who did not have the luxury of an employer's sick pay scheme and their only income was Statutory Sick Pay at £118.75 per week which was in our view inadequate.
- (g) The eligibility criteria of average earnings of £125 per week (from a single employer) penalised low-income workers especially in industries particularly hard

hit by COVID restrictions and/or on flexible hours or zero hours contracts. Workers in these industries were often at higher risk of COVID-19 and developing Long COVID.

- (h) Individuals had to be an employee and so self-employed people were excluded.
- (i) Individuals do not get Statutory Sick Pay for the first 3 days of illness. This works for Illness as Usual but fails with Long COVID's fluctuating nature.

17.8. Statutory Sick Pay has the concept of "linked periods of sickness". To be linked, the periods must:

- (a) Last more than 3 days in a row
- (b) Be 8 weeks or less apart
- (c) Be a series of linked periods that lasts no more than 3 years.

17.9. The "linked periods of sickness" does not deal with Long COVID's varying nature. For example:

- (a) a full-time employee has a relapse, or crash as it's called by the Long COVID community. They may need to take one or two days sick leave to rest and recover enough to be able to return to work. This would not count as a linked period.
- (b) A part-time employee works Monday, Wednesday and Friday. This is a common pattern for people with Long COVID as the breaks on Tuesday and Thursday provide time to rest and recover. However, if the person experiences crash after working Monday or Wednesday that requires them to take the next working day off then this also does not count as a linked period.

17.10. Our view, based on the experience of our members is that Statutory Sick Pay needs four pathways not one.

- (a) The current pathway which covers most acute illnesses and many chronic ones that are well managed, stable and have effective clinical pathways.

(b) A new long-term disease pathway for Long COVID. This could also consider other similar conditions / diseases. For example many people with Long COVID also meet the criteria for ME/CFS or fibromyalgia. The need for a new disease pathway has reached critical mass in the NHS. It is looking at clinical service frameworks that cover multiple long-term fluctuating and varying illnesses and conditions. Some Long COVID clinics are already moving to this model. We note that on the 9th July 2025, the NIHR opened a new call for research covering “Post-acute infection syndromes, including long COVID and myalgic encephalomyelitis/chronic fatigue syndrome”.

(c) New pandemic disease during the acute (infection) stage pathway.

(d) New pandemic disease post infection long-term sequelae pathway.

17.11. The two new pandemic disease pathways would need to support different disease scenarios and benefit design scenarios, giving the Government flexibility to tailor the response to the actual pandemic disease at the time. That flexibility would also allow the Government to rapidly deploy and rapidly adapt the eligibility criteria and the benefit outcomes as knowledge of the new disease increases, as the different restrictions are deployed to reduce transmission rates, and to target different population groups if necessary (e.g. employed vs. self-employed, patients and carers). The financial support offered also needs to have a range of different options. For example, income protection similar to the furlough scheme, flat rate for all, higher rate for low income families to name just a few.

17.12. The three new pathways could be created as part of Statutory Sick Pay or as new benefits. In our view that choice should be part of the design process.

17.13. The new pathways, and any re-design of the existing Statutory Sick Pay pathway should use Co-design methods including both advocacy organisations and individuals with lived experience. Co-design was very effective during the pandemic for the design of a number of economic interventions and helped the Government teams recover to some degree from the pre-pandemic preparedness failures.

COVID-19 sick pay

C, Case study 3, 49, Nurse, (now medically retired)

“Covid Special Leave – applied from initial infection in 2020 until its removal by government on 31 August 2022. This was at a full time rate for any absences between April and August 2020, subsequently on the temporary reduced hours salary until February 2022, at which time i had my full pay under the T&Cs of Covid Special Leave – note: There was a lot of issues between employees and employers over this, which led to periods of my Covid related absence not being recorded as such, as well as another issue in early 2022, when HR and management tried to move me to absence management stage 2, which was not Covid special leave policy.”

R, Case study 4, 31, Nurse (now medically retired)

“I was eligible for Covid special pay from the NHS from the date I went off sick. The NHS trust didn’t calculate it correctly resulting in me being underpaid for two years. A formal grievance was submitted and it went through the whole process without being rectified. In the end it went to employment tribunal and the trust paid out one hour before court with a COT3 agreement. They also tried to impose a nondisclosure agreement which I refused. I then ran out of sick pay entitlement but met the criteria for NHS temporary injury allowance. This was also refused by the NHS trust I worked for.”

- 17.14. In March 2020 the NHS made an economic intervention by putting in place an income protection scheme for COVID-19 related illness for many, but not all, NHS staff.
- 17.15. COVID-19 sick pay was available to some healthcare workers; it was a lifeline for those that were in receipt of it but not every healthcare worker was eligible. We have seen Long Covid SOS comments about the scheme in their witness statement and agree with those concerns. Many categories of healthcare workers were excluded such as, self-employed locum GPs, outsourced hospital staff such as bank and agency staff, cleaners. The scheme was issued as guidance, rather than mandatory, leading to different healthcare organisations taking different approaches, and managers applying

the policies inconsistently. In our view COVID-19 sick pay should have been available to all of those working in healthcare settings as they all faced the same high-risk environment.

17.16. On the 7th July 2022, DHSC gave notice that these provisions would be removed:

*“Under transition arrangements, from 1 September 2022 all staff receiving the special COVID-19 Sick Pay reverted to standard sick pay rules, set out in the terms and conditions of their contracts. From then on, any staff member absent from work owing to long covid would be able to claim full pay for as long as six months and then half pay for the following six months. Many staff with long covid are expected to get reduced payments from 1 March 2023, when the first six months of the transition period ends”.*⁴

17.17. As a result, those who had already been off sick with Long COVID for extended periods saw their pay drastically cut once these provisions ended. Further, those who contracted COVID-19 and Long COVID after these provisions ended have found themselves forced to return to work despite suffering severe ongoing symptoms, putting their health – as well as patient safety – at serious risk.

17.18. Furthermore, healthcare professionals who were eligible for COVID-19 sick pay were eligible to NHS Temporary Injury Allowance and Industrial Injuries Disablement benefit if they could demonstrate they had contracted COVID-19 through occupational exposure (as contracting COVID-19 is recognised as an injury although it is still not recognised as an occupational disease).

17.19. Our members report that many healthcare workers were not informed that they could apply for industrial injury benefits, such as NHS Injury Allowance or Industrial Injuries Disablement Benefit, and those that are aware of it explain that the application process is gruelling with inconsistent outcomes.

17.20. Many people with Long COVID were denied access to one or both of these schemes because they were unable to prove that they had contracted COVID-19 at work. A

⁴ Waters A. COVID-19: Reduction in payments for NHS staff with long term symptoms is “short sighted” BMJ 2023; 380 :p274

contributory factor was that NHS Trusts were not submitting RIDDOR reports for occupational exposure, including for staff outbreaks.

- 17.21. Further, in our members experience despite COVID-19 sick pay being in place, healthcare workers with Long COVID were dismissed on the grounds of sickness capability. We note the evidence of healthcare workers Nicola Ritchie and Patricia Temple provided to Module 3 [LCS/094 – INQ000492258 and LCS/095 - INQ000486012] on the impact of Long COVID upon their ability to work.
- 17.22. In September 2022, the NHS suspended their sickness absence policy for COVID-19 (which also benefited Long COVID cases, for some but not all) and the accompanying full pay. After this, healthcare workers reverted to only being entitled to sick pay as set out in the standard sickness absence terms and conditions in the Terms and Conditions of Service Handbook. These terms and conditions differ across the four devolved nations.
- 17.23. As a further consequence of suspending the COVID-19 sick pay, healthcare workers were put through the normal sickness absence policies resulting in a wave of dismissals, early retirement, changes in roles and working hours.
- 17.24. The acknowledgement that there was a need for a bespoke long-term sick pay policy during the pandemic, clearly suggests that there will be an ongoing need for appropriate financial support. There should have been proper consultation on how this support should best be provided (disablement benefit, increased/expansion of statutory sick or a fit for purpose benefits structure) prior to terminating the COVID-19 sick pay.
- 17.25. The Royal College of Nursing in their Module 3 Opening Statement to the COVID-19 Inquiry stated: *"The most recent available ONS statistics [March 2024] estimate that 4.14% of staff working in health care and 5.07% of staff working in social care reported having symptoms of Covid more than 12 weeks after contracting it, compared to 2.7% in the wider population. Support for these staff members needs to continue and the impact of Long COVID in terms of increased long-term absence needs to be factored into workforce planning."*

- 17.26. NHS England Chief Executive, Amanda Pritchard, in her Oral Evidence to the COVID-19 inquiry on 11 November 2024 stated that: *“Q...My question is, is NHS England collecting data now on the number of healthcare workers, both clinical and non-clinical, who are absent from work due to Long COVID?”* Amanda Pritchard: *“So the simple answer to your question, I'm afraid, is “no”. But there is a process which is currently underway to re-procure the electronic staff record system which I think does give us a chance to look at the sickness coding that is embedded in that system. They've committed, the team who are doing it, which is led by the BSA, but in partnership with NHS England and many others, to have wide stakeholder involvement in that process. So, again, speaking personally, rather than on behalf of the organisation, I think that is a very good and important opportunity for us to look at making sure we have got that coding in place.”*
- 17.27. This Inquiry evidence highlights that over four years after the NHS implemented an income protection scheme that included Long COVID, and over two years after it was withdrawn, the NHS was still not able to record Long COVID absence amongst their staff – despite their increased risk of Long COVID. Denial and minimisation is clearly still an ongoing issue.

Non-healthcare key workers

S, case study 10, age 41, Special Needs teaching assistant, Wales

I was able to return to work very slowly, it took me around 8 months To go back full time. Unfortunately full time hours and work related stress made me much worse and I had to leave work in April 2022, been bedbound for months. My contract finished during my time off.

- 17.28. Teachers and other key workers did not receive the same financial support from their employers as some healthcare professionals working in the NHS. Teachers were only entitled to sick pay per their contracts or in some cases they were only entitled to standard sick pay as set out in their absence terms and conditions, i.e. six months on full pay and the following six months on half pay.
- 17.29. Many other key workers did not receive the same financial support as healthcare workers who received COVID-19 sick pay. It is possible that without that financial

support many key workers may have lost their jobs compared with healthcare professionals who could access COVID-19 sick pay. The lack of research or studies into the financial and economic impact of Long COVID on workers means that there is no direct evidence on this point.

Coronavirus Job Retention Scheme (“CJRS” or “Furlough”)

C, Case study, age 52 Corporate communications consultant, England

“Prior to falling ill in March 2020 I was employed as a corporate reporting consultant, working 4 days per week from the office. When I was diagnosed with Long Covid I was furloughed....My employer was extremely accommodating and allowed me to do a phased return, from home, doing much reduced duties in a different role as I was cognitively as well as physically very affected by Long Covid. I still am only able to work from home, in a less senior position and for fewer hours per week. I now earn £30,000 two thirds of what I did prior to first contracting Covid.”

17.30. The Coronavirus Job Retention Scheme (“CJRS”) also known as furlough, was introduced to avoid the economic impacts to the labour market. Employers used the scheme to retain employees however, it was clear that as furlough was coming to an end employers began to lay off employees they could no longer afford. Moreover, it was clear that Long COVID was a matter for *“an economy which is already facing an existential struggle: large numbers of long-term sick leave will significantly impact the workforce as it emerges from furlough”* [LCS/096 - -INQ000238582].

17.31. We found that contrary to fit colleagues entitled to furlough under government schemes, no similar support scheme has been in place for those unable to work due to ill health post-Covid. The economic and psychological pressure has forced those with Long COVID back into work prematurely when unfit, resulting in further damage to health, more time off work, reduced performance and, in some cases, loss of employment.

Self-Employment Income Support Scheme (“SEISS”)

R, case study 6, age 44 self employed fitness instructor

“I lost my fitness business which was a big part of my income.”

- 17.32. The self-employed experienced disproportionate economic impacts during the pandemic. Many of our members ran small businesses that were either required to close during the pandemic or they were unable to implement the required NPIs such as social distancing and/or infection controls. The Self-Employment Income Support Scheme (“SEISS”) was designed to support self-employed people where they had been adversely affected by the pandemic. However, initially the eligibility criteria seriously limited the amount of people who could receive the grant.
- 17.33. Self-employed people were forced to continue working to protect their livelihoods or to find an employed position. Many self-employed members had to continue working despite debilitating Long COVID symptoms in order to retain an income, resulting in a worsening of their health. Some have had to scale back their businesses resulting in loss of profitability and laying off employees. Some self-employed people have become too unwell and thus lost their business and often as a result their homes.
- 17.34. No financial support schemes were available for the newly self-employed.
- 17.35. Also, where our self-employed members were ‘owner directors’ they did not qualify for the SEISS. During 2020, many businesses saw their incomes reduce by as much as half from the previous year.
- 17.36. A particularly poignant example of how self-employed people have been affected is illustrated through the experience of professional athletes. Our membership includes previously fit, professional and amateur athletes who have been particularly affected by Long COVID. They report no longer being able to train as doing so can bring on a significant worsening of symptoms. In the case of professional athletes this has resulted in them no longer being able to compete; their income is performance related and therefore having an energy limiting chronic illness denies them the opportunity to progress in their chosen career. For example, our ambassador, Oonagh Cousins, had

been selected for the Olympics, prior to becoming disabled by Long COVID. We refer the Inquiry to her enclosed case study [LCS/085- INQ000652535].

- 17.37. Tanysha Dissanayake, a professional tennis player, also had to stop playing due to Long COVID.

Access to state benefits for people with Long COVID

AG, Case Study 7 -58, Charity Worker

“Long covid’s impacts are not recognised by assessors at DWP, nor by large employers, in my experience. Many symptoms fluctuate and remain hidden and there is a lack of understanding to consider such conditions within eligibility criteria. Once the word ‘fluctuating’ enters the picture, the attitude is the claimant/employee is not that bad, every day. If cognitive impairments are assessed, these are done so through the lens of either a mental health condition, or likelihood (or not) of dementia. Neither demonstrates an accurate understanding of long covid.”

- 17.38. Many of our members could only access benefits as a means of financial support, i.e. ESA, PIP and UC.
- 17.39. Many members reported difficulties knowing which benefits they were entitled to, and difficulties completing the benefits forms due to the cognitive and physical symptomatology of Long COVID. Some were found ineligible, not awarded benefits or were provided with insufficient awards of benefits due to lack of knowledge about Long COVID, further traumatising them. The application processes and criteria for claiming both PIP and ESA are too complex. As Long COVID is a novel disease, unless DWP assessors and decision makers are specifically trained they will not understand the extent of functional impact that it has. The Joint TUC and LCS report set out above evidences the barriers that people with Long COVID face [LCS/056 - INQ000272240]. In our surveys of the Long COVID community we found that many respondents had not yet claimed any form of benefits; they said that they were unsure if they were eligible and that the process was too confusing and overwhelming. [LCS/062 - INQ000272247]

- 17.40. Further, if people are not claiming benefits, then they will not get National Insurance Credits automatically or in some cases where they are required to apply for them. This will have a potential impact on claiming benefits in the future and their eligibility for state pension.
- 17.41. Our members report experiencing delays in processing their applications or appeals which has been exacerbated by the lack of appropriately trained assessors, resulting in many people being left without essential financial support for extended periods. This has contributed to worsening health outcomes because the stress and bureaucracy involved detracts from individuals' ability to focus on recovery.
- 17.42. Our members report receiving inconsistent outcomes when applying for PIP, as it does not consider cyclical and varying severity of Long COVID. For example, due to post-exertional symptom exacerbation, they may be able to do an activity once but then be unable to do it again for days, and also will be unable to do other activities.
- 17.43. Furthermore, aspects of independent living are not considered in the assessment process for PIP, it omits to ask questions about how a person undertakes certain activities of daily living such as food shopping, housework and laundry. Therefore, the current questionnaire and medical assessment does not reflect or take into consideration the full range of activities a person needs to undertake to live an independent life.
- 17.44. We have highlighted the pitfalls with the PIP and ESA assessment process, for example, failing to consider care and support from the perspective of the service users.
- 17.45. The Office for Disability Issues supports the use of the social model of disability which recognises the barriers people often face are caused by negative attitudes, lack of access to services and failing to think about care and support from the perspective of service users. Our view is that this is not reflected in the PIP or ESA assessment process which tends to focus on individual biological function in isolation. Needing support does not preclude individuals from living an independent life. Occupational justice is *"the right of every individual to be able to meet basic needs and to have equal opportunities and life chances to reach toward her or his potential but specific to the*

individual's engagement in diverse and meaningful occupation.” (Wilcock & Townsend (2009, p. 193)

- 17.46. Regarding employment support we note that during the pandemic there have been reports about remote WCAs failing to capture the full extent of a person's illness. There have also been delays in people receiving the higher rate of payments. There is evidence that the average claim takes several months to be processed by the DWP.
- 17.47. We also advocated for DWP to *urgently review its processes and ways of working to ensure their duty of care is not compromised for disabled people with Long COVID. This is especially important given the numerous concerns that have already been raised about the problems with the DWP's duty of care for example see Chronic Illness Inclusion.*
- 17.48. Furthermore, these finding raise concerns whether a medical assessor will have the knowledge, skills and competencies to understand how the multiple and complex nature of Long COVID may be experienced by an individual and how this illness can wax and wane. To mitigate against any errors in assessments we believe it is important for people with Long COVID to submit medical evidence, where this is available, from any healthcare professionals involved in their care for example, General Practitioners, Long COVID clinics or other health related services, which could include documents such as the Allied Healthcare Professional (AHP) Health and Work Report in support of their claim. Unfortunately, it is also evident that some people living with Long COVID may be too unwell to work and will meet the criteria for the support group. [LCS/057 - INQ000249010]
- 17.49. For those that are unsuccessful, the appeals process is stressful and exhausting.
- 17.50. The online application process for Universal Credit and other UK Government schemes provided accessibility for many Long COVID sufferers but posed a barrier for others, particularly those who were older, had limited digital literacy, or were too ill to engage with complex online systems. Conversely, the PIP renewal application can only be completed on paper, meaning that those who are reliant on dictation software have to get someone to help them fill out the form.

- 17.51. We noted that patient groups have been “disseminating and connecting existing good practices to innovating a furlough-type or UBI scheme to retain key staff to avowing patients losing jobs and exiting the workforce.” [LCS/057 - INQ000249010]
- 17.52. Many members have also been denied their benefits claim and/or ill-health retirement on the grounds of Long COVID and/ or the recovery process being unpredictable. This leads to financial hardship and increased debts. Of those who successfully apply for, and are awarded, ill-health retirement, they often receive significantly reduced pensions again leading to financial hardship. Pensions can also be reduced because of loss of employment or reduction in working hours due to Long COVID.

Universal Credit and other benefits

J, case study 14, 60, Chemical Process Technician, Wales

“Now retired due to ill health. I received varying levels of help via Universal Credit dealing with which was extremely difficult. I was glad when I could remove myself from this system, I had entered it not owing any money but left in some debt due to their mistakes and misinformation.”

“Both Universal Credit and Employment and Support Allowance made errors and delays which left me owing both systems money

The people at Universal Credit clearly have a poor understanding of the systems that they work with. On a number of occasions, we were given incorrect information and when later questioned they appeared not to care. It is also of no use using their contact system as they will never reply on it. Their systems and employees served only to make me unwell on numerous occasions.”

- 17.53. It is obvious to us that the benefits system was not prepared for a new cohort of claimants for those suffering Long COVID. The case studies we have provided evidence the problems people experienced. This could have been avoided if there had been clear guidance from central government at the beginning of the pandemic that a number of people would suffer long term from COVID-19. However, this did not

happen. As such our members were left trying to argue for benefits when they were severely unwell and facing financial difficulties. Further the evidence from our members as set out in our survey and case studies is that the processes themselves present barriers for people seeking support; for example, completing lengthy online forms is cognitively challenging and leads to exacerbation of symptoms.

17.54. Finally, the level of financial support is inadequate. During the relevant period Universal Credit was only increased by £20 a week despite the increased cost of living, energy bills and associated costs with being disabled, i.e., transport costs for attending medical appointments. In our view this was insufficient.

What would help people with Long Covid access benefits

17.55. In a separate survey in October 2021 conducted by LCS, we asked members what would make applying for benefits easier. The majority of responses included:

- better understanding by decision-makers of Long COVID (78%);
- assessments that reflect the relapsing nature of Long COVID (78%),
- simpler, shorter forms (70%),
- medical evidence accessible in one place (51%) and
- help with applications (41%).

17.56. In terms of assessment format, 28% of respondents preferred telephone assessments, versus 23% each favouring video or face-to-face assessments. This data was presented to the government in October 2021 for the purpose of the Health and Disability green paper being drafted by the DWP [LCS/063 - INQ000249013].

17.57. In our view the benefits system should be reviewed to take account of Long COVID. The benefits review should take account of the evidence that the system was complicated, difficult to navigate and should consult with stakeholders with Long COVID on how this may be improved. The review should consider policy and guidance on how to better support people with Long COVID return to work and providing a benefit system that fully supports people back to work and where they cannot return to

work, guidance to assessors that understand Long COVID and properly assess people with Long COVID so they are not left financially devastated. The review should include terms to provide guidance to ensure that people with Long COVID who are assessed as having limited capability for work with requirements to engage in work preparation activities have the required adjustments that they need, and are financially and practically supported to ensure a sustained recovery.

Fraud

- 17.58. We have been asked about “*risk of fraud and erroneous claims.*” This is not our members experience and as noted, we are more concerned about the Government deliberately minimising the impact of Long COVID to avoid having to provide financial support [LCS/098 - INQ000652549]
- 17.59. Significant numbers of people with Long COVID, the majority of whom have worked hard all their lives, have found themselves let down and without support at the point in their lives they most need it. The system disproportionately focuses on eradicating fraudulent claims and in doing so overlooks the needs of people who are genuinely seeking help. During a global pandemic, when many individuals risked their health to take care of others, adequate education of benefits assessors as to the long-term health impacts and subsequent care needs should have been a priority. Instead, a lack of understanding of Long COVID has led to additional suffering for those affected.

18. Intersection of Long COVID with inequalities

- 18.1. Studies have shown that women, middle-aged people, people living in deprived areas, people with pre-existing health conditions and disabilities, and those working in health and social care were more likely to develop Long COVID.
- 18.2. Women along with people from ethnic minority backgrounds are more likely to work in lower paid roles, including primarily people facing roles in retail and in healthcare. Because of the nature of their jobs they also tend to be more likely to be exposed to COVID-19 and thus impacts of Covid, including developing Long COVID.

People from ethnic minority backgrounds

- 18.3. As an organisation we have raised concerns about health inequalities and barriers to healthcare that our ethnic minority members experience. People from ethnic minority backgrounds are over-represented in frontline jobs, including in the frontline of NHS healthcare, and in precarious jobs thus exposing them to greater economic and health risks which has been exacerbated by COVID-19.
- 18.4. The prevalence of Long COVID amongst people from ethnic minority backgrounds remains unclear, potentially because of under-reporting of Long COVID symptoms. In the Reach-OUT report, August 2023, by the NHS Race & Health Observatory, they noted that of the participants in their study 40% of the participants had Long COVID, having survived acute COVID-19 [LCS/099 – INQ000302497]. Targeted policies and occupational support need to be implemented to address the ongoing impact of Long COVID and support this particular cohort of people, including addressing potential under-reporting of Long COVID symptoms because of fear of job security and stigma, communicating in a culturally appropriate way to ensure that there is increased awareness of Long COVID and its impacts on workforce capacity and to mitigate absenteeism and presenteeism.
- 18.5. In the NHS Race and Health Observatory's third report, November 2024, they recommended healthcare institutions develop and implement support programmes to provide access to financial assistance, and flexible working arrangements particularly for those experiencing prolonged illness and disability." [LCS/100 – INQ000652551]

Long COVID and Socio-economic inequalities

- 18.6. There was early recognition of the risk of COVID-19 affecting people from economically deprived communities disproportionately. SAGE produced a report on COVID-19 and Health Inequalities, dated 13 November 2020, in that report it was noted that people from more economically deprived communities were more likely to experience adverse outcomes from COVID-19 because of:
- (a) co-morbidities and reduced immune response associated with poverty and stress,
and

- (b) occupational exposure and inability to shield at home
- (c) inadequate self-isolation and sickness benefits meaning they continue to work
- (d) Lack of access to and adequacy of health and social care services”

18.7. In our letter to Jeremy Hunt, dated 20 August 2020, we referred to the ONS statistics that evidenced the “relationship between mortality and co-morbidities such as diabetes that are often diseases associated with social and economic deprivations”. [LCS/035 - INQ000248911].

18.8. The Health Equity North West Report: Navigating the Long Haul [LCS/101- INQ000652552] concludes *“there is a need for comprehensive support systems, nuanced absence reporting systems and increased awareness to address the multifaceted challenges posed by Long COVID. Government should develop programmes for employers to support members of their workforce with Long COVID. Further, a government consultation with Long COVID sufferers and employers should be undertaken to better understand their condition and to implement care plans to facilitate rehabilitation and management of the condition.”*

18.9. There is evidence that people living in the most deprived areas and working in the healthcare and education sectors had the highest risk of Long COVID compared to the least deprived areas:

- In the Ministerial Roundtable on Long COVID meeting on 12 December 2020 it was also noted that there was a slight trend toward higher proportion of Long COVID in the most deprived quintile [LCS/102 – INQ000112676].
- Workers with lower socioeconomic status have poorer health outcomes and higher premature mortality than those with higher socioeconomic position but a similar occupation [LCS/103 – INQ000652553] [LCS/104 – INQ000657078]

18.10. We are not aware of the Government taking any action to address the disproportionate impact of Long COVID in the most deprived areas.

People with pre-existing disabilities

- 18.11. People with pre-existing health conditions and disabilities were more vulnerable to COVID-19 and susceptible to developing Long COVID. Long COVID in many cases exacerbated existing health conditions, making the person unable to work through cumulative impact on their health [LCS/105 – INQ000652554]. Disabled people face additional barriers in recruitment; they can find it difficult to re-enter the workspace. Furthermore, they already face higher costs to access society.
- 18.12. We are not aware of the Government taking any action to specifically support disabled persons that developed Long COVID.

Age

- 18.13. We are not specially focussed in supporting elderly people with Long COVID but wish to raise this as an area of investigation for the Inquiry as it was known to decision makers during the relevant period. For example, on 12 December 2020, at a Long COVID Ministerial Roundtable hosted by DHSC a representative from the Zoe app reported that there was evidence of an increased risk of Long COVID with age. [LCS/102 – INQ000112676]
- 18.14. The Inquiry heard evidence from Age UK in Module 3 about the impact of Long COVID and age. Caroline Abrahams, Director Age UK, gave evidence that *"For diagnosis and treatment of both Covid and Long COVID, AGE UK remains concerned that symptom presentation in older people can be different and this has been poorly understood and articulated..." "atypical presentations is critical to facilitate early intervention..."* and that *"There may also be under recognition and under or delayed diagnosis of Long COVID in older people whose symptoms including problems with balance, mobility and chronic fatigue may be written off as age" . " Further, we are increasingly concerned by emerging evidence of prolonged risk of cardiovascular outcomes following infection...."* [LCS/106 - INQ000319639]. In our view the delayed recognition of Long COVID generally no doubt impacted and continues to impact the support being offered to elderly people with a history of infection and who develop Long COVID.

- 18.15. We are not aware of any policy steps implemented by the DHSC to support the elderly with Long COVID.

Carers

- 18.16. In households where, multiple family members have Long COVID, the family members with Long COVID may be in a position of caring for themselves as well as caring for others. For example, if a child has Long COVID they may not be able to attend school and this may result in the parent or guardian having to reduce their hours or even give up work to take on caring duties. In some cases, this has placed increased financial demands on their family.

- 18.17. In our case studies, we have documented members reporting their increased reliance on family members for care [LCS/085 – INQ000652535]:

- Another member explains that *“the costs of covering carers is probably still beyond me.”*
- And one member states: *“Our needs for additional support like domiciliary care and adapted housing will increase. Our rates of leaving the workforce due to permanent ill health will increase. Our repeated visits to emergency care and multiple secondary care teams will increase.”*
- One member explains that their wife has received Carers' Allowance due to their care needs.

- 18.18. In the study *“Impact of Long COVID on productivity and informal caregiving”* by Kwon et al, it highlights the value and cost of being an *“informal caregiver”*, it states: *“It is important to value the ‘invisible’ contributions of informal caregivers in providing services, which would otherwise result in unmet care needs, incur substantial private care expenditures, and/or place additional strains on the health and social care sectors.”* The report echoes that *“productivity losses are incurred when caregivers reduce or give up their jobs.”* The report also highlights that studies do not always include the estimated economic value of informal caregiving attributable to Long COVID. [LCS/027 - INQ000651341]. It found that the costs for informal care giving for

people with Long COVID was £4.8 billion (£2.6 billion - £7.0 billion: 95% confidence interval).

- 18.19. The impact of Long COVID on carers and the associated economic burden is a matter that has been under reported and under investigated.
- 18.20. We are not aware of the Government taking any specific action to support or assist carers impacted by Long COVID.

Devolved nations

- 18.21. There was significant variation in how COVID-19 sick pay rules were applied across the 4 nations and the LCS groups in Scotland and Wales are best placed to speak to the impact of those different approaches.
- 18.22. When the UK Government was considering ending COVID-19 sick pay for NHS staff, our members raised concerns about the inconsistent deadlines for withdrawal across the Devolved Nations. COVID-19 pay arrangements ended in Wales from 1 July 2022, in Scotland on 31 August 2022, in Northern Ireland on 1 October 2022 and in England from July 2022 however, it was at the discretion of individual NHS Trusts whether to follow the guidance for staff with Long COVID. Our members report that this was a postcode lottery with some staff remaining on full pay, others on half pay while others lost their jobs.
- 18.23. Scotland and Wales introduced some additional and locally tailored measures, however, self-employed individuals and those with complex and fluctuating symptoms continued to face gaps in financial assistance. It is our understanding based on our members reports that patients with Long COVID in Northern Ireland received limited support compounded by pressure on healthcare services.
- 18.24. Our Welsh members have commented that they are aware of members in Wales facing difficulties in benefit assessments due to their concerns that Long COVID was not understood or well known. This echoes the concerns we established in our work with the TUC set out above.

- 18.25. Our Scottish members note that many individuals with Long COVID faced difficulties navigating the application process for Scottish Government schemes due to the complexity of their symptoms and lack of recognition of Long COVID as a qualifying condition for benefits whilst battling illness and cognitive challenges. They report that it was only from 21 March 2022 that there was eventually access to Adult Disability Payments (“ADP”). The scheme was initially rolled out in Dundee City, Perth and Kinross, and the western isles before being expanded across Scotland in staged and becoming nationwide on 29 August 2022. ADP replaced PIP and Disability Allowance for individuals of working age in Scotland, with Social Security Scotland administering the benefit.
- 18.26. Our Scottish members have commented that there was a lack of financial support for people with Long COVID. They explain that people in Scotland experienced the perfect storm of poor economic protections, unclear medical pathways and slow government response. There was an absence of national strategy, inadequate sick pay (£95.85 per week), and inaccessible benefits combined to leave many people without a safety net during a time of profound illness and uncertainty.
- 18.27. Financial schemes available to people in Scotland included the Home Energy Scotland Grant and Warm Home Discount. The Scottish Welfare Fund was a discretionary emergency grant administered by local authorities.
- 18.28. Scotland introduced the Scottish Government Self-Employed Hardship Fund in April 2020; it was a one-off payment distributed by local authorities. It was introduced to compliment SEISS to support people who were self-employed but were unable to qualify for SEISS or whose income was severely affected. The funding was discretionary and limited, requiring applicants to demonstrate financial hardship beyond what SEISS covered. The pitfall of the fund was that as it did not account for the fluctuating symptoms common in Long COVID, it made it difficult for people with Long COVID to demonstrate continuous inability to work thus they faced challenges meeting the eligibility criterion. Furthermore, for those who had reduced or unpredictable income, it made it hard to prove the extent and duration of the financial hardship required for grants.

Case studies

- 18.29. We refer the Inquiry to the case studies above and exhibited to this statement which sets out members experiences in Wales, Scotland and Northern Ireland. LCS/85 - INQ000652535]

PART D: Analysis and Reflections

19. COVID-19 pandemic was a “wicked problem”

- 19.1. Without doubt the COVID-19 pandemic was a “wicked problem” [LCS/107-PHT000000009] characterised by high stakes, uncertain decisions, no single solution but instead a series of choices between interventions with uncertain outcomes that could be better or worse than other interventions, extreme time pressure, and many stakeholders with conflicting priorities and goals (e.g. economy vs. health). The science was incomplete, uncertain and rapidly evolving. As such, it required a coordinated whole-system response from all stakeholders in government - national, devolved, and local.
- 19.2. The Inquiry has identified the failures in pre-pandemic planning which heavily impacted the quality of the UK Government’s initial responses. It has also identified the failures in the actual pandemic response.

Government’s response to the immediate visible victims

- 19.3. Our view is that much of the Government response was framed around the immediate visible victims, people in hospital, people in ICU beds, people dying because of ambulance response times, people dying because of lack of ventilators, people dying because of lack of ICU beds. And rightly so.

Long COVID - the delayed, invisible victims

- 19.4. However, the 2 million victims of Long COVID, in England and Scotland alone (at March 2024), are not immediate visible victims. We are the delayed, mostly invisible victims. One of the drivers behind that invisibility is that the vast majority of people with Long COVID were never hospitalised.

20. Three fundamental failings of the Government response for Long COVID

20.1. We discussed a number of critical failure factors in Part A Section 9. In this section, we will focus on just the three failure factors that fundamentally drove the response and drove other critical failure factors to increase the cumulative impact of the failures. The three are, pre-pandemic preparedness planning, not recognising the gap on foreseeable long-term sequelae, and minimisation and denial of Long COVID.

Pre-pandemic Preparedness Planning & Pandemic Response.

20.2. It did not include any disease scenario other than an influenza outbreak. It also did not include the impact of long-term sequelae. As a result, there were no relevant pre-designed economic interventions to be used.

20.3. All the factors for designing effective economic intervention blueprints were available and understood. For example, the groups (e.g. self-employed, small business, enterprises, people on benefits), for targeting, for defining selection criteria and payment methods. However, because of the identified issues with pre-pandemic preparedness planning, we are not aware of any economic intervention blueprints.

20.4. The result was that the economic interventions deployed during the pandemic were built at speed, targeted at the majority of the population and were known at launch to exclude people (e.g. Self-employed people who had not traded in 2018 to 2019 and submitted their Self-Assessment tax return on or before 23 April 2020). Some went through multiple design iterations and/or were repeatedly extended.

20.5. As far as we are aware, no economic interventions assessed the impact of Long COVID on their target groups. The different groups had different benefits available; many employees had access to employer sick pay schemes as well as Statutory Sick Pay, while self-employed individuals in many cases were able to access grants from the SEISS. However, for many people with Long COVID, (which is a complex, multisystemic condition that significantly limits energy and can be profoundly disabling, with a range of symptoms and varies greatly in terms of severity, duration and recovery outcomes) at some point their extra support would run out, their savings would run out and they would be dependent on welfare benefits.

Foreseeable long-term sequelae not foreseen – even when forewarned

- 20.6. The Government were cognisant about the risk of long-term sequelae as this was well known and established from other coronaviruses and viral diseases [Expert report Module 2 Long Covid, Professor Brightling and Dr Evans, 26 September 2023 [INQ000280198/7.1]; Professor Whitty statement dated 1 February 2024 INQ000410237/4.106]. Further Matt Hancock gave evidence that he was warned by Professor Whitty of those risks in January 2020⁵ and the Academy of Medical Sciences on 14 July 2020 warned of post-acute sequelae [LCS/108 - INQ000440246/24 3.3.2].
- 20.7. The government failed to account for the foreseeable long-term sequelae and failed to trigger a parallel whole-system programme to look at the risk and potential impacts. That programme would have looked at aspects as diverse as:
- (e) Identifying the emergence of long-term sequelae.
 - (f) Identifying public health, economic, healthcare and benefits impacts – initially as a range of scenarios and narrowing them down as evidence emerged.
 - (g) Identifying the economic interventions needed to support people with long-term sequelae.
- 20.8. The results of this work, and the experts involved would feed directly into the policy decision making process so that both the acute illness and the long-term sequelae were fully accounted for.
- 20.9. We would invite the Inquiry to consider how different the economic interventions and support for Long COVID would have been with an investment of £500m - similar in size to the Nightingale hospitals.

⁵ 21/11/2024 Day 36 Transcript [page 180-182 || 2-16

Minimisation and disbelief of Long COVID – which continues today.

- 20.10. The Inquiry has heard appalling evidence in other modules of the minimisation and disbelief of Long COVID emanating from the Prime Minister [LCS/109 - INQ000251910/9] and similar attitudes reflected in comments by the Minister for the Department of Work and Pensions (“DWP”) [LCS/020 - INQ000092025].
- 20.11. That level of minimisation and disbelief from the highest levels of Government had catastrophic impacts for people with Long COVID.
- 20.12. Our view is that the minimisation and disbelief meant that Long COVID was rapidly excluded from any consideration. Proposals or issues that included Long COVID would at best not get a favourable response, and most likely got a strongly negative response. That created a negative feedback loop that rapidly entrenched minimisation and disbelief at the institutional level. Long COVID would be excluded from discussion, minutes, terms of references, scope definitions, risk registers, data gathering, questions that were asked of SAGE or external bodies.
- 20.13. We also note that disbelief and minimisation that is institutionally entrenched means that organisations don't believe that they are, and don't take actions to change. Examples of disbelief and minimisation are detailed below.
- Government commissions to external agencies will likely not include Long COVID. If an external agency questions the omission, then they risk an unfavourable response, potentially jeopardising their opportunity to win business or funding from the Government.
 - When the risk of long-term sequelae was raised, it was effectively ignored, most notably in Boris Johnson's response to the first NIHR review in October 2020. [LCS/109 - INQ000251910/9]
 - No steps were taken to gather data on the prevalence of Long COVID until the introduction of regular questions about persistent symptoms were introduced in the ONS Covid Infection Survey from April 2021 (following a preliminary survey in December 2020) [LCS/041 - INQ000272260 and LCS/051 - INQ000320261]. Absence of evidence is not evidence of absence.

- There was no effective public health messaging on the risks of Long COVID (we say no effective as there was only one video by the DHSC in October 2020 about Long COVID which we have given evidence about previously had very limited impact and was not seen by most of our members [LCS/031 - INQ000280197/74] and [LCS/110 - INQ000272244]).
- The April 2021 advice to the Cabinet Office on Long COVID causing workplace absenteeism, loss of earnings and labour market inactivity [LCS/052 - INQ000292660] estimated for just the 61,755 people who were impacted “a lot”, for the period March 2020 to March 2021, that the Long COVID related workdays lost would be between 15% and 30%, giving a cost between £158 million - £316 million. We have reviewed the advice and the cited papers, and we believe that this advice is a clear example of minimisation. We cannot comment on whether this was by accident, design, or due to confirmation bias in looking for evidence that supported the prevailing view at the time that Long COVID was not having a significant impact.
- The advice made no estimate of workdays lost for the remaining 328,000 people of working age who were reporting symptoms of Long COVID of varying duration and severity. It also minimised the impact of Long COVID by comparing Long COVID workdays lost for 61,755 people to the total of workdays lost in England, giving an answer of between 0.02% and 0.04%. A more meaningful comparison for decision making would have been to compare the average workdays lost per person in England to the average workdays lost per person for the 61,755 people impacted “a lot” by Long COVID using the 15% and 30% assumptions.
- The advice also included estimates for QALYs lost – but failed to convert those to a monetary valuation as per the Treasury Green Book. They identified that 48,085 QALYs were lost in just the hospitalised population with Long COVID. The Green Book valuation of those QALYs lost is £3.6Bn (48,065 x £70,000). In our view that is a clear example of minimising Long COVID - 48,085 QALYs lost vs. £3.6 billion value of QALYs lost.

- The Keep Britain Working Review, Discovery [LCS/018 - INQ000652464] published 20 March 2025, shows the number of people with work limiting conditions has risen from 6.7 million in 2019, 7.0 million in 2020, 7.3 million in 2021, and 8.7 million in 2024, an increase of 31% since 2019. It is particularly striking that Long COVID is not mentioned once in the document, despite the growing evidence of the impact of Long COVID on economic inactivity and reducing economic activity.

20.14. It appears that the minimisation and denial of Long COVID during the relevant period continues to the present day. The impacts, then and now, meant that for people with Long COVID:

- The huge barriers to remaining in work were made worse.
- The huge barriers to returning to work were made worse.
- The huge barriers to leaving work due to ill-health on fair terms with adequate financial support were made worse.
- The huge barriers to accessing welfare support were made worse.

21. Recommendations for Change

21.1. 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 UK situation caused by the decision making in the relevant period and for future pandemics.

21.2. We fully support all the Module 1 Recommendations, and would like to draw attention to Recommendation 10 as this clearly articulates the best approach:

“The UK government, in consultation with the devolved administrations, should create a UK-wide independent statutory body for whole-system civil emergency preparedness, resilience and response. The body should provide independent, strategic advice to the UK government and devolved administrations, consult with

the voluntary, community and social enterprise sector at a national and local level, as well as with directors of public health, and make recommendations.”

- 21.3. Our recommendations are grouped into departmental or whole-system. Departmental recommendations are typically the responsibility of one department, but in some cases, it might be two or more, for example as funding sources, and others where all departments would need to implement the recommendation within their department. For the whole system view, recommendations are structured around the systemic issues that drove poorer outcomes rather than identifying specific errors and omissions in individual economic interventions. The recommendations and principles behind them cover the Module 9 scope but are equally applicable to all areas of the inquiry scope.
- 21.4. All recommendations should take account of the Inquiry’s evidence on Long COVID.

22. Departmental Recommendations - Summary

- 22.1. **“Nothing about us, without us”.** Cabinet Office, DWP and HMT to implement departmental Long COVID Involvement Groups (LCIGs) including people with lived experience, advocacy groups, Long COVID clinical and academic experts. LCIGs should be involved from the very start of any process to maximise the benefits, and they will cover a wide range of activities, for example Co-design and ‘red-teams’.
- 22.2. **National Economic Impact Assessment to establish current baseline and at least 3-years foresight.** The Government should acknowledge the economic impact of Long COVID and commission a full and independent economic analysis. This would assess historical impact and forecast impacts over the next 3 years.
- 22.3. **Data – restart the Long COVID component of the ONS 2023/24 Winter CIS survey.** The government should fund the ONS to restart the survey. This would provide critical information for economic impact assessments and sizing healthcare costs for the UK Long COVID population.
- 22.4. **Economic support packages** - Long COVID has a significant impact on the economy, individual and household finances. The Government should commission an independent review to identify economic support packages for people with Long

COVID, and their informal carers. If people are well enough to return to work, the packages should support employers to maximise the opportunities for, and the success of return to work.

- 22.5. **DWP review of welfare benefits** – The DWP should commission a review, which includes LCIGs, which assesses the impact of Long COVID, and support for people with Long COVID, across all benefits.
- 22.6. **DWP staff awareness of Long COVID** – The DWP must ensure their staff and supervisors, whether civil servants or outsourced, who have contact with people with Long COVID, have sufficient knowledge, training, guidance, frequency of contact to maintain knowledge, and vulnerability awareness to carry out their duties effectively and avoid discriminatory behaviour.
- 22.7. **Work support** - 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.
- 22.8. **Occupational support** – The Government should commission bespoke guidance for employers about Long COVID from the Office for Equality and Opportunity in consultation with other stakeholders, such as Long Covid Groups, ME association, CPID etc.
- 22.9. **Approach to Long COVID under equality law:** We endorse the TUC's calls for the Government to strengthen the Equality Act by prescribing Long COVID as a disability under schedule 1 paragraph 6 of the Equality Act 2010. In our view formal recognition of Long COVID as a disability under 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 on Employment by reference to the evidence in the Inquiry.

23. Whole System recommendations - Summary

- 23.1. **The Government should establish an Independent statutory body (ISB) responsible for COVID-19 and Long COVID** focused on the current long-term stage of the COVID-19 pandemic to reduce current and future impacts.
- 23.2. **“Nothing about us, without us” – strongly recommend that development of economic policies rely on consultation with Whole-System Groups (WSG)** bringing people with lived experience of Long COVID and advocacy groups together with external experts from a wide range of disciplines, business and the 3rd third sector.
- 23.3. In our view, we see the *Independent Statutory Body for COVID and Long COVID* and the *Whole-System Groups* discussed above as the most effective step forward. The Departmental recommendations will take small steps forward if implemented but our experience to date is that the minimisation and denial presents a very high risk of “do nothing”.

24. Principles

- 24.1. Our recommendations are underpinned by the following principles:
- 24.2. **Take a whole-system view wherever possible.**
- 24.3. **Uncertainty is the “new normal”** and all organisations must work with uncertainty effectively. This is very different from the historical ways of working the Inquiry has documented in the Module 1 report and has already made recommendations to change.
- 24.4. **The next pandemic disease is unknown.** We must not repeat the “influenza” failure simply by adding a second scenario of “COVID-19” with or without long-term sequelae.
- 24.5. **A future pandemic will need a whole-system view** of the potential scenarios for how the disease, in its acute stage and its long-term sequelae, will impact the UK, and how it might progress over 3 months, 6 months, a year etc. All government bodies

(national, devolved, local), business and the third sector would need that core view, updated as new information becomes available, to allow them to respond effectively. During the Inquiry's relevant period, that whole system core-view did not exist.

- 24.6. **The COVID-19 and Long COVID whole-system view does not exist today.** As a result, the ongoing public health crisis and responses are still being driven by decisions made during the Inquiry's relevant period. Those decisions are still damaging people's lives, damaging the future lives of our children, and damaging the economy. We need whole-systems interventions **now** to start the process of improvement.
- 24.7. **Long COVID is caused by COVID-19.** To reduce Long COVID cases we must address COVID-19 cases. Despite the acute emergency phase of the pandemic fire having passed, Long COVID continues to be a slow-burning public health emergency. Long COVID is indiscriminate, affecting individuals of all ages and previous health status.
- 24.8. **The ongoing COVID-19 and Long COVID public health crisis demands whole-system improvements.** The UK can learn from making improvements and changes to our responses, by seeing what works and what doesn't, by understanding why something worked and why it did not. That continuous learning needs to feed back into today's whole-system approach as well into the future pandemic whole-system resilience.
- 24.9. Transparency and external challenge are essential. The earlier external involvement occurs the easier and cheaper it is to resolve issues.
- 24.10. "Licenced disruptor", red teams, devil's advocates, assumption challengers are all essential roles.
- 24.11. Standard terms such as Quality Adjusted Life Year ("QALY"), Disability Adjusted Life Year ("DALY") and Statistical Life Year ("SLY") should always be used and should always be displayed with both their value and their monetary value.

25. Departmental recommendations

“Nothing about us, without us”.

- 25.1. Cabinet Office, DWP and HMT to implement departmental Long COVID Involvement Groups (LCIGs) comprising people with Long COVID lived experience, and Long COVID advocacy groups, Long COVID clinical and academic experts. These LCIGs would follow the well-established and successful Public Patient Involvement approach in research. The LCIGs should be involved at every stage and as early as possible in the process for maximum benefit. Their activities would likely be focused on Co-Design and ‘red-teams’ but they could be tasked for other activities such as testing new online benefit systems.

National Economic Impact Assessment to establish current baseline and at least 3-years foresight.

- 25.2. The Government should acknowledge the economic impact of Long COVID and commission a full and independent economic analysis. The LCIGs should be involved from the start of process, including scoping, signing off Terms of Reference, working directly on delivery activities, providing lived experience insight on Long COVID, reviewing and signing off interim deliverables and final sign-off for the analysis.
- 25.3. Note that being able to express dissenting opinions is a crucial part of the process. Dissenting opinion may not stop sign-off for example, but they must be recorded in a transparent manner.

Data – restart the Long COVID component of the ONS 2023/24 Winter CIS survey.

- 25.4. As we submit this witness statement in October 2025 the existing ONS data is 19 months out of date. In effect the UK is flying blind on Long COVID.
- 25.5. The Cabinet Office should fund the ONS to restart the Long COVID component of the 2023/24 Winter CIS survey on at least an annual basis. This would provide critical information for economic impact assessments and sizing healthcare costs for the

Long COVID population. There should also be the capability to trigger ad-hoc surveys, for example if we have a large summer wave.

- 25.6. The survey design should be reviewed and updated to capture all necessary economic and healthcare evidence to provide maximum value for decisions across Government. One specific high value area would be tracking how individuals vary over time across health, symptoms severity and impact on day-to-day living.
- 25.7. The LCIGs would be involved in the survey review and analysis.

Economic support packages

- 25.8. Long COVID causes workplace absenteeism, presenteeism, loss of earnings, reduced economic activity and economic inactivity. A stakeholder panel, including the LCIGs, should be convened to provide recommendations to the Government for consideration.
- 25.9. Economic support packages should be considered for individuals who have suffered financial losses due to Long COVID with the goals of:
- Enabling return to work, within individual capability boundaries, through ensuring reasonable adjustments, including flexible working, and that recommendations by healthcare and occupational health professionals are binding on the employer.
 - Providing a sufficient and stable income if they are too ill or disabled to work.
 - Providing financial support for informal carers who may be supporting the individual with Long COVID to return-to-work, to stay in work or provide the care that the individual needs.

DWP review of welfare benefits

- 25.10. The DWP should commission a review, which includes the LCIGs, to assesses the impact of Long COVID, and support for people with Long COVID, across all benefits. The review should take account of the Inquiry's evidence on Long COVID.

- 25.11. The review should account for Long COVID as a multisystem disease that can be fluctuating, highly varying across symptoms, severity and duration. These Long COVID characteristics should be tested across the complete lifecycle of claim or re-claim to ensure that the people with Long COVID are effectively assessed and supported, for example being marked as vulnerable provides the support that matches an individual's symptoms. We are concerned in particular that there are systemic flaws in the PIP system as set out in our submissions on the PIP reforms [LCS/111 - INQ000652560]. Assessment criteria across all benefits must be amended to reflect the complex, fluctuating, multisystem nature of Long COVID and ME as many people with Long COVID meet the ME diagnostic criteria. This must include the impact of Post Exertional Malaise / Post Exertional Symptom Exacerbation.
- 25.12. The DWP and the LCIGs should review Long COVID guidance and training for staff so that all frontline staff and supervisors who have contact with people with Long COVID are receiving accurate information.
- 25.13. For many people with Long COVID it's critical that they have opportunities to do activities without jeopardising their benefits. The NHS and other services give them approaches to manage their condition. They need the opportunity to test these approaches, learn new adaptations to maximise what they can do, and understand the reasonable adjustments they may need in the workplace. These sorts of activities can prepare individuals for a successful return to paid employment, if and when it's the right time to do so.
- 25.14. The cumulative impact of multiple symptoms and impairments of Long COVID on daily function and work capability need to be expressly recognised, and employment support needs to be tailored to that. Otherwise efforts to work at intensity and hours that are beyond the individual's functional limitations could cause their health to deteriorate, resulting in long-term or permanent loss of employment.
- 25.15. Employment support needs to be decoupled from welfare sanctions. It has been shown by multiple studies, including the DWP's own, that conditionality and sanctions do not result in positive work outcomes and in some cases can push disabled people from work.

DWP staff awareness of Long COVID

- 25.16. The DWP need to ensure their staff and supervisors, whether civil servants or outsourced, who have contact with people with Long COVID, have sufficient knowledge from their training and guidance, frequency of contact, and vulnerability awareness to carry out their duties effectively and avoid discriminatory behaviour. All assessors should receive mandatory, condition-specific training to improve accuracy and fairness.
- 25.17. This should apply to all frontline staff, and their supervisors, in roles such as work coaches, disability employment advisers in the Jobcentre, PIP assessors, other employment support provision as well new support programmes and making use of permitted work options for people in receipt of ESA.
- 25.18. Consideration should also be given to the number of times per week a staff member, or supervisor, would have to engage with a person with Long COVID to gain and maintain the required level of competence and knowledge. This could mean, for example, specialist teams to deal with people with Long COVID.

Work Support

- 25.19. The 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.

Occupational support

- 25.20. 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).

Approach to Long COVID under equality law

- 25.21. We endorse TUC calls for the Government to strengthen reliance on the Equality Act. In our view, formal recognition of LC as 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 EHCR reviews the Code of Practice by reference to the evidence in the Inquiry.

26. Whole-system recommendations

- 26.1. COVID and Long COVID are a “wicked problem” and require whole-system approaches to economic impact, interventions and financial support. Our view is that Whole-System approaches are also required for all other aspects of the current long-term stage of the COVID-19 pandemic. We believe that COVID-19 and Long COVID is an ongoing public health crisis with ongoing impacts on the UK economy.

UK-wide independent statutory body (ISB) responsible for COVID and Long COVID

- 26.2. The Module 1 recommendation to create “*a UK-wide independent statutory body for whole-system civil emergency preparedness, resilience and response*” has established the precedent for the whole-system approach, including responses. In our view this approach should be adopted by Module 9.
- 26.3. We invite the Chair to recommend that the UK Government establishes an independent statutory body focused on the current long-term stage of the COVID-19 pandemic.
- 26.4. The ISB will work with government stakeholders at all levels (national, devolved, local), business, and the 3rd sector to identify, define and deploy whole-system interventions that reduce current and future impacts of COVID-19 and Long COVID. Our view is that the ISB in its work should include (but not be limited to):

- Flag emerging risks or blind spots for ministerial and other stakeholder's review – not just answer the specific questions raised by stakeholders.
- Define and embed 'red team' capabilities within the ISBs remit from the very start of design processes – following Co-Design principles.
- Deliver transparency by publishing both its thinking and its conclusions for external scrutiny. That transparency must include dissenting views.
- Develop and maintain a whole-system "intelligence" capability to provide a common understanding for decision makers across government (national, devolved, local), and information for business and citizens. It would collate, synthesise, link and analyse information from multiple sources, ranging from research, clinical medicine, government data (e.g. HMRC, DWP, DHSC, ONS, UKHSA), business data, insurance companies as well as government and not-for profit bodies like the IFG, or IFS, and crucially Long COVID advocacy organisations. Scope would be global to make use of information and learning internationally. The intelligence capability would provide regular briefings, dashboards, reports and would be able to answer questions from stakeholders. We note that Dr Tetlow's expert witness report, *Economic policy making systems and structures*, [LCS/112 - INQ000652561] mentions a similar capability.

- 26.5. The ISB's initial drive would be to establish effective integration into relevant teams such as departmental Policy teams, Chief Science Officers and Chief Medical Officers and their respective teams, Government Office for Science and other non-ministerial departments. An example of that type of work would be doing red team reviews of departmental *Areas of Research Interest* to ensure that Long COVID is included where relevant and that research outcomes support the drive to reduce the impact of Long COVID on the economy as well as individuals and their families.
- 26.6. The ISB would also act as a channel for departments to get support for their work from the Long COVID Whole-System Groups of experts as discussed below.

- 26.7. We believe that the ISB should have an immediate deliverable of a Long COVID Whole-System impact assessment on the UK today and a 5-year foresight. This would cover the economy, workforce, benefits and healthcare costs, and assess the impact on reduced economic activity as well as economic inactivity. This would build on any existing departmental impact assessments. Two key objectives would be to identify the overall impact and, the feedback loops between the areas in scope. This would highlight situations where reductions in expenditure in some areas trigger much greater economic impact across other areas and the reverse where increasing expenditure in some areas brings greater benefits overall, for example increasing vaccine eligibility as it reduces Long COVID risk [LCS/113 - INQ000652562], deploying “clean air” devices into public buildings reducing COVID-19 and Long COVID cases as well as overall sickness absence, central investment in biomedical research and accessible healthcare to deliver faster and more successful return to work.
- 26.8. Our view is that the combination of the ISB and the Whole-System Groups of experts is essential to overcome the institutionalised minimisation and denial of Long COVID.
- 26.9. Finally, we want to briefly cover the relationship between the ISB and the Module 1 independent statutory body. The ISB on COVID-19 and Long COVID is a live instance of some of the capabilities that will be delivered by the Module 1 independent statutory body. It will work closely with the Module 1 independent statutory body so that knowledge, skills, lessons learnt, capabilities and intervention designs flow freely between the two. We have considered whether the ISB should be part of the Module 1 body. Our view is that they should be separate as the scope and the deliverables for the two bodies are different. The ISB is focused only on COVID-19 and Long COVID, and only the long-term phase. Module 1 independent statutory body is focused on planning and resilience for new pandemics.

“Nothing about us, without us” - mandated Whole-System Groups (WSG)

- 26.10. All work impacting people with Long COVID must use Whole-System Groups. These should be seen as an evolutionary step from departmental LCIGs. As mentioned above the ISB is the channel for effective deployment of WSGs into stakeholders

workstreams. The WSGs need to be involved in each stage of policy development e.g. problem identification, idea generation and evaluation, policy formulation and implementation. They can also be involved with systems and operations (e.g. new online benefit portals, rollouts of new policies).

- 26.11. External stakeholder representation should be mandated, ideally by statute to ensure effective expert composition. This would include (but not be limited to) people with Long COVID, Long COVID advocacy groups, voluntary and community sector, public health, clinical medicine, behavioural science, environmental science, epidemiologists, modellers, data science, critical thinking specialists, economists and health economists, and institutions such as the Institute for Government, Institute for Fiscal Studies, business institutions such as the BCC and FSB, and academic institutions.
- 26.12. Stakeholder involvement will vary on each work package. The involvement could range for example from direct involvement, information provision, to agreeing scope and terms of reference, risk register and mitigation reviews, quality assurance involvement, output reviews, red team reviews and assumption challenges. A fundamental point is that each stakeholder determines what is their appropriate involvement for the specific work to be done. To be clear, it should not be solely down to the stakeholder leading the work who should be involved or how.
- 26.13. The question of ownership needs to be addressed, lead department vs. whole-system, for each work package. As we have seen in the Module 1 findings, the lead department model is not an appropriate solution for pandemic responses planning. We believe that the default start point should be a whole system owner and by exception a lead department. Any stakeholder must be able to request a whole-system review if they believe that a lead department is taking a siloed position rather than a whole-system position.

Future recommendations for a future as yet unknown pandemic:

- 26.14. **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.

- 26.15. **Surveillance systems** should be in place from the outset, for example in the form of sleeping studies. These should identify and monitor data on the impact of longer-term sequelae so that long-term health implications and economic impacts 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.
- 26.16. **Socio economic impacts:** There should be informed analyses by objective metrics such as QALYS and DALYs.
- 26.17. **Pandemic planning** should take account of bespoke financial support for those suffering long term disease including carers support.
- 26.18. Pandemic planning and response on **long term morbidity should involve all Devolved nations**. We 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.
27. **Strengths and weaknesses of the overall economic response to the pandemic by the State**

Weaknesses of the overall economic response to the pandemic by the State

- 27.1. As discussed above the single biggest weakness in the economic responses is both the historical and ongoing denial and minimisation of Long COVID. People with Long COVID are ignored, not accounted for in both historical and ongoing policy decisions. The Long COVID fire is burning, and as there is no ongoing national surveillance of Long COVID, we don't know how far the fire has spread. Every COVID-19 infection carries the risk of Long COVID.
- 27.2. **The first immediate action required** is to urgently address public health, ongoing COVID-19 infections, and Long COVID, as a matter of national policy. [LCS/114 – INQ000652563]. A weakness has been the failure to acknowledge Long COVID. In our statement to the 'Get Britain Working White Paper' we called for the Government

to “urgently... acknowledge Long COVID and its impacts on long term health and employment in this country, and to work with the patient community instead of ignoring our lived experience...it is time for welfare sanctions to be removed and workplace safety to be made central to the UK Government’s approach to tackling unemployment”.

- 27.3. The **second immediate action** is address Long COVID’s specific nature. Long COVID is a complex, multisystem condition that significantly limits energy and can be profoundly disabling. Critically, symptoms often fluctuate and tend to worsen with exertion—whether physical, cognitive, or emotional—essentially any form of stress on the body. This fluctuating and recurring nature was, and is, fundamentally not covered in the structure of the financial support available, whether that was employer absence policies and sick pay arrangements, benefits such as PIP, ESA and Statutory sick pay. There was, and is, a lack of support for workers with Long COVID in accessing legal advice for tribunals over workplace discrimination, unfair or constructive dismissal on the grounds of their illness. Claimants were and are disadvantaged in tribunals both financially and through cognitive and energy limitations, tribunal hearings tended to be scheduled over an extended period running into years, and cases were settled or abandoned without financial compensation for the claimant.
- 27.4. Generally, there was a significant gap in financial support for those who were not eligible for COVID-19 sick pay and employer sick pay. In addition, Statutory Sick Pay was and continues to be inadequate. Although the furlough scheme allowed employers to retain sick employees on full pay it was at their discretion to move them onto Statutory Sick Pay. No additional financial support was made available to existing caregivers and many new unpaid carers were created as a result of the pandemic. These were often previously employed people who had to forego employment in order to take care of loved ones who had become newly disabled due to Long COVID. No financial support schemes were created for the homeless.

Strengths of the overall economic response to the pandemic by the State

- 27.5. We have found this a very challenging question to answer. We acknowledge the herculean efforts of so many people in the UK who worked to recover the country from the pre-pandemic planning failures. Without their efforts, the economic response to the pandemic would have meant far more people in the UK would have experienced the severe financial hardships that many of our members experienced and continue to experience. Our members have the additional on-going burden of Long COVID which massively impacts their ability to recover financially.
- 27.6. From the perspective of our Long COVID community we can see no strengths in the overall economic response. Far too many of us were not protected.

Design and implementation of economic interventions

- 27.7. We have been asked to comment on the strengths and weaknesses in our view of the design and implementation of economic interventions.
- 27.8. The University of Bristol and the Standard Life Foundation ran a periodic survey of the financial state of the UK population. Their report “Who are the Excluded?”⁶ (Feb 2021) looked at the individuals who had been unable to benefit from either the Coronavirus Job Retention Scheme or the Self-Employment Income Support Scheme. They estimated that in January 2021:
- *“as many as 3.8 million adults in Britain (between 6-7 per cent) are living with reduced earnings as a direct result of the pandemic and are not currently furloughed or getting help from the Self-Employment Income Support Scheme.”*
 - *“almost half (47%, equivalent to 1.8 million) have lost a third or more of their total household income – around five times more than among the rest of the population (9%)”*

6 Collard, Sharon & Collings, David & Evans, Jamie & Kempson, Elaine. (2021). Who are the excluded.

- *The remainder have lost up to a third of their total household income*
- *About half of the excluded are no longer earning an income (permanently or temporarily) because they have lost their job or have ceased trading as self-employed.*

27.9. We note that the report does not differentiate between people who are excluded by the scheme criteria vs people who have not claimed. However, it does show the scale of the problem.

27.10. The scale of the fraud and error in the COVID-19 loan guarantees, which The Department for Business, Energy & Industrial Strategy ("BEIS") estimated in its 2020-21 annual report, to be within "a range of 8.15% to 14.15%, reflecting £3,615 million to £6,275 million" is shocking. The range of uncertainty, £3.615 billion to £6.275 billion, also raises huge concerns about the design and implementation of the scheme.

27.11. Our view is the failure in pre-pandemic planning to design blueprints for economic interventions led to the frantic efforts to cover the majority of the population at the expense of groups that were difficult to target. People may have been in an "easy target" group before they developed Long COVID, but afterwards they fell into a difficult to target group.

27.12. Under the government COVID-19 sick leave policy from 13 March 2020, workers were entitled to Statutory Sick Pay from day one of illness or isolation. The Statutory Sick Pay rate was £95.85 per week, lasting up to 28 weeks. The removal of the "first 3 days" criteria was a slight improvement as it provided a little more financial support and encouraged people to not work while sick and helped reduce transmission.

27.13. The design of the schemes, and particularly the furlough scheme (Coronavirus Job Retention Scheme) created structural injustice. Under furlough, employers could reclaim 80% of a worker's salary, up to £2,500 per person, as an alternative to having to lay off workers whose salaries the employer would have had to pay despite them being unable to attend work due to lockdown rules. This prevented job losses and the loss of salaries for workers. By contrast, workers who became ill with COVID-19 and developed Long COVID suffered a substantial salary loss, having to survive on

Statutory Sick Pay of £95.85 per week while unable to work due to ill health. If they did not recover within 28 weeks, they lost all income, but even within a shorter time-frame many faced unfair or constructive dismissal or capability procedures on ill-health grounds, due to not being well enough to work at their usual capacity.

- 27.14. LCS's ask was for income protection to rectify this structural injustice that disadvantaged workers developing Long COVID after a COVID-19 infection versus healthy workers off work during lockdown on full pay.
- 27.15. The TUC "Workers experiences of Long COVID" report [LCS/115 - INQ000377697] asked that the Statutory Sick Pay weekly rate be permanently raised to at least the equivalent of a week's real living wage (£330 per week) and the lower earnings limit ("LEL") must be scrapped. This would guarantee that everyone who had to take time off work when sick would still at least be paid enough to live on. Even a temporary raise would have been a very significant improvement for people with Long COVID.
- 27.16. It is estimated that the number of people who earned less than the lower earnings limit ("LEL") (para 27) ranged from 1.3 million to 2 million. According to the TUC and the ABI, 70% of the people excluded by the LEL were women – who were at a higher risk of Long COVID. The other critical issue with the LEL was if someone was working multiple jobs. They might earn more than LEL in total but if none of their jobs reached the LEL then they were not eligible for SSP. Working multiple jobs is common in the hospitality sector – which has a higher risk of Long COVID than the general population.
- 27.17. The other aspect to SSP is that it does not support phased returns to work. Many employers sick pay schemes support phased returns to work. In "Health is everyone's business" published in July 2019 [LCS/116 - -INQ000652566] by the DWP and DHSC, they noted that "the benefits of phased returns to work which have been shown to reduce the likelihood of an individual falling out of work and increase the time spent at work in the long-term." For people with Long COVID, phased returns to work over a number of weeks is a critical approach for a successful return to work. As soon as an individual returns to work on any level of reduced hours they lose SSP.

- 27.18. Occupational sick pay schemes can offer more generous benefits. According to the Fabian Society's written evidence to Parliament in December 2023 employees get sick pay benefits for a period defined by the employer, 66% of employees get full pay, 18% get somewhere between full pay and SSP and 16% have no employer sick pay scheme and are only eligible for SSP [LCS/117 - INQ000652567. According to a government-commissioned survey [LCS/118 – **INQ000652568** in July 2021 over 2,500 UK employers, just under half of hospitality employers offered only Statutory Sick Pay, while around 30% offered sick pay above SSP, leaving around 20% who offer no sick pay at all. In the hospitality sector specifically, SSP-only provision is common, especially among small and micro employers.
- 27.19. Overall, the COVID-19 economic interventions and the welfare safety (e.g. SSP) net had many large holes for people with Long COVID. The combination of factors such as gender, ethnicity, socio-economic status industry sector increased their risk of developing Long COVID but it also increased their risk of falling through the holes.
- 27.20. We believe that as a result of the minimisation and denial of long-term sequelae and Long COVID, it was not accounted for in decision making and the design of the economic interventions. As an added barrier, SSP made it harder for people with Long COVID to return to work if they were well enough due to the lack of support for phased returns-to-work.

Strengths and weaknesses of the engagement of the UK and Devolved Administrations

- 27.21. We have been asked to comment on the strengths and weaknesses of the engagement of the UK and Devolved Administrations with us and what we would recommend for such engagement in the future.
- 27.22. We engaged with the government and key decision makers seeking financial support, raising awareness of the wider economic impact of Long COVID, seeking UK policy changes regarding non-pharmaceutical interventions, employment, welfare, research, healthcare provision, and rehabilitation for sufferers of Long COVID.

- 27.23. We advocated to the highest level of government, from the very early days of the pandemic, for morbidity and specifically the risk of Long COVID, to factored into considerations by decision makers.
- 27.24. Our letters to Prime Ministers and relevant Government Ministers were met with stock responses often delivered by junior ministers.
- 27.25. Despite our engagements with Government representatives, it is clear that the Government did not consider the reality of huge numbers of people suffering from Long COVID. Nor did it take steps to prevent Long COVID.
- 27.26. We responded to numerous consultation requests to government departments on matters relevant to this Module. However, we were not invited to or involved in any direct meetings with HM Treasury, DWP or other relevant departments.
- 27.27. We gave evidence at APPG's, Select Committees and Ministerial Round Tables but were at no point invited to participate or provide any specific information or evidence to economic or fiscal decision makers in the UK Government.
- 27.28. It is our opinion that Senior-most decision-makers in Government ignored early signs and advice of prolonged symptoms of COVID-19 and failed to commission timely advice on Long COVID to ensure that decision making considered the long-term health impacts of COVID-19 on the population.
- 27.29. It is also our opinion that decision makers continued to ignore new evidence on Long COVID as it emerged throughout the pandemic and that this was driven by systemic denial and minimisation as discussed.
- 27.30. Clear and comprehensive messaging from Governments regarding the impact of Long COVID on quality of life, ability to earn a living and care for others would have enabled people to make more informed choices about their personal risk.
- 27.31. As more is understood about the vascular nature of Long COVID, the repeated damage to the immune system of reinfections and the increased risk of serious long-term health issues such as heart attack, stroke, diabetes and dementia, more must be done to increase awareness and protect the public. Without action Long COVID

will continue to burden healthcare systems, reduce workforce participation, and deepen health inequalities.

27.32. As the Chair recorded in the Module 1 report: *“An unhealthy population is at significantly greater risk of experiencing higher rates of serious illness and death as the result of an infectious disease. If levels of poor health are left unchecked over an extensive period of time, the inevitable consequence will be that those who are vulnerable due to poor health will be the hardest hit.”*

27.33. In 2025, that unhealthy population continues to grow as a consequence of Long COVID. Poor public health as a consequence of COVID-19 infection bears upon the UK's future resilience, the legacy of which will hit our children hardest.

Conclusion

27.34. In our view, the government response to Long COVID was a catastrophic failure. Despite our campaigning and advocacy, the government neglected Long COVID, missed opportunities to provide support for people with Long COVID and caused avoidable harm. As it stands, the government's legacy will be that of exacerbation of pre-existing inequalities and failure to adequately support a cohort of newly disabled people. We invite the government to work with us to implement the recommendations made in this statement, to improve the futures of people with Long COVID and to prevent the same mistakes happening again.

Statement of truth

IMichael Ormerod.....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.

Personal Data

Dated.....06.03.2025.....

I Natalie Rogers.....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.....

Personal Data

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Dated.....06.03.2025.....