UK COVID-19 PUBLIC INQUIRY
MODULE 3

CLOSING STATEMENT
ON BEHALF OF
LONG COVID KIDS, LONG COVID PHYSIO,
LONG COVID SOS AND LONG COVID SUPPORT

I. INTRODUCTION: THE CURRENT HARM OF LONG COVID

1. Long Covid ("**LC**") remains an *"invisible illness"*[1] despite significant numbers of adults and children continuing to develop debilitating, disabling long-term illness from new Covid-19 infections and reinfections. On 10 December 2024, the Director General of the World Health Organisation ('**WHO'**), Dr Tedros Ghebreyesus said "*We cannot talk about COVID in the past tense. It's still with us, it still causes acute disease and "Long Covid", and it still kills...The world might want to forget about COVID-19, but we cannot afford to."*[2] LC is a current public health threat, for which there is no cure and no validated treatments. An effective response to long-term sequelae requires the healthcare system to plan for lasting structural and systemic changes for ongoing surveillance, continuing research, access to specialist multi-disciplinary services, improving public health awareness as well as reducing health and healthcare inequalities.

2. In stark contrast, public health officials in the UK foresaw the possibility of long-term sequelae, but did not proactively respond to it. It was left to patient advocates to prompt the healthcare system to react. The evidence shows that even then, the response was reluctant, delayed, piecemeal and myopic. There was, and remains, pervasive disbelief about LC within the medical community.[3] The limited LC healthcare services, and the systems that were put in place to protect and promote the UK's overall public health, have either been disbanded or are at risk of service reduction. The Inquiry's investigations in this module therefore have urgent relevance to almost two million adults and children and counting who suffer from LC today. As the Chair

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[1] [23/1/15–23/61/22].
[2] WHO Director General's Opening Remarks at media briefing, 10 December 2024. Available online at: https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing---10-december-2024.
[3] [22/74/1–7].

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.*"[4] In 2024, that unhealthy population is growing as a consequence of LC. Poor public health as a consequence of Covid-19 infection, bears upon the UK's future resilience.

3. The Long Covid Groups ('**LCGs**') submit that there is sufficient evidence for the Inquiry to make the following fifteen findings:
   I. LC presents a current and indiscriminate risk to all adults and children (§§11-16).
   II. There was, and remains to this day, a failure to protect patients and healthcare workers ('**HCWs**') (clinical and non-clinical) from long-term injury in healthcare settings (see urgent recommendation) (§§17-20).
   III. The was (and there remains) a failure to recognise airborne transmission as a dominant route of transmission for Covid-19 and to update national IPC guidance to mitigate for airborne transmission (§§21-24).
   IV. LC was foreseeable but the UK healthcare systems were not prepared for the long-term illness and disability caused by Covid-19 (§§25-26).
   V. The approach to research for LC has been disjointed, delayed and insufficient (§§27-29).
   VI. The UK public health bodies abrogated their responsibilities to warn the public of the risk of LC and there is still no adequate public health messaging on the current risks of LC (§§30-35).
   VII. There was a systemic failure to collect data on the long-term effects of a novel virus (a failure which continues to date, contrary to current WHO guidance) (§§36-40).
   VIII. Patient advocacy raised the alarm on the long-term effects of a novel virus (§§41-51).
   IX. There was a delayed response to LC (§§52-54).
   X. The UK healthcare system's response was inadequate and access to LC services remains inequitable (§§55-67).
   XI. The harm and risk of LC to children and young people was minimised (§§68-72).
   XII. Paediatric LC services were delayed and inadequate (§§73-75).
   XIII. The healthcare system failed to take a preventative approach to LC (§§76-79).

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[4] UK Covid-19 Inquiry Module 1 Report § 3.54.

XIV. LC exacerbated pre-existing inequalities and has created new inequalities (§§80-85).

XV. The healthcare system failed and continues to fail in its regulatory duties to protect HCWs (§§86-97).

4. The LCGs seek specific recommendations as set out below at §§103-104. Given the overwhelming evidence on airborne transmission of Covid-19, and the ongoing risks in healthcare settings, the LCGs invite the Chair to make an urgent recommendation that:

> *By 1 March 2025, UKHSA, NHSE, DHSC and other public health agencies (including those in the Devolved Nations), with the benefit of multi-disciplinary input from experts in physical sciences and the UK's Health and Safety regulator, the HSE, revise IPC guidance in the NIPCM and HTM guidelines to ensure:*
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> > *(a) recognition of the role of airborne transmission of SARS-Cov-2; and*
> > *(b) there is appropriate guidance on measures to limit airborne transmission of respiratory viruses such as Covid-19 including the use of FFP3 masks, improved standards of ventilation and air filter devices in healthcare settings (both clinical and non-clinical) and ensure the distribution of those guidelines to all employers/providers of clinical and non-clinical healthcare workers.*
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> *Any such review must include consultation with key stakeholders*

II. STATE WITNESSES: OVERLOOKING LONG COVID

5. The approach taken by many, albeit not all, of the key state witnesses to LC has been either not to mention it at all, or to refer to it in passing. This gives rise to three concerns: (i) there are gaps in the witness statements' coverage of LC, (ii) limited disclosure, and (iii) witnesses providing limited assistance in their oral evidence. At best, the approach of these witnesses to LC mirrors the lack of priority LC has received in the healthcare system to date; at worse, it indicates unwillingness to take responsibility for multiple failures. Of 312 witness statements disclosed in this module, only 130 refer to LC. Of those that did refer to LC, in many cases the reference was brief, and often left significant gaps in the evidence. The LCGs point to the following examples.

6. **In England,** Professor Susan Hopkins, and Professor Dame Jenny Harries from UK Health Security Agency ('**UKHSA**') did not address Public Health England ('**PHE**') and UKHSA's work on LC apart from brief reference to PHE's contribution to the NICE/

SIGN/ RCGP Guidelines consultation.[5] For example, Professor Hopkins provided a detailed description of PHE / UKHSA's role in the SIREN study at §§189-206 but did not refer to the study on the effects of LC on HCWs, nor did she mention the work of UKHSA in gathering data on LC. This is despite the SIREN study (of which she is co-author) of 5,000 HCWs demonstrating: (i) that half of HCWs had suffered persistent symptoms in the "wild" variant; and (ii) of those that were impacted by LC, 14% were impacted "a lot" and had changed their working patterns. Staff lost an average of 50 working days up until 31 September 2022, with 25% of staff taking between 51 and 680 days in that period.[6] Dame Harries did not set out in her statement her understanding of the delineation of responsibility in responding to LC as between UKHSA and NHS England ('**NHSE**'). Rather, she mentioned LC for the first time in oral evidence in relation to work done on vaccine effectiveness in reducing LC.[7] Further, she did not take the opportunity afforded to clarify the impact of LC, rather than acute Covid-19 on CYP, and warn parents of the risk of this significant childhood disease.[8]

7. **In relation to Wales,** the CMO for Wales, Sir Frank Atherton, referred in his statement to the emerging risk of LC reported in a TAC summary survey but said no more about the issue.[9] The witness statement of his deputy, Professor Christopher Jones, who was involved in the LC response, also failed to deal with LC.[10] Professor Fu-Meng Khaw, Public Health Wales ('**PHW**'), failed to explain why he did not think PHW has a role in identifying long-term impacts of pathogens.[11] Alex Howells, Health Education and Improvement Wales, did not make any reference to consideration of LC in relation to workforce strategy, planning and development.[12] Dr Andrew Goodall, Former Director General of Health and Social Services Group Wales until November 2021 was directly involved in the Welsh response to LC. Yet he was unable to assist the Inquiry on the decision-making process, confirming only that funding was provided.[13]

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[5] Professor Hopkins referred only briefly to PHE comments on the NICE/SIGN/ RCGP rapid guidelines on LC [INQ000410867/23-24]. Dame Harries refers to her involvement in LC as dCMO but not thereafter. [INQ000489907].

[6] [INQ000410867/89-91]; [7/223/24-7/224/25]; [7/225/20-25]; Foulkes, et al Prevalence and impact of persistent symptoms following SARS-CoV-2 infection among healthcare workers: A cross-sectional survey in the SIREN cohort, Viruses and Viral Diseases, Vol 89, 4, 2024.

[7] [27/209/10 - 27/210/11].

[8] [27/210/12 - 27/213/7].

[9] [INQ000474224/19].

[10] [INQ000326303].

[11] [INQ000056330/3]; [26/38/5 - 11].

[12] [INQ000413867].

[13] Save for brief reference to funding agreed for LC [INQ000485721/91].

8. **In relation to Scotland**, Mary Morgan, the Chief Executive of NHS National Services Scotland, failed to provide any information in her witness statement about the Scottish LC programme and the work of the National Strategic Network for LC.[14] A statement has been received from all the Scottish Territorial Health Boards and yet only one, Professor Emma Watson, referred to the impact of LC on staff members.[15] None explained their approach to the provision of LC services according to Scotland's LC service plan, nor the failure to provide paediatric pathways until 2024, or what impact this delay had on patients, children and parents desperate for care.[16]

9. **In relation to Northern Ireland**, Aidan Dawson, Public Health Agency Northern Ireland ('**PHA NI**'), did not address LC in his statement despite PHA NI carrying out work on the public's knowledge, beliefs and attitudes to Covid-19 including LC in September 2021.[17] None of the statements provided on behalf of the Department of Health of Northern Ireland (two from Peter May and a joint statement from Eugene Mooney and Lisa McWilliams) mentioned LC.[18]

10. A second concern is the limited disclosure about the response to LC. Where possible, the LCGs have sought to fill the gaps in evidence by providing the Inquiry with material available from open sources.[19] The third concern arises from the incomplete oral evidence offered by State witnesses in relation to LC. Many witnesses were able to provide only vague or incomplete evidence on the response to LC. This underlines the LCGs concern about the lack of prioritisation of LC. For example, the absence of any evidence about the Office of the CMO ('**OCMO**') Wales's response to LC was pointed out to Sir Frank Atherton during his oral evidence. He denied that this omission meant LC was not a priority for his office but could provide only general comments about the healthcare response to LC in Wales.[20] The LCGs observe that these omissions are not reserved to the OCMO of Wales; rather, they reflect a broader pattern of the healthcare response paying insufficient attention to LC.

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[14] [INQ000475249]; [INQ000309005]; [INQ000108620] ; [INQ000474612/3] ; [INQ000401271/19].
[15] [INQ000480949/11].
[16] [INQ000492648]-[INQ000492669]; [INQ000494741].
[17] [INQ000485720]; [INQ000416821].
[18] [INQ000485167]; [INQ000421800]. [INQ000474243/3-4].
[19] Email from Bhatt Murphy to ILT dated 21 October 2024 providing: Letter from Jenni Minto MSP to Jim Fairlie MSP [INQ000510079]; and Adferiad Reports [INQ000510076] [INQ000510077] [INQ000510078].
[20] [13/133/19 - 13/134/25]; [13/133/16 - 13/134/25].

III. "EVERYBODY IS AT RISK"[21] – THE PERVASIVE IMPACT OF LONG COVID

11. **LC presents a current and indiscriminate risk to adults and children.** LC has a life-changing impact on (i) adults, (ii) children, (iii) workers, and has changed (iv) the demands and capacity of the healthcare system. It can impact an individual's ability to function, undertake daily tasks, attend school, study, exercise, work, care for family, socialise and engage in society. LC has also increased demand on the healthcare system, whilst simultaneously reducing its workforce capacity. Professor Whitty stated that effects were "*very profound.*" Professors Brightling and Evans have compared the prevalence of LC to the combined prevalence of the UK's commonest chronic heart and lung conditions.[22] On last count in April 2024, LC affected almost two million adults and children in England and Scotland alone.[23] It impacts a growing and sizeable proportion of the population. The Inquiry also heard evidence on its economic impact, namely that the Institute for Fiscal studies, relying on ONS data up until May 2022, estimated the loss of income was in the order of £1.5 billion per year and *"somewhere in the region of 0.5 of the UK GDP."*[24]

12. Professor Charlotte Summers described Covid-19 as a multi-system disease that can attack every organ in the body.[25] The profound physiological impact of LC has created a cohort of newly disabled people. Dr Nathalie McDermott is now disabled, having suffered neurological symptoms and damage to her spinal cord due to LC. Owing to the relapsing and remitting nature of LC, her symptoms are still developing. She describes being in the initial stages of autoimmune thyroiditis, which could lead to further kidney issues.[26]

13. In relation to children and young people ('**CYP**'), LC is a new childhood disease which affects over 55,000 children in England and Scotland which means its prevalence exceeds that of childhood diabetes.[27] A 16 year old with no underlying conditions

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[21] [22/71/6].
[22] [22/73/10 - 22].
[23] ONS, Winter CIS for England and Scotland, April 2024. Available online at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/selfreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland.
[24] [22/128/19 - 25]; [INQ000421758/16] §38.
[25] [19/129/13].
[26] [INQ000492279/8] §§ 30-36.
[27] ONS 25 March 2024 Winter CIS (including those children who have suffered symptoms of Covid-19 for over 12 weeks). Available online at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/selfreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland. Royal College of Paediatrics and Child Health, March 2020 indicator on Childhood Diabetes. Available online at: https://stateofchildhealth.rcpch.ac.uk/evidence/long-term-conditions/diabetes/#ref-1.

before Covid-19 *"has been completely bedbound for 14 months and seriously unwell for 23 months. She developed a 36-degree reactive scoliosis and intense pain in her right hip at exactly the same time as Covid Pneumonia was diagnosed."*[28] LC destroys children's childhoods and impedes development. As recognised by the WHO, the disabling physical symptoms have an impact on *"everyday functioning such as changes in eating habits, physical activity, behaviour, academic performance, social functions (interactions with friends, peers and family) and developmental milestones."*[29] Despite the potential severity of LC, the majority of CYP do not have access to specialist paediatric care.

14. The impact of LC was exacerbated by the healthcare system's response. Patients and parents were maligned, disbelieved, and excluded from accessing care. Individuals with LC were forced to fight the healthcare system in order to access care. Dr Sarah Powell illustrates the psychologisation of LC: *"I felt like I was arguing with this medic, an NHS doctor, and I was having to convince him that LC was an actual thing."*[30] Nicola Ritchie, an NHS physiotherapist, sets out her two-and-a-half-year failed fight to access NHS care: *"In March 2023 I had basically had enough. I had been fighting, trying to get some form of treatment from the NHS since probably from December 2020 and I kept getting knocked back every time but I was researching everything that I possibly could to help myself. I eventually found there was a private GP seeing patients with LC so I thought: I've got nothing to lose."*[31] This disbelief still endures: *"Despite being diagnosed with LC, I have often encountered medical professionals who dismiss my concerns*;"[32] although Professor Evans has characterised any scepticism of LC as *"deeply unscientific."*[33] LC sufferers were isolated by their physical symptoms and further isolated by the disbelief of the healthcare system.

15. The Inquiry has heard ample evidence of the disproportionate impact of Covid-19 on HCWs who were said to have been put at a six-fold increased risk of contracting the virus.[34] The impacted healthcare workforce includes those in non-clinical and administrative roles, individuals staff who are privately-employed and those on fixed-term contracts, as well as agency staff, security guards, porters and cleaners.

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[28] [INQ000370954/48] §5.10.
[29] WHO Clinical Case Definition for Post-Acute Covid-19 condition in children and adolescents by expert consensus. Available online at: https://www.who.int/publications/i/item/WHO-2019-nCoV-Post-COVID-19-condition-CA-Clinical-case-definition-2023-1.
[30] [21/8/23-25].
[31] [22/57/14 - 21].
[32] [INQ000421866/3] §11.
[33] [22/105/6 - 10].
[34] [21/105/6 - 10]; [INQ000410237] §4.78.

Witnesses have explained how the debilitating symptoms of LC has left HCWs with LC unable to fulfil their roles: *"they'd spent some of their funds on fitting stairlifts for paramedics that can't even walk up the stairs without becoming breathless"*[35] and *"staff that may be unable to undertake a full range of shift duty, so there may be staff that just can't work nights anymore."* This has often meant they are offered alternative employment or re-deployed so *"it's less activity, less strenuous, maybe with less shift work, shorter working days."*[36] Some HCWs have had to forego career ambitions and others, like Patricia Temple, have been discharged from service altogether due to illness.[37] The SIREN study on the impact of LC, considered data up to September 2022 and found that 50% of respondent HCWs had persistent symptoms which impacted their day-to-day functioning *"a little"* and 24% were impacted *"a lot."* It further illustrates that HCWs with LC are regularly re-infected and that an increasing number need greater adjustments to their work pattern following every re-infection.[38]

16. The debilitating impact of LC symptoms, and its disproportionate and enduring impact on HCWs has inevitably squeezed the healthcare system from both ends. LC has caused an increased demand on all NHS services.[39] Whilst there is no quantitative measure of the prevalence of LC on the healthcare workforce, the qualitative evidence points to LC reducing the overall capacity of the healthcare workforce to deliver health services.

IV THE HEALTHCARE RESPONSE

(I) The failure to protect HCWs and patients from Long Covid

17. As set out above there is a compelling and urgent need for the Inquiry to exercise its powers under section 24(3) of the Inquiries Act 2005 to issue an interim report and recommendations addressing the need to review current Infection Prevention Control ('**IPC**') guidelines by 1 March 2025. These recommendations cannot wait until the publication of the Module 3 Report in 2026.

18. This should be uncontroversial given the evidence heard: the experts to the Inquiry on IPC controls Professor Clive Beggs, Dr Ben Warne and Dr Gee Yen Shin all agree that Covid-19 is transmitted through the airborne route.[40] They also agree that FFP3

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[35] [9/123/13 - 24].
[36] [14/102/8 - 20].
[37] [INQ000492279/8] §§32-37; [17/139/1-5]; [INQ000339027/21] §110; [INQ000486012/7] §23.
[38] [INQ000513026/8] Table 3.
[39] [INQ000409251/169] § 631; [INQ000339027/16] §79.
[40] [3/41/12-15]; [8/164/23-/165/2].

respirators provide more protection for HCWs than surgical masks,[41] and that there is an urgent need to update IPC guidance to recommend routine use of FFP3s and to improve standards of ventilation and introduce air filtration devices in the NHS estate to mitigate airborne transmission of Covid-19 and other respiratory viruses.[42] Given the WHO's warning about the ongoing risks of Covid-19 and that NHSE has publicly acknowledged that increased rates of transmission of Covid-19 in Winter 2024/25 is causing pressure on NHSE services, their recommendations should be acted upon and the IPC guidance to be updated without further delay. These recommendations will be equally effective in reducing the transmission of other airborne viruses including RSV and influenza which are contributing to the pressures on NHS.[43]

19. The potential for airborne transmission as a dominant route of transmission for Covid-19 should have informed IPC guidance from the beginning of the pandemic response. The reluctance by the UK IPC Cell to recognise this transmission route meant that HCWs and patients' lives and long-term health were sacrificed in the pandemic response. Professor Beggs explained to the Inquiry that he held the view that Covid-19 is transmitted "*predominantly by an airborne route,*"[44] since early 2020 and observed that there was sufficient evidence to support this view from September 2020.[45] Despite this, it was assumed from the outset of the pandemic that that Covid-19 was primarily transmitted through droplets. This assumption was based on *a priori* position but not informed by evidence.[46] Professor Beggs agreed with the Chair's question that "*…surely you should guard against every possible route of transmission until you know…*" and attributed the reluctance to recognise aerosol transmission to "*a kind of confirmation bias.*"[47]

20. Dr Barry Jones' evidence was that decision makers required "*high level evidence to prove that the airborne route*" was dominant despite there being no evidence to justify reliance on droplet transmission – the disparity being a "*reflection of the culture.*"[48] Indeed, the reluctance to recognise that Covid-19 was airborne from the early stages of the pandemic is difficult to understand when considered with reference to the known transmission modes of SARS-Cov-1 and MERS. Dr Jones observed that SARS-Cov-

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[41] [8/163/10 - 13]; [8/164/23 - 8/165/2]; [3/178/19 - 3/179/18].
[42] [3/175/12 - 3/177/15]; [8/5/24 - 8/6/15]; [8/172/3 - 25]; [8/47/5-10].
[43] See for example Dr Shin's evidence on infection prevention controls for seasonal winter challenges to multiple respiratory viruses. [8/8/8-10/23].
[44] [3/41/12 - 15].
[45] [3/42/20 - 23].
[46] [3/118/1 - 3/119/18].
[47] [3/120/1-8]; [3/121/2-10].
[48] [4/19/8 -21].

2 was the only virus whose modes of transmission were ‘changed’ (by the UK IPC Cell): from initial recognition of aerosol transmission similar to SARS-Cov-1 and MERS to transmission primarily by droplets on downgrading of the HCID classification.[49] His views are supported by Professor Hopkins’ suggestion that airborne transmission for SARS-CoV-2 was rejected due to insufficient evidence of that transmission route compared to droplet and contact transmission.[50] As Professor Noakes explained in Module 2: “*in truth [the evidence] was weak for all transmission routes. I think there was just a tendency to assume the other transmission routes and then require the evidence for airborne transmission.*”[51] Professor Hopkins appeared to apply a higher evidential standard for airborne transmission than other routes.[52]

21. **The failure to recognise the *potential* that airborne transmission was a dominant route for Covid-19 had significant implications for national IPC Guidance**. HCWs were required to wear FFP3 masks in ICUs and HDUs classed as aerosol generating procedures (“AGPs”) ‘hot spots,’ but FFP3s would otherwise only be recommended in wards when performing AGPs.[53] Professor Beggs was clear that the hierarchy which prioritises AGPs is misplaced. Both Dr Warne and Professor Beggs confirmed that coughing is “*likely to produce as much or more aerosol than many procedures on the list of AGPs.*”[54] Dr Warne’s caveat that the evidence was not available at the start of the pandemic does not comfort many HCWs who observed the lack of any real distinction between AGPs and non-AGPs in the course of their work.[55] For example, Nicola Ritchie, a HCW denied FFP3, subsequently suffered LC following occupational exposure. Further, the lack of focus on airborne transmission meant that insufficient attention was paid to improving ventilation in healthcare settings.[56]

22. According to Professor Beggs it is “*common sense*” that wearing a respirator provides increased protection to a surgical mask.[57] Yet proposals to recommend widespread use of FFP3 masks were resisted at every point by the UK IPC Cell, even when PHE informed the UK IPC Cell in December 2020 that their “*understanding of aerosol transmission has changed*” and they advised a move to FFP3 masks.[58] The evidence

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[49] [4/9/10-19].
[50] [7/78/20 - 7/80/6].
[51] M2 [13/17/21-25].
[52] M2 [13/17/18-13/18/5].
[53] [INQ000474282/65] §6.14.
[54] [6/51/10-24]; [3/122/22-3/123/13].
[55] [6/51/10-24].
[56] [7/163/10-7/164/7]; [INQ000474276/106] §303.
[57] [3/137/1-3/138/15]. See also Sir Gregor Smith [11/173/12 - 11/174/15].
[58] [INQ000398244]; [INQ000398242/2]; [5/141/15- 5/142/12].

before the Inquiry suggests that concern about the "*stock availability*" of FFP3 masks was prioritised over HCW and patient protection in the formulation of IPC Guidance.[59]

23. HCWs have given evidence about the fear engendered as a result of being provided with inadequate PPE. According to Tracy Nicholls of the College of Paramedics, the response of their members to guidance to wear FRSM was "*horror actually*" and they felt like "*cannon fodder.*"[60] Nicola Ritchie, LC Physio, said "*it was quite a scary time to be working….*"[61] She communicated her concerns that they should generally be wearing more appropriate PPE to no effect. Professor Bamrah of FEHMO said "*Black, Asian and Minority Ethnic HCWs suffered disproportionately …our members are overrepresented on the frontlines of NHS care and in patient facing roles and therefore were in urgent need of the protection afforded by suitable PPE.*"[62]

24. Scandalously the lack of proper protection for HCWs persists. The current NIPCM guidelines <u>still</u> list SARS-COV-2 as being transmitted by the droplet/ aerosol route and <u>still</u> only require FFP3 masks to be worn when AGPs are performed.[63] HTM guidelines do not address the risks of transmission from airborne infectious viruses "*at all*" and "*cannot be considered fit for purpose.*"[64] As set out above the Inquiry is invited to make an urgent recommendation to address these omissions.

(ii) "Standing Up From A Standing Start" [65] – A lack of preparedness for Long Covid

25. **The long-term sequelae of SARS-CoV-2 was foreseen and discussed by decision makers at the very outset of the pandemic, yet none of the healthcare systems of the four nations planned or prepared for its effect.** Professor Whitty discussed the possibility of long-term sequelae with Matt Hancock as early as January 2020, yet it took patient advocates to obtain a response. In response to questions from the Chair, Professor Sir Gregor Smith said that they kept alive to the prospect of long term sequalae and "*watched*" for the evidence.[66] Sir Frank Atherton, CMO to Wales explained that LC "*wasn't top of the mind*", confessing it simply was not "*a priority*" early on.[67] Professor Sir Michael McBride indicated a similar lack of focus on LC in Northern Ireland when asked why the foreseeable post-viral consequences of SARS-CoV-2 were not tracked, "*I don't know how we would've undertaken that at that point*

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[59] [INQ000398244/3]; [4/43 1-14]; [5/47/11- 5/48/4]; [7/132/21-7/133/2] [INQ000398244].
[60] [9/82/8-23].
[61] [22/47/2-8].
[62] [INQ000399526/8] §24.
[63] [INQ000474276/59].
[64] [3/158/21-24]; [INQ000474276/94-95].
[65] [28/164/13-14].
[66] [11/75/15-16]; [34/56/1-7].
[67] [13/87/12-19], [13/87/19-21].

in time, and particularly as we were dealing with so many issues in responding to the pandemic."[68] There was a delay in recognising and responding to LC in all four nations. Former First Minister Humza Yousaf accepted *"that the (Scottish) Government just didn't move at a quick enough pace and that's something we have to reflect on."*[69] Professor Whitty similarly accepted that *"we probably should have been swifter off the mark in spotting LC as it emerged."*[70]

26. As the Chair observed, *"it's well-known for a virus to have sequelae, and therefore why would medical health professionals not be ready for LC."*[71] However, the healthcare sector's lack of readiness for foreseeable long-term sequelae must be considered within a broader context of under-research and under-investment into post-viral syndromes.[72] Former Cabinet Secretary of Health and Sport, Jeane Freeman, acknowledged that the prevailing mindset around post-viral conditions coming into the pandemic was one of disbelief, such that she asked to ensure that there wasn't a *"repetition of what people had experienced around ME, where for some time there was a refusal to recognise it as a physical condition and not say it was purely psychological."*[73] Yet, like ME, the LC experience is one of being maligned and disbelieved. The de-prioritisation of LC caused an inevitable delay in the healthcare system (i) building understanding about LC, (ii) taking responsibility for public health communications and (iii) effectively monitoring its prevalence and impact.

27. **A delayed and incomplete research portfolio:** in keeping with the healthcare system's overall response to LC, research was approached in a disjointed, short-term manner, which has failed to produce long-term clinical benefit for LC sufferers. Professor Brightling, who undertook the UK's first research into the post-acute symptoms of hospitalised patients with the PHOSP study, has confirmed that *"people should have been prepared,"* but LC *"didn't seem to have the same priority early on, and the scepticism that you were asking about is clearly unfounded."*[74] Professor Evans stated that there should have been more research and clinical care from the outset examining those developing LC in the community,[75] the absence of which delayed understanding of the nature of LC.

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[68] [10/137/1-4].
[69] [34/182/5-7].
[70] [12/95/17-18].
[71] [22/74/13-17].
[72] [22/74/18-22].
[73] [34/59/7-12].
[74] [22/74/23-22/75-8].
[75] [22/70/1-9]; [INQ000249062]; [INQ000292630].

28. Even once funding was committed, there were further delays in allocating committed funds to commissioned LC projects. STIMULATE-ICP for example, a study which was intended to research therapeutics for LC, suffered delays in the consideration and approval of drugs, and delays of up to 6 months for amendments by the MHRA, which can be contrasted with the much faster approval of amendments for acute Covid-19 trials such as RECOVERY and PANORAMIC.[76] Four years after its initiation, STIMULATE-ICP remains the only government funded study testing pharmacological interventions.

29. In relation to continuing research, Professor Whitty implied in oral evidence that there is ongoing further research by reference to the "*very active LC research group led by Professor Kamlesh Khunti.'*"[77] The real picture, as confirmed by Professors Brightling and Evans, is that dedicated Government funding for research into LC has stopped since February 2021. This has meant that the original portfolio of research studies that were begun three to four years ago have now come to an end, with nothing in place to build on their findings to *"have further understanding around mechanisms, around potential diagnostics, so leading you on to treatments."*[78] Professors Brightling and Evans stated that *"research for LC is very much a marathon and the UK has won the first 400 metres but has now paused."*[79] This is in stark contrast to other countries.[80]

30. **UK public health bodies abrogated their public health communications responsibilities by failing to warn the public of the risk of LC to adults and children.** The Inquiry cannot accept in any future pandemic that the risk of long-term illness and disability from a novel virus is best raised by a "*critical mass*"[81] of patients, parents, children, volunteers and charities on social media platforms. It is a catastrophic abrogation of responsibility for and leadership in public health. Public health must necessarily encompass long-term and acute disease.

31. Decision makers often cited in evidence the limited understanding of LC as the reason for not discharging their public health responsibilities on LC.[82] This approach is irrational. The pathophysiology of acute covid-19 was also little understood initially, but a precautionary approach was nonetheless taken to communicating risk. None of the public health bodies, the NHS or the Department of Health have accepted

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[76] [INQ000370954/66] §9.8; [22/106/1-9]; [INQ000421758/20] §50.
[77] [12/100/7-17].
[78] [22/102/20-23-12].
[79] [22/103/10-12].
[80] [INQ000421758/9] §§15-19
[81] [23/34/8-14].
[82] E.g. Humza Yousaf [34/142/6-14]; Professor Hopkins [7/191/9-19]; Professor Whitty [12/95/17-24].

responsibility for the dearth of public health messaging of LC. It is hard to avoid the impression that the widespread disbelief and psychologisation of post-acute sequalae affected the failure to warn the public.

32. In relation to England, NHSE claims they only have a *"limited role in disseminating public health information"* and were *"not responsible for core public health campaigns which occurred throughout the pandemic."*[83] This runs counter to NHSE's own Public and Patient Activity Communications Strategy.[84] NHSE point to the Cabinet Office and PHE as leading on the wider Covid-19 public health messaging, which was then simply incorporated into NHSE communications.[85] By contrast, PHE's evidence is that all communications handling was first led by the DHSC and then the Cabinet Office.[86] The Cabinet Office meanwhile only accepts *"playing a role"* in helping to ensure guidance was *"joined up across other government departments."*[87] Only one public health video has been published to inform the public of the risk of LC in adults on 21 October 2020, which Natalie Rogers states her members were unaware of at the time.[88] This is despite public health bodies in England having recognised the risk of LC by summer of 2020.[89] The avoidance of responsibility persists. For example, when asked what UKHSA is currently doing to communicate the risks of LC to the public, Dame Harries floundered pointing to a *"distribution of responsibility…it's more to do with different parts of the health system and the responsibilities we have."*[90]

33. UKHSA, the CMO and NHSE now defend their failures to communicate the risk of LC as a conscious decision. Professor Hopkins has said *"I think at the time, and I would say even still, we don't understand enough about LC to be able to give the right messaging…from a public health point of view it is very difficult to give a message if we don't know what we're trying to do or reduce."*[91] Professor Whitty, who heads the National Institute for Health and Care Research ('**NIHR**'), has similarly justified the absence of public health messaging by reference to the lack of a clear outcome, *"I don't think that any different messaging would have led to any different behaviours. I*

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[83] [INQ000485652/228] §§837, 840; [INQ000485652/229] §842.
[84] [INQ000470621/4].
[85] [INQ000485652] §§843, 844, 855; [INQ000474664/7] §24-25.
[86] [INQ000410867] §431.
[87] [INQ000436880] §1.5.6.
[88] [INQ000071194]; [INQ000071192]; [23/34/18-20].
[89] The need for advice on public communication of LC was recognised by the Cabinet Office as early as June 2020 [INQ000069853] , the NHS had identified the need to support patients with LC by July 2020 when the Your Covid Recovery Platform was launched [INQ000232195 § 45] and PHE acknowledged the Long-Term Health effects of Covid-19 in September 2020 in its published guidance [INQ000089708].
[90] [27/209/24-27/210-3].
[91] [7/191/9-16].

think at the point when we started off in Covid, the key – you know, what you don't want to do is overload large numbers of messages that don't lead to a particular change."[92] Professor Sir Stephen Powis has defended the lack of NHSE communications strategy on LC by saying *"Getting that balance of how we provide enough information but not too much information is important"*, despite simultaneously accepting *"in principle I am in favour of doing as much as we possibly can to ensure that the public is well informed of a wide range of medical conditions and I would include LC in that."*[93] The LCGs ask the Inquiry to question the rationality of this approach given that it led to the public being unable to make informed decisions in relation to the risk Covid-19 posed to them. The public were mis-led to believe Covid-19 would be short, mild and flu like of short duration, and left to suffer in isolation without care, guidance or information explaining their symptoms.[94]

34. In Scotland, the demarcation of responsibility for public communication is clearer, the Scottish Government led on public messaging around the pandemic,[95] yet the duty to inform the public about LC was still not effectively discharged. A small sum of £40,000 was allocated in September 2021 for a targeted LC marketing campaign in community pharmacies and primary care settings.[96] In 2022/2023, a further £10,000 was earmarked for an eight-week online campaign on LC. The Scottish Government has not explained why the original allocation of funds for public messaging was delayed until September 2021, almost one year after the SIGN guidelines on LC had been published. Further, both campaigns were ineffective. The Covid-19 Recovery Committee's LC Inquiry, which ran in January and February 2023, described still hearing *"concerning evidence"* of the lack of awareness and recognition of LC in Scotland, noting that an additional public health campaign was still needed to more effectively improve public awareness of LC.[97] This has still not materialised.

35. To date there is *still* no public health messaging on LC.[98] The LCGs invite the Inquiry to recommend this is implemented.

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[92] [12/93/16-20].
[93] [29/44/12-13] - [29/45/8-13].
[94] E.g. [INQ000492258/8] §33.
[95] [INQ000401271/166] §§12.1.1-12.3.1. PHS had a supportive role by providing data to support daily briefings, sharing information with the public and stakeholders through social media and on countering misinformation. Local NHS Boards had responsibility for public messaging in hospitals and other healthcare settings.
[96] [INQ000320569/6].
[97] [INQ000510079/4].
[98] [7/190/25-7/191/3].

36. **There was a systemic failure to collect data on the long-term effects of a novel virus, contrary to the current WHO guidance.**[99] Poor preparedness meant that neither NHSE or PHE entered into the pandemic with systems in place that were able to collect data on the long-term effects of a novel virus. This inevitably delayed their ability to discharge their separate statutory responsibilities to monitor and report on LC, such that by 2021, a note to the CMO concluded "*we are lacking robust, real time data*" and *"we are lacking clear operational and surveillance data."*[100] By April 2021 NHSE itself noted that there was still *"an urgent need for data to inform clinical management and health access."*[101]

37. The Covid-19 Data Store developed by NHSE and NHSX was designed to provide *"secure, reliable and timely data to make informed and effective decisions"*[102] but it was not established, or developed, to gather data on LC. The only data that NHSE collected on LC in England was SitRep data, which commenced in January 2021 and later, the National Patient Registry.[103] Whilst these were effective sources for measuring the impact of LC on <u>*patients*</u> of the LC services, this data collection was delayed and limited. Both datasets rely on data derived only from the LC Assessment clinics and so do not show national prevalence. The LCGs note that NHSE's ongoing stocktake of data on LC is also limited to data collected around LC services.[104]

38. Primary care records have not been a reliable source of prevalence data on LC due to poor clinical coding.[105] A study published in July 2021 concluded that LC in primary care was low compared with other reports of LC prevalence.[106] The RCGP acknowledged this, reporting to the LC Ministerial Roundtable that improved coding was one of the three key areas for its work on LC,[107] but in oral evidence Dr Mulholland could not answer whether this had now been remedied.

39. Professor Hopkins accepted that PHE and UKHSA have not themselves collected data on LC, noting that the current *"predominant data collection for LC is happening in the NHS, in the NHS-funded clinics."*[108] The data gap on prevalence of LC remains

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[99] WHO Policy Brief: Covid-19 surveillance, 10 December 2024. Available online at: https://www.who.int/publications/m/item/who-policy-brief-covid-19-surveillance.
[100] [INQ000283397/1,6].
[101] [INQ000283438/29].
[102] [INQ000409251/97].
[103] [INQ000283438/29, 32].
[104] [INQ000474664/4] § 11.
[105] [7/224/11-18].
[106] [INQ000283458/13].
[107] [INQ000061094/1].
[108] [7/225/3-5].

unfilled. Concerningly, Professor Hopkins was unable to outline any plans that UKHSA have, to ensure their responsibility to collect data on LC is met in the future.[109]

40. Public health bodies relied on the ONS Coronavirus (Covid-19) Infection Survey ('**CIS**') to fill the data gap on prevalence of LC.[110] However, the ONS published its final regular CIS report on prevalence of LC in the four nations in March 2023, and its last Winter CIS data on prevalence of LC in England and Scotland in March 2024. The halting of the ONS surveys and the inability of public health bodies to collect reliable prevalence data on LC themselves, renders it impossible for the UK's healthcare system to effectively model current and future LC service provision. This data gap also limits overall understanding of the scale of LC as a public health concern.

(iii) Patient advocacy raised the alarm on the long-term effects of Covid-19[111]

41. **The gap in public health authorities' response meant that it was left to patients and individual clinicians to raise the alarm**. In April to May 2020, as the weeks passed since the first infections in the UK, patients started reporting on social media that they were not recovering from Covid-19. Patients formed advocacy groups to campaign for recognition from early May 2020.[112]

42. Natalie Rogers, LC Support said that "*…many patients were met with complete disbelief that they could possibly still be suffering the ongoing effects of the virus. If they were believed, as you said, there weren't any known services to refer in to, there was a lack of knowledge and understanding of the symptoms that patients were experiencing amongst GPs…*"[113] Natalie Rogers explained that for her and many others coming across the LC Support Facebook group became a "*moment of enlightenment….because there was just story after story of people going through similar experiences…*"[114]

43. Many witnesses have described the relief they experienced in finding peer support in the LCGs. Dr Sarah Powell, a clinical psychologist working with deaf people, said that she joined a group on Facebook for LC around July 2020 and "*at last I felt that I was*

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[109] [7/226/14-24].
[110] [7/222/18-25].
[111] [INQ000249034].
[112] [INQ000370954/12].
[113] [23/28/6-14].
[114] [23/32/16-18].

in a community that understood my symptoms…"[115] Nicole Ritchie also joined LC Physio in January 2021, stating that she joined "*for peer support."*[116]

44. The LCGs were a source of recognition and support for previously isolated LC patients. They were forced to raise awareness about LC through campaigns and correspondence to key decision makers and amongst the general public.[117] In July 2020, LC SOS wrote a letter to the Prime Minister, the Secretary of State for Health and Social Care and Chief Executive of NHSE and other key decision makers across the four nations on behalf of "*thousands of forgotten victims."*[118] Natalie Rogers explained that people with LC felt "*invisible because there was no public health messaging…"*[119] The WHO was one of the first to listen: at a meeting with WHO on 21 August 2020, Director General Dr Ghebreyesus personally acknowledged the work of LC patients and the need for recognition, guidelines, research and ongoing patient input.

45. Professor Powis said that the long-term effects of Covid-19 were brought to his attention by LC SOS who wrote to him in August 2020. This led to a meeting on 11 September 2020 and it was "*a turning point"* for him in terms of LC. He remembers in graphic detail that they said "*they were having difficulty getting clinicians to believe or understand their symptoms and whether this was actually a thing."*[120]

46. Similarly, in September 2020, LC Kids published "My Unhappily Ever After" a powerful and moving oral testimony direct from children of the debilitating impact their persistent symptoms were having upon them.[121]

47. While NHSE responded to patient concerns about the long-term sequelae of Covid-19 in adults, formally commissioning guidelines at the end of September 2020, there was lost time and opportunity because they had not been proactively monitoring the signs and symptoms of long-term sequelae of Covid-19. The reluctance to proactively communicate the risk of and identify the long-term sequelae of Covid-19 developed the culture of scepticism amongst clinicians to patients reporting the long-term symptoms of Covid-19, particularly in children, which persists to this day. LC SOS'

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[115] [21/7/23-24].
[116] [22/54/10].
[117] [INQ000370954/20].
[118] [INQ000238582/1].
[119] [23/35/12-18].
[120] [28/164/18-28/165/2].
[121] [INQ000272195].

survey of patient experiences documented experiences of being dismissed or minimised as patients were told "*post covid doesn't exist…*" or "*dismissed my symptoms as mere anxiety*" and "*symptoms varying in intensity (i.e. peaks and troughs) meant it couldn't be viral…*"[122]

48. The advocacy by patient advocates in England was critical to ensuring adequate service provision for LC. For example, Professor Powis said "*[The LCGs] made it very clear to me that what they didn't want was to go pillar to post, from one service to another service, because they had a range of conditions affecting different parts of the body, they wanted a holistic, joined-up service. And they wanted this to be a specific service.*"[123] This enabled NHSE to design a service provision drawing on the need of LC patients for access to multi-disciplinary teams.

49. Following on from the formative campaigns for recognition of LC, the LCGs continued to play a crucial role in steering the response to LC including campaigning for: data collection on impact and prevalence, funding for research, improved service provision and occupational support for HCWs and other LC patients.[124] An example of an area where patient advocates played an instrumental role in improving the response to LC was in relation to the campaign for data collection on LC to monitor both prevalence and impact. Natalie Rogers stated "*...if you don't measure what's going on you can't plan to deal with it. It's hidden…*"[125] In September 2020, a social media campaign #CountLongCovid was started. The LCGs also raised the need for data collection on LC at the LC Ministerial Roundtables and in direct correspondence and subsequent meetings with the ONS.[126] Following the LCGs input, ONS published its first estimates on LC in April 2021.[127] The data gathered by ONS came to be relied on extensively across the four nations to inform service provision and the public health response to LC. Yet these achievements have been undone since the ONS study concluded as there is no ongoing monitoring of the prevalence and impact of LC as set out above at §40.

50. In England, the input of patient advocates was formalised through representation at ministerial roundtables hosted by Lord Bethell and at the NHS Covid-19 Taskforce. While initially a useful forum, the meetings lacked a clear purpose. Further, despite

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[122] [INQ000370954/14].
[123] [28/165/16-21].
[124] [INQ000370954/30].
[125] [23/53/19-21].
[126] [INQ000370954/30-31].
[127] [INQ000370954/31].

the presence of Government ministers, the policy changes advocated by the LCGs were not implemented.[128] The concerns that the LCGs have raised in these submissions at §§41-49 have been raised before with relevant decision makers through and outside of these forums.[129] Unnecessary suffering could have been avoided if they were heard.

51. The pattern of delay and reactive response to patient advocates is replicated across the four nations, however, the input of patient advocates was not formalised in the devolved nations. Welsh LC patient advocacy groups met with the Welsh Government in February and March 2021 to explain how the response to LC was leaving patients falling through the gaps in services.[130] There was no record of the Scottish Government meeting with LCGs until November 2021 when then Health Secretary, Humza Yousaf began meeting with LCGs including LC Kids. Humza Yousaf recognised "*how valuable those interactions with LC representatives and those with lived experience were…*"[131] It was only in August 2022 that the National Strategic Network in Scotland established a formalised system for people with lived experience to contribute to the development of pathways for care and support.[132] There should have been a formalised system in each nation for patient advocates to contribute their lived experience and inform the healthcare response to LC.

(iv) Unprepared and Inadequate – Long Covid Healthcare

52. **The Inquiry must find based on the evidence that the UK healthcare systems response was inadequate and access to LC services remains inequitable.** The healthcare systems across the four nations were not prepared to respond to the significant number of people suffering from a complex, multi-system disease which causes long-term ill health and disability. Each nation needed to invest significant funding, guidance and dedicated support as the existing infrastructure lacked the knowledge and capacity to respond to the demands of LC care. Provision of funding and support to date have not been sufficient to meet demand.

53. **Primary care response:** before July 2020, GPs were reporting to RCGP that patients were suffering from the prolonged symptoms of Covid-19. In an RCGP survey carried out between August to September 2020, 81% of GPs reported needing more guidance

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[128] [INQ000370954/35] §4.7.
[129] [INQ000370954] §§3.3, 3.10, 3.12, 3.16-3.17.
[130] [INQ000469207]; [INQ000469224].
[131] [34/180/23-181/3]; [INQ000327754].
[132] [INQ000474595/4].

on how to treat LC symptoms.[133] Despite often being the first point of contact for people with LC, GPs lacked any information. Dr Mullholland stated *"..it was difficult to diagnose some of the longer-term symptoms of Covid-19 at this stage due to the lack of guidance and information."*[134] In response, RCGP wrote a 'top tips' document for GPs, requested NHSE commission NICE to publish guidelines for LC and developed e-learning modules and webinars.[135] GPs are an important element of the pathway for LC care and to ensure access to LC services.[136] Critically, the NHSE was not proactive in ensuring GPs were adequately informed about the signs and symptoms of LC. Despite the best efforts of the RCGP and a time limited NHSE Enhancement Service Specification for GPs,[137] a study by Healthwatch England in May 2022 reported that many GPs were still unsure of or dismissive of LC symptoms and did not know if there was a LC specialist clinic.[138]

54. **Investment in services**: as set out above at §§47-48, time was lost in England as the NHSE waited until patient advocates raised the alarm before Professor Powis prepared his five-point plan to commit resources, guidance and research into LC.[139] Outside of England, the Devolved Nations were even slower to commit the necessary resources and provision has not been sufficient to meet need. The delay in the Devolved Nations cannot be attributed to lack of knowledge:

    I. **In Scotland,** although discussions about the need for guidance on LC began in 2020, it was only in September 2021 that Humza Yousaf created a £10 million LC support fund to give health boards the additional financial resources they needed to support those suffering from LC.[140]

    II. **In Wales,** ministerial advice noted that people with long-term effects of Covid-19 would need rehabilitation services in May 2020.[141] Yet, only £200,000 was agreed for support for community pathway guidelines in October 2020.[142] It took a further eight months before significant – and necessary - funding amounting to £5 million was committed in June 2021.[143]

    III. **In Northern Ireland,** the Minister of Health, Robin Swann, requested a clinical working group to examine the needs of those recovering from Covid-19 in July

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[133] [INQ000339027/33].
[134] [INQ000339027/33] §196.
[135] [INQ000058981/1]; [INQ000061094].
[136] [21/85/4-20].
[137] [INQ000470536]; [INQ000193524].
[138] [INQ000381156] §30; see also [INQ000272247].
[139] [INQ000470495].
[140] [INQ000365756/2]; [INQ000320569/7].
[141] [INQ000235893].
[142] [INQ000361635].
[143] [INQ000145131/1].

2020. Dedicated funding of £1 million and the establishment of a LC clinic were announced a year later in June 2021,[144] but it only became operational in November 2021.[145]

55. In the absence of dedicated funding and support for healthcare services, people with LC were left without the care they needed. In Scotland, one LC service had to close because it was unable to meet demand due to a lack of funding.[146] Jeanne Freeman suggested that only one clinic was affected in this way,[147] yet reports found that other health boards were reluctant to promote LC services "*for fear of being overwhelmed…*".[148] Humza Yousaf accepted that before dedicated funding was provided for LC services in Scotland there was a *'postcode lottery'* and he added that "*to this day there is still feedback from those with LC that they feel there is still not as consistent a level of services as they would like to see.*"[149]

56. Adequate funding for dedicated services remains a pressing concern.[150] In England, some Integrated Care Systems are repurposing funding and instructing LC services to close contrary to the NHSE commissioning guidance.[151] Sir Sajid Javid agreed that dedicated funding was needed to maintain the level of services directed by the commissioning guidelines noting that this was "*justified*" because of the number of people living with LC.[152]

57. **Need for dedicated services:** the variation in service design within and across the four nations was a major impediment to achieving equitable access to healthcare. In England and Northern Ireland, LC clinics were accepted as the appropriate model for provision of care (although there was an inordinate delay in Northern Ireland to their creation).[153] Wales actively resisted creating dedicated LC clinics and committed to the provision of integrated services instead while Scotland left the decision to the discretion of the Health Boards (some established LC clinics and others established care pathways).[154]

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[144] [INQ000348831/2].
[145] [INQ000348832].
[146] [INQ000421758/13].
[147] [34/60/20-34/61/1].
[148] [INQ000421758/13].
[149] [34/148/4-12].
[150] [INQ0000421758/38] §111; [21/61/1-5].
[151] [INQ000498103/1].
[152] [38/125/3-24].
[153] [INQ000421758/13-14] §31.
[154] [INQ000421758/13] §28.

58. Professors Brightling and Evans have described LC as a complex condition which requires multi-specialist input. It was unknown how the long-term sequelae would manifest and Professor Brightling was clear that they have "*learnt a lot over the first few years since the beginning of the pandemic*"[155] notably that the gold standard of care is a specialist clinic with clinical supervision, input from multi-disciplinary teams and early development of specialist knowledge.[156] Professor Brightling said that LC clinics provided a "*meeting where you've got the expertise of all these different professionals...... and you then bring in that extra expertise that you need through virtual meetings, and so that we're not sending people for multiple appointments.*"[157]

59. There are other advantages beyond the immediate benefits to patients. They maximise opportunities for training of doctors and other professionals. Professors Brightling and Evans observed (when discussing the service provision in Wales) that there are knock on implications for training if there "*isn't a group of specialists that are then actually evolving the subject area and it also then becomes a barrier for research and taking things forward...*"[158] Further, LC clinics also provide a base in which medical professionals can look at new diagnostics, new disease understanding and new therapies.

60. The expert evidence is consistent with early guidance on long-term symptoms of Covid-19. The NICE/ SIGN/ RCGP guidelines on the long-term symptoms of Covid-19 recommended that service organisation should "*provide access to multidisciplinary services (these could be 'one-stop' clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations. They should be led by a doctor with relevant skills and experience and appropriate specialist support, taking into account the variety of presenting symptoms...*"[159]

61. Former Welsh Health Ministers Vaughan Gething and Eluned Morgan defended the Welsh approach saying that the model was premised on "*convenience*" to prevent people having to travel to secondary care centres and a desire not to "*over medicalise.*"[160] Whilst accessibility of care is a laudable objective, the result was that people with LC could neither access appropriate care near their home nor further afield.

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[155] [21/78/20-22].

[156] [INQ000421758/26] §74; [21/81/18-20]; [21/82/10-18]; [21/96/10-21].

[157] [21/82/10-18].

[158] [21/91/8-14].

[159] [INQ000272222/22].

[160] [INQ000353884/3] §11; [35/49/11-25]; [35/51/19-25]; [35/159/1-7].

Only 3.5% of people with LC in Wales were referred to secondary care services.[161] This small percentage is unreflective of the true demand for secondary care for people with LC.

62. Contributors to Every Story Matters ('**ESM**') explained that "*the main support offered for LC symptoms was being referred to a LC clinic.*"[162] In nations or regions without LC clinics, there were reports of barriers to accessing care:

> "*In Wales in particular, the LC services have been a bit of an after-thought. There isn't a really good LC clinic like you've got in England, you know? You've got the one consultant in Cardiff doing her best. She had to start that service for LC in her own time, it wasn't an official service at all, and she hasn't really been supported with it either.*"[163]

63. The lack of clear direction in Scotland similarly impacted LC patients. Scottish contributors to ESM reported delays of up to 2 years before LC clinics were set up in Scotland noting that "*..and you were hearing from America and they had clinics and England had clinics and we had nothing…*"[164] Former Health Secretary, Humza Yousaf, suggested that the Scottish Government resisted pressure to instruct Health Boards to create dedicated LC clinics because of anecdotal accounts that the English LC clinics were "*essentially creating a middleman where people would go to a LC clinic for assessment and generally be seen with relative speed and ease, they were then being referred on to the appropriate department …..to me that was just creating an additional stage and step….*"[165] Instead the choice of creating dedicated LC clinics was left to the discretion of the Health Boards.[166] Humza Yousaf also suggested that the closure of LC clinics in England was supportive of the Scottish approach - without recognising that those closures were due to funding restrictions as opposed to the relative merits of the structures.[167] He also overlooked the value of the LC clinics in co-ordinating care between many disciplines.

64. Further, and contrary to Humza Yousaf's suggestions, research commissioned by the Scottish CSO found that the advantages of dedicated LC clinics and services outweigh those presented by LC care being integrated into existing services. The study "LOCO-

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[161] [INQ000480089/1].
[162] [INQ000474233/181].
[163] [INQ000474233/184].
[164] [INQ000474233/184].
[165] [34/147/1-14].
[166] [34/147/10-14].
[167] [INQ000498103/1].

RISE: LC rehabilitation in Scotland: an evaluation" concluded that *"dedicated LC services may be better for delivering LC rehabilitation than attempting to integrate LC rehabilitation in pre-existing services."*[168] The study found that "*community rehabilitation services have much to offer people with LC but their delivery is complex and presents multiple challenges*" and that "*barriers to LC rehabilitation included managerial and organisational uncertainty and inertia, most evident in integrated services*."[169] The study noted the correlation between publicity of dedicated services and increased demand which "*outstripped rehabilitation capacity."*[170] In the absence of appropriate service provision, people with LC were being forced to pay for private healthcare services and/ or suffer without clinical supervision and management of their symptoms.[171]

65. **Variation in services:** where LC clinics exist, patients report variation in quality. The LCGs benchmark for LC clinics includes: "*a one-stop shop with a mix of specialities, professionals allied to healthcare and, importantly, a point of contact for the patient…"*[172] These criteria are consistent with those listed in the NHS Commissioning Guidelines which establishes the minimum standards expected for those services.[173] Despite these clear standards, the LCGs report a "*significant divergence in the standard and nature of service provision."*[174] Some clinics are medically led and have in-house access to multiple specialists, others do not, affecting the services and advice available to patients. While there has been some recognition of these problems for example through the publication in July 2022 of the NHS Plan for improving LC services,[175] the LCGs confirm that "*these observations remained accurate throughout the relevant period and continue to be so to date."*[176] Consistent with their reported concerns, the LC experts reported that only 16% of LC services offer the highest level of service in terms of complexity of assessment and available intervention.[177]

66. Professor Powis admitted in evidence that he was so concerned about "*too much variation*" that he had asked NHSE to undertake "*a stocktake of the existing services."*[178] Professor Powis agreed that there needed to be a focus on provision of LC care as a pre-existing service addressing post-viral conditions would give NHSE more resilience

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[168] [INQ000468128].
[169] [INQ000468128].
[170] [INQ000468128].
[171] [INQ000474233/180].
[172] [INQ000283496/8]; [INQ000370954/41] §4.22.
[173] [INQ000283496/8].
[174] [INQ000370954/40-41] §4.21; [INQ000272247].
[175] [INQ000238590].
[176] [INQ000370954/43] §4.24.
[177] [INQ000421758/34] §98; [INQ000421758/30] §81.
[178] [28/168/6-23].

in a future pandemic.[179] The NHSE review should ensure ringfenced and sufficient funding as well as concrete action to remedy inconsistencies in access to and standards of services.

67. It is imperative that LC services are funded. The UK government and devolved nations should ensure equitable access to dedicated, multidisciplinary, clinician-led LC clinics as recommended by WHO. Dedicated funding for LC services should be ringfenced beyond 2025. Pandemic planning should include pre-planned approaches for creating scalable specialised services for the assessment and care of the long-term sequelae of a novel virus

(v) The healthcare system was reluctant to accept that Covid-19 can harm children

68. The UK approached the pandemic with an unfounded belief that SARS-CoV-2 would not adversely affect children. **Initial focus on the response to the virus centred on adults, to the exclusion of children, which led to reluctance, delay and disbelief in accepting the significant and enduring impact Covid-19 has on CYP, including death and injury from Long Covid and Paediatric Inflammatory Multisystem Syndrome ('PIMS').**[180] Sammie McFarland on behalf of LC Kids told the Inquiry "*In the UK, throughout 2020, there was no information published by the Government stating that children and young people could have any, let alone have debilitating, symptoms from Covid-19 and LC. Early public health statements suggested the contrary, that Covid-19 posed only a minimal risk to children. In LCK's experience, this meant that when our families sought assistance for children suffering from harmful symptoms, they were routinely dismissed and unable to access healthcare.*"[181]

69. The most recent CloCK study indicates that prevalence of LC amongst CYP respondents is at around 7%, with 30% of those CYP with LC not recovering after 2 years.[182] Even for those CYP that do recover within 2 years, the associated loss of education, daily function and development can have a lasting impact. The LCGs note with concern the absence of an expert report on paediatric LC in this module, and the Inquiry's reluctance to indicate that this expertise will be sought in Module 8.

70. The healthcare system's delayed recognition of LC in children was exacerbated by the lack of public acknowledgement of LC occurring in CYP. Instead of taking a

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[179] [28/168/11-25];
[180] [INQ000370954/49] §§5.14 - 5.15.
[181] [INQ000370954/46] §5.6.
[182] [INQ000474714].

precautionary approach, the OCMO put out a statement minimising the harm that Covid-19 had on children, before studies into LC in children had even started. On the 23 August 2020 the OCMOs stated that *"overall consensus is that children…definitely have a much lower rate of hospitalisation and severe disease…very few, if any, children or teenagers will come to long-term harm from Covid-19 due solely to attending school."* [183] Dame Harries was unable to answer why the OCMO had failed to publish a subsequent public statement informing the public and parents of the risk of LC in CYP.[184] The OCMO's public minimisation of the risk of LC to CYP perpetuated dominant and dangerous assumptions about CYP and Covid-19, which in turn continues to prolong the disbelief, misdiagnosis and inaccessibility of healthcare for CYP with LC.[185]

71. In Module 2 Sir Chris Wormald stated unequivocally that *"whatever we knew and the NHS knew about LC was put in the public domain."*[186] The evidence in Module 3 demonstrates that in relation to children, this is incorrect. Meeting records reveal that in April 2021 DHSC were concerned that patient advocacy groups had produced materials for schools on the risk of LC to children which they saw as requiring *"reactive communications."*[187] In a further meeting in July 2021 the minutes note that *"messaging should focus on reassuring people that occurrence of LC in children is rare."*[188] Thus rather than informing parents and schools of the real risk posed by LC, DHSC minimised the risk, as the OCMO had done previously. To date, there has been no public health messaging campaign on LC in CYP.

72. Further, the impact of LC in CYP has been minimised by comparing its prevalence, to the prevalence in adults. The recent CLoCK study has confirmed however, that LC is different in CYP to adults and so requires a child-centred approach. Adult studies and indicators cannot accurately be used to determine policy and services for CYP.[189] Professor Evans has said *"there was even more delay for children and young people"* in understanding and delivering LC healthcare.[190] This delay still persists. Professors Brightling and Evans reported that by the end of July 2023, only 1,265 CYP had been assessed by LC services in England. The vast majority of CYP are therefore not accessing specialist paediatric LC healthcare.

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[183] [INQ00070464].
[184] [27/211/1-25].
[185] [INQ000370954] Section 5.
[186] M2 [17/168/18-25].
[187] [INQ000283437].
[188] [INQ000283463].
[189] [INQ000474714].
[190] [21/100/20-25]; [32/138/18-22].

73. **Paediatric LC services were delayed and inadequate.** The provision of guidance and the creation of services for CYP with LC lagged behind adults. The NICE guidelines on LC were first published in December 2020, but it wasn't until November 2021 that they were reviewed to include evidence on children and young people. The provision of services remains patchy, with several now at risk of closure, despite the warning in a recent joint letter from the Clinical Post Covid Society and the British Society of Physical and Rehabilitation Medicine that depriving children of LC services can cause stunted biophysical development.[191]

74. Children under 16 in Northern Ireland and Wales still have no specialist paediatric services for LC. As of summer 2024, four and a half years after the first Covid-19 infection, only one clinical care pathway for children with LC had been published, in just one of 14 health boards in Scotland.[192] Similarly in Wales, the one LC pathway for CYP that had been developed by one Welsh Health Board, has now been shared with the other Health Boards. The paediatric services that are now in place in England are under threat, with several having already closed and more likely to follow suit. This is because demand for LC services is being incorrectly assessed. NHSE is relying on numbers being referred into LC services to determine demand, despite acknowledging the limitations of this approach given non-uniform referral rates by GPs, an enduring lack of knowledge of LC and continuing mis-diagnosis of LC.[193]

75. It follows that the reality for CYP on the ground is a long way from the dedicated specialist paediatric multi-disciplinary clinics recommended by the Inquiry's experts and in the medical literature.[194] The ongoing, harmful delay in responding to LC in CYP was compounded by the institutional minimisation of the risk of LC. This is despite the acceptance by Dame Harries that the risk of LC to CYP is *"well-known amongst the medical profession and among health services."*[195]

(vi) The healthcare system failed to take a preventative approach to Long Covid

76. Witnesses to the Inquiry have repeated the slogan *'Stop Covid, Stop LC'* as a definitive answer of how best to respond to LC. **The focus on acute Covid-19 alone fails to take a preventative approach to the specific risk posed by LC.** The public have not been informed that all adults and children are at indiscriminate risk of LC, of the possibility of experiencing protracted symptoms, or of what those extended symptoms

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[191] [INQ000498103].
[192] [32/138/24].
[193] [29/42/15-18].
[194] [21/132/5-17].
[195] [27/212/7-10].

might be. This lack of information affects people's ability to take self-protective measures against the transmission of Covid-19. It also means that people are less likely to identify the symptoms of LC if they present. Professors Brightling and Evans have recommended that *"to improve 'access' to LC clinical care, the first step is to improve awareness of the general public equitably about LC, to enable people to recognise their ongoing symptoms and to encourage seeking healthcare when needed."*[196]

77. Beyond the one public health video on LC in adults, most of the public information that was available required individuals to have prior knowledge of LC, to know the extended symptoms of acute Covid-19, in order to understand that their protracted symptoms could be attributed to Covid-19 infection. Professor Powis points to the Your Covid Recovery website as a central source for specific information on LC,[197] describing it as a *"rehabilitation platform"* to help people recovering after infection with Covid-19.[198] The LCGs have provided detailed evidence of the failings of the Your Covid Recovery Platform, which they consider to be *"unfit for purpose"*[199] and damaging. The experts describe it as a *"light-touch information-sharing platform and really aimed at those probably at the milder end of the LC spectrum."*[200] In any event, for someone to navigate to the YCR platform, they would have had to know they are suffering from LC (we further note that the YCR website is now defunct).

78. The primary available information mis-informed the public about Covid-19's symptomology in the acute phase, making it harder for individuals with LC to identify the disease they were suffering from, particularly when testing was limited. The NHS.uk website was the first port of call for most people, yet it was not updated to be consistent with the symptomology understood by NICE, DHSC, PHE/UKHSA, NHSE and the Cabinet Office, contrary to the assertion by Professor Powis.[201] Until April 2022 the site continued to describe acute Covid-19 as short, mild and flu-like with only limited symptoms of fever, cough, shortness of breath and loss of taste/smell. The absence of clear, accurate, timely information about the acute wider symptoms of the virus prevented the public from recognising that their illness was Covid-19, and consequently, from taking steps to reduce their transmission of the virus. Natalie Rogers describes '*from the very early days there was a pervasive and damaging misconception...that*

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[196] [INQ000421758/29] §79.
[197] [INQ000474664/7] §27.
[198] [INQ000485652/235] §870.
[199] [INQ000370954] §4.10-4.19.
[200] [22/80/9-22].
[201] [INQ000474664/7] §25.

Covid was going to be a very short, mild, flu-like illness."[202] Professor Powis's post-hearing supplementary statement attempts to address this but incorrectly conflates acute Covid-19 with LC symptoms.[203]

79. Similarly, Professor Whitty, Professor Hopkins, Dr Phin and Dame Harries have confirmed their understanding that vaccination reduces the severity and impact of LC.[204] Vaccination was a key measure introduced to protect the population, yet its preventative property against the indiscriminate risk of LC did not form part of a public health communications plan to encourage vaccine uptake. Again, otherwise healthy adults, young people and children, do not know that vaccination can protect them from the risk of LC. In his evidence, Professor Whitty accepted that this was an oversight, *"arguably, we could have added that in, the point about reducing the risks of long-term sequelae."*[205]

IV. THE UNEQUAL BURDEN OF LONG COVID

80. **LC has both exacerbated pre-existing inequalities and created a new cohort of disabled people.**

81. **Creating inequalities:** The ONS CIS Survey reported in April 2024 that of the 1.5 million reported that their day-to-day activities were "*adversely affected*" and 381,000 "*limited a lot.*"[206] A significant proportion of people with LC have been disabled by the condition, are no longer able to live and work as they used to. The incidence of LC is higher in more deprived areas, for people aged 35-69 years and of white ethnicity.[207] Women are also disproportionately affected by LC.[208] Children with LC remain overlooked despite the significant impact on childhood. Despite these inequalities no work has been undertaken to consider how to mitigate the impact of LC on these groups.

82. **Exacerbating inequalities:** there are existing underlying inequalities in the healthcare system. Thus, disparities in access to care and support arise from multiple and intersectional barriers including sex, age, immigration status, digital literacy, language barriers and different health seeking behaviour. Examples of how pre-existing inequalities are exacerbated in the context of LC are abundant: women frequently

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[202] [23/24/14-17].
[203] [INQ000474664/8] § 29.
[204] [27/209/17-21]; [26/57/5-12]; [12/101/20 – [12/102/18]; [7/191/20-22].
[205] [12/101/20] – [12/102/18].
[206] ONS 25 April 2024 Winter CIS (s*upra* 23).
[207] [INQ000231669] (M2 Disclosure); [INQ000421758/29,32] §§79, 87, 91; [INQ000370954/69] § 10.6
[208] [INQ000421758/32] §88.

experience their symptoms being dismissed or misdiagnosed as menopause or mental health conditions;[209] vulnerable older people with LC have their symptoms dismissed as ageing;[210] British Sign Language ('**BSL**') users cannot access information in BSL about LC;[211] migrant health workers have reported being labelled as 'hypochondriac' and diagnosed with anxiety forcing them back into work despite suffering debilitating symptoms of LC.[212]

83. Another significant gap remains in relation to people with intellectual disability. Dr Lade Smith, Royal College of Psychiatrists, stated that members have reported that "*sufficient and systematic longer term LC monitoring has not been carried out for people with intellectual disability,"*[213] and called for "*research into LC, particularly for its impact on vulnerable and neglected groups."*[214]

84. Further, geographical variation persists with waiting times varying significantly between regions. More deprived areas remain significantly underserved by LC services in sharp contrast to the higher rates of LC reported within them.[215]

85. **The data blind spot:** there remain concerns that people with LC from diverse ethnic backgrounds may be hidden from the data. Professor Evans said that a major factor limiting understanding of health inequalities is data from clinical healthcare records. They suspect that the data of people accessing LC clinics does not represent the general population.[216] Professor Bamrah said FEHMO is concerned about the absence of data on the impact of LC on BAME HCWs as they know that "*many ethnic people were actually struck by LC and the absence of that data certainly worries us..."*[217] Understanding of the prevalence of LC amongst different ethnic minorities has been stymied by the compounding lack of data on both ethnic minorities and LC.[218] This means even to this day, there is a lack of clarity on the prevalence of LC amongst ethnic minority communities. The Final Report on Progress to address Covid-19 health inequalities published by the Race Disparity Unit, Cabinet Office in December 2021

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[209] [INQ000370954/69] §10.6.
[210] [INQ000319639/25].
[211] [INQ000421866/4].
[212] [INQ000474298].
[213] [INQ000417461/59].
[214] [INQ000417461/60].
[215] [INQ000370954/68] §10.3.
[216] [21/115/10-25].
[217] [18/14/5-22].
[218] [18/14/5-22].

recognised that there was a need to improve collection and coding of ethnicity coding and LC codes to address this gap.[219]

V. 'A SCARY TIME'[220] – THE HEALTHCARE SYSTEM FAILED IN ITS REGULATORY DUTIES TO PROTECT ITS WORKFORCE

86. The healthcare workforce has been lauded as the greatest asset of the NHS, yet the Inquiry has negligible evidence of any real steps taken by employers, ministers, the DHSC and the Health and Safety Executive ('**HSE**') to mitigate the impact of LC on HCWs. Patricia Temple explains simply *"we expected the NHS and management would look after us as required. I fear they failed to do so."* **The three key systems that should have been mobilised to monitor and properly protect HCWs from LC, (i) risk assessments (ii) RIDDOR reporting and (iii) data collection on HCWs, all failed.**

87. Firstly, in relation to risk assessments, the Government diluted longstanding statutory protections created for worker safety. Employers have a statutory duty to assess all risks posed by Covid-19 to workers, including the risk of developing LC.[221] Despite this requirement, the evidence shows that risk assessments in the healthcare sector of all four nations did not routinely account for Covid-19, and the risk of developing LC.[222] As a result, risk assessments failed to recognise the need for adequate PPE, improved IPC measures like enhanced ventilation, air filtration systems and routine use of respirators in healthcare settings. This moved the burden from the employer to the individual, with HCWs left to ask for appropriate respiratory protection.[223] For example, Patricia Temple stated: *"I believe that I caught Covid at work due to a lack of appropriate PPE, and the lack of appropriate management support, such as a guided risk assessment that considered my age and clinical vulnerabilities and which actually asked whether I was aware of the risks and willing to continue."*[224]

88. Instead of taking steps to ensure the risk posed by Covid-19 to each worker was properly assessed, the Prime Minister's 'Living with Covid' plan of February 2022 *removed* the health and safety requirement for every employer to consider Covid-19 in their risk

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[219] [INQ000089747/ 23,39]; [INQ000215534/31].
[220] [22/47/4].
[221] Regulation 6 of the Control of Substances Hazardous to Health Regulations 2022 and Regulation 3 of the Management of Health and Safety at Work Regulations 1999 has required employers to assess exposure to SARS-CoV2, and to identify steps to control this risk, as it is classified as a Hazard Group 3 biological agent.
[222] [INQ000269869] § 3.31.
[223] [21/114/9-17].
[224] [INQ000486012/5] § 20.

assessments. This approach conflicts with employers' statutory duties and leaves workers vulnerable to the known risks of Covid-19 such as LC, as the TUC warned at the time.[225]

89. The RIDDOR reporting system is the second mechanism that failed in the context of Covid-19, to fulfil its aim of providing accountability and a public record of work-related injuries to regulate risk in the workplace. Accurate RIDDOR reporting is crucial to understanding *"how infection spreads within healthcare settings and how to better protect staff and patients,"*[226] and it is a legal requirement for employers to report instances of workplace-acquired Covid-19 infections, yet there was systematic under-reporting of Covid-19 in all four Nations.[227] The House of Commons Work and Pensions Select Committee were aware of RIDDOR under-reporting as early as June 2020 and were not persuaded that HSE was going *"far enough or fast enough"* in their efforts to tackle it.[228] Many employers actively delayed and discouraged RIDDOR reporting of Covid-related illnesses citing reasons of administrative burden.[229] Professor Banfield, for example, gave evidence that the BMA *"did a survey of over 600 people with LC and a large proportion of them said that they had asked for their Covid to be reported under the RIDDOR's reporting mechanism and it had been declined."*[230]

90. It is against this context of a confused and ineffective approach to RIDDOR reporting, that the HSE's evidence on reporting of LC needs to be considered. The LCGs are concerned that the Regulator mis-understood the nature of LC in its evidence that *"as LC occurs later it is not reportable."*[231] In this statement Richard Brunt incorrectly separated LC from Covid-19, contrary to HSE's own publicly stated understanding of LC as persistent symptoms that develop *during*, and not distinct from, acute infection of Covid-19.[232] Moreover, his evidence incorrectly suggested that developing LC from infection in a workplace does *not* trigger RIDDOR reporting requirements. On a plain reading of the statute, a diagnosis of LC where there are reasonable grounds to attribute it to occupational exposure of Covid-19 is reportable under Regulation 9(b) of RIDDOR.[233] This is expressly confirmed at §427 of Richard Brunt's statement, and suggested at §430 where he recorded that HSE have received 36 RIDDOR reports

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[225] [INQ000250961].
[226] [INQ000477304] § 290.
[227] [INQ000192256]; [INQ000400723 § 104]; [INQ000119177_0004].
[228] [INQ000192256] § 250.
[229] [INQ000119177/4]; [INQ000255782] § 3.10; [INQ000492279] §§ 39-43.
[230] [21/147/21] – [21/148/3].
[231] [INQ000347822] § 426.
[232] [INQ000269715/14] §1.3.
[233] [INQ000347822] § 427.

relating to LC. HSE's own interim report confirmed that the classification of SARS-CoV-2 as a biological agent under COSHH Regulation 9 means that *any* incident involving the virus is reportable under RIDDOR when it involves occupational exposure.[234] The LCGs are concerned that the position regarding LC was not presented accurately by HSE. These are important points that have an ongoing effect on statutory reporting obligations relating to LC, and workplace protections for all Covid-19 related injury.

91. The HSE went on to suggest that the system was not intended to be used in a pandemic. Whilst this may be correct, RIDDOR offered a readymade system to record instances of deaths and LC developed from workplace-acquired Covid-19 infections, which was not effectively used. Under-reporting of LC diminished the overall picture of occupational harm caused by Covid-19, which has in turn prevented HSE from developing necessary guidance on sector-specific improvements to working conditions for HCWs. Even Richard Brunt accepted in evidence that the consequence of RIDDOR under-reporting is that *"you don't have a picture of what's happening there."*[235] The BMA meanwhile have said that *"reporting also assists staff with LC…in seeking access to benefits, such as the NHS Injury Allowance or wider compensation. The considerable under-reporting and subsequent failure to investigate what we believe took place across the NHS has made access to this financial recompense significantly more difficult for those staff suffering from LC who wish to form a claim."*[236]

92. Thirdly, the true quantitative measure of harm LC caused to HCWs is still unknown. The President of the Royal College of Physicians ('**RCP**') in his Bulletin recognised that *"hard data"* on the impact of LC on HCWs was necessary,[237] yet there is still no systematic data collection of (i) the number of HCWs with LC, or (ii) rates of sickness absence of HCWs due to LC. The Royal College of Nursing ('**RCN**') have said that *"there was no visible systematic data collection or reporting on deaths, infection rates and self-isolation amongst the health and care workforce. It is unacceptable that we did not know, at any given time, how many health and care staff were unwell or had died because of Covid-19. Infection and self-isolation rates amongst health and care staff would have been a key indicator of what impact the government's approach was having, and this information was therefore a key piece of scrutiny which was missing."*[238]

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[234] [INQ000269707] § 5.4.15.
[235] [4/93/1].
[236] [INQ000477304] § 291.
[237] [INQ000226564/290].
[238] [INQ000475580] § 131.

93. Some individual hospitals did, of their own initiative, collect data on LC from their work force. Leicester Royal Infirmary for example monitored staff absence due to LC and recorded a total of 692 staff requiring time off for LC between 1 March 2020 and 30 June 2022.[239] The Royal Victoria Infirmary in Newcastle started coding HCWs who had been referred to Local Occupational Health Service for LC from April 2020 onwards, allowing the hospital to monitor the impact of LC on staff members.[240] These examples are exceptions, however, rather than the rule.

94. In January 2021, a note to the CMO, Professor Whitty, recorded that *"we have an incomplete picture on potential affects on workforces" (sic).*[241] These data gaps continue to exist today. When pressed, NHSE said that their data collection ability *could* determine the number of employed HCWs who access LC services.[242] However, there is no evidence to suggest that this data is being extrapolated and analysed for protective policy-making decisions. In any event, the data is limited to employed NHSE HCWs who need to, and have been able to, access LC services, which will represent only a small percentage of overall LC sufferers working within NHSE. Decision makers accept that it is essential to monitor the scale and impact of LC on all HCWs.[243]

95. Risk assessments, RIDDOR reporting, and data collection should have been deployed in concert to protect HCWs from all of the harms caused by Covid-19, including LC, but they were either not used at all, or used inaccurately, rendering them ineffective. The consequence of this three-fold failure is that many HCWs have been dismissed from employment, some because of a lack of reasonable adjustments, others because of the devastating impact of their symptoms, whilst others continue to work in a reduced role, and others work without any support due to a fear of losing their livelihood, careers and immigration status.[244]

96. Further, HCWs who have developed LC, require occupational support. As DHSC noted in November 2020 but failed to initiate,[245] and as was again recorded by Matt Hancock in February 2021,[246] there is an urgent need to provide sickness injury benefit for HCWs who are no longer able to work at all. Economic and occupational support including reasonable adjustments need to also be made available to assist HCWs with LC in

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[239] [INQ000474221/9] § 41.
[240] [INQ00047890/11].
[241] [INQ000283397/6].
[242] [INQ000474664/3] § 10.
[243] [37/31/21]-[37/32/12]; [29/173/1-25]; [30/176/2-6]; [32/182/1-3].
[244] [INQ000492279/9 § 36].
[245] Document disclosed in Module 2 [INQ00058872].
[246] [INQ000292652].

returning to work. The Covid Sick Pay provisions that some HCWs were able to avail of, came to an end in September 2022, leaving HCWs without the specific financial and occupational support that they need.[247]

97. LC has created a new vector of health inequality amongst HCWs. Professor Banfield has said *"the biggest and most obvious consequence to that is an enormous number of healthcare workers who really can only have caught Covid (from work) -- and are now disabled and unable to work or earn a living, are having to undertake individual litigation to get their work-acquired Covid recognised."*[248] The Inquiry has heard a clear call from HCWs, Professional Bodies, Trades Unions, civil society organisations and patient advocates, for LC to be recognised as an Occupational Disease.[249] The prescription of LC as an occupational disease would ensure that HCWs who sacrificed their health on the frontline of the pandemic can access the financial and physical occupational support that they need.

VI. CONCLUSION: CONSOLIDATING LONG COVID HEALTHCARE

98. LC has caused lasting change to how the healthcare system will look, and operate, going forwards. Covid-19 remains in circulation, and there is no cure for LC. This means the demands of the historic and new cases of LC will be felt on the UK's health system for years to come. Yet, instead of improving the structures, learning and systems that were put in place, there is a winding down of LC services and an abandonment of data collection systems and research. The experts to the Inquiry warn that this regression will impact current and future LC sufferers *"if you start to undermine the clinics then the whole discipline of being able to look after people with LC starts to become undermined…perversely, the problem seems to go away, because then you're not actually seeing the condition, because it's no longer visible. And to me that would be -- that would be a real travesty?"*[250]

99. The current scale and impact of LC shows the obvious need for accessible, specialist LC services for adults and children, to be operationalised and maintained throughout the four nations. These services must be data-driven to meet the actual health needs of the population. The healthcare system needs to recommence surveillance of the

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[247] E.g. Dr Mulholland notes the urgent need for occupational support for GPs with LC. [9/178/3-24].

[248] [21/146/9-14].

[249] [5/59/22-25]; [27/108/23-25]; [27/109/6-14]; [40/37/9-12]; [41/5/17-20]; [INQ000477304/110] § 252a; [INQ000435429/6]; [INQ000409079/18] § 57.

[250] [22/96/10-13]; [22/124/4-17].

prevalence and impact of LC, and funding for research into LC, to ensure LC healthcare is effective and data-driven to meet care needs. Whilst there is no cure for LC, the most senior public health officials recognise that vaccination can reduce the severity and impact of LC. LC sufferers should be identified as a cohort for ongoing vaccine prioritisation. The steps taken to support sufferers of LC need to be matched by preventative measures to prevent further incidence of LC. Improving public awareness of the indiscriminate risk of LC is key to protecting future adults and children from developing it. Twinned with this is the need to limit overall transmission of SARS-CoV-2 by re-introducing Covid-safe measures like improved ventilation and air filtration in all public spaces.

100. The LC experts describe this as a moment of opportunity, where the learning and clinical development of LC can be built upon to improve current suffering and advance the UK's future preparedness.[251] The LCGs hope is that their experience of suffering in isolation, of being misinformed, disbelieved, and having to fight to access healthcare, is one that will be learnt from. As Professor Evans has said "*this could be the proper legacy to get this right for next time.*"[252]

VII. RECOMMENDATIONS

101. The LCGs look to the Inquiry to make strong recommendations to address both the immediate needs of people with LC in the current pandemic and prepare for a future pandemic. The LCGs welcome the Inquiry's commitment to monitor the implementation of recommendations already made in Module 1 and anticipate that Inquiry will continue that work through the following modules including Module 3.[253] They also note that the Chair will only make recommendations which are "*reasonable and deliverable*" so that implementation in a timely manner is achievable. The Chair is invited to include an overarching recommendation for the establishment of a system of monitoring, implementation and accountability for the findings and recommendations of this Module and others to ensure implementation of these recommendations.

102. As set out above at §4, the LCGs invite the Chair to make this interim recommendation without further delay noting (i) the recent warning of Professor Powis on 5 December

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[251] [22/124/4-24].

[252] [22/98/14-15].

[253] Inquiry publishes first report and 10 recommendations focused on pandemic resilience and preparedness, 18 July 2024 https://covid19.public-inquiry.uk/news/inquiry-publishes-first-report-and-10-recommendations-focused-on-pandemic-resilience-and-preparedness/.

2024 about the increased rates of transmission of Covid-19 and other airborne viruses this winter and impact on the NHS, echoed by the WHO releasing 4 policy briefings on Covid-19 on 10 December 2024,[254] and (ii) that the UK remains unprepared to respond to the risk of airborne transmission of a novel respiratory virus. In relation to the ongoing Covid-19 pandemic, the LCGs emphasise that this urgent recommendation has the twin benefits of protecting the NHS from being overwhelmed in the short-term from increased numbers of hospitalised patients from respiratory viruses but also from the long-term costs of supporting new cases of LC.

103. **In addition to this urgent recommendation, the LCGs call for the following recommendations to address the immediate concerns arising from LC:**

(1) **Covid-safe measures:** All health providers in the four nations should re-introduce Covid-safe adaptation measures in all healthcare settings (clinical and non-clinical). This should include the implementation of adequate ventilation, provision of HEPA filtration systems and the routine use of FFP3s in all healthcare settings. Covid-19 testing must be made available to ensure HCWs with Covid-19 can isolate, to protect HCWs and patients.

(2) **Ventilation:** the UK government should establish an independent statutory body responsible for clean air and monitoring of airborne pathogens; the body should conduct an independent review to improve ventilation and clean air in public buildings (prioritising healthcare settings and schools) with 6 months of publication of the Module 3 report

(3) **Data gathering on LC:** UKHSA and the public health authorities of the devolved nations should immediately resume surveillance of the prevalence and impact of LC in the wider population and amongst HCWs as recommended by WHO.[255]

(4) **Patient Advocates:** The UK government and devolved administrations should maintain and/ or formalise structures to gather input from people with lived experience of LC to inform the development of LC services.

(5) **Clinical Education:** NHSE in consultation with Royal College of Physicians (RCP), the Royal College of General Practitioners (RCGP), Chartered Society of Physiotherapists (CSP), Royal College of Occupational Therapists (RCOT) and allied healthcare bodies should prepare clinical education materials on LC in light of evidence before this inquiry and coordinate with patient advocacy groups on the content of those materials.[256]

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[254] WHO Policy Briefing: Covid-19 surveillance, 10 December 2024 available at: https://www.who.int/publications/m/item/who-policy-brief-covid-19-surveillance.
[255] WHO Policy Brief, Covid-19 Surveillance, December 2024, p.2-3.
[256] See for example, LC SOS GP Leaflet: https://www.longcovidsos.org/gp-leaflet.

(6) **Clinical management**: the UK government should request NICE to update the clinical guidelines for managing the long-term effects of Covid-19 in light of evidence before this Inquiry and the latest research and developments in understanding of LC.

(7) **Communications:** UKHSA and the public health agencies in the devolved nations should launch a public health messaging campaign on the indiscriminate risk of LC including specific campaigns on (a) the benefits of vaccination on reducing the severity and impact of LC and (b) the risk and impact of LC in children and young people.

(8) **Research:** the UK government and devolved nations should develop a more focused and better funded approach to research into LC. This should include research into paediatric LC as a priority, as well as research into pharmacological and non-pharmacological treatments for adults and children alike.

(9) **LC clinics:** the UK government and devolved nations should ensure equitable access to dedicated, multidisciplinary, doctor-led LC clinics as recommended by WHO.[257] Dedicated funding for LC services should be ringfenced beyond 2025.

(10) **CYP:** NHSE and the health authorities in the devolved administrations should undertake to provide all CYP with LC access to dedicated, specialist, multi-disciplinary LC paediatric services. Clinicians, patients and parents should be informed about LC in CYP through public health campaigns and clinical educational material.

(11) **Prevention:** the UK government should request JCVI to review the evidence on the impact of vaccines on LC with a view to ensuring both that LC patients be treated as a priority cohort for vaccinations, and that booster vaccinations be made more widely available to prevent new cases of LC.

(12) **Healthcare workers**: the UK government should prescribe LC as an occupational disease. Additionally, it should implement the recommendations from November 2022 by the IIAC that the 5 post-hospital Covid-19 conditions are prescribed as an occupational disease.

(13) **Support for HCWs:** the UK government and devolved administrations should ensure that dedicated economic and physical occupational support should be provided for HCWs who are unable to work and to assist those who are able, to return to work.

(14) **Inequalities:** the UK government and devolved administrations should monitor and study the differential impact of LC and NHSE and all other health authorities

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[257] WHO Policy Brief, Clinical Management of Covid-19, 10 December 2024, p.4.

ensure that LC healthcare addresses and overcomes new, and pre-existing healthcare and health inequalities.

104. **The LCGs call for the following recommendations to inform the response to a future pandemic:**

(15) **Pandemic planning:** the Module 1 recommendation (6) provides that the UK government and devolved administrations should hold a UK-wide pandemic response exercise every three years, these exercises must include specific provision to manage the risk of long-term sequelae and involve patient and public involvement representatives.

(16) **Data gathering systems:** the Module 1 recommendation (5) provides that the UK government and devolved administrations should establish new mechanisms for timely collection, analysis, secure sharing and use of reliable data for informing emergency responses. These mechanisms should include provision for surveillance of long-term sequelae.

(17) **Healthcare services for long-term sequelae:** the UK government and devolved administrations should ensure that pandemic planning includes pre-planned approaches for creating scalable specialised services for the assessment and care of the long-term sequelae of a novel virus.

(18) **People with lived experience:** the UK government and devolved administrations should ensure that pandemic plans include formalised mechanisms for people with lived experience to contribute to a future pandemic response.

(19) **RIDDOR:** The UK government should ensure that a new reporting system is developed for use in pandemics to replace RIDDOR.

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