UK COVID-19 PUBLIC INQUIRY

MODULE 3

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

I. INTRODUCTION

1. The Long Covid Groups (‘**LCGs**’) represent the patients and healthcare workers (‘**HCWs**’) suffering from life-changing illness and disability as a consequence of infection from Covid-19. The long-term, multi-system and relapsing nature of Long Covid (‘**LC**’) means that it has had a profound and debilitating impact on individuals, the healthcare system, and the country.

2. Long Covid was foreseeable; previous coronaviruses and other viruses caused long-term sequelae similar to SARS-CoV-2, yet there were no plans in place to monitor long-term symptoms, or respond to the demands of a new patient cohort requiring care and support. LC was instead identified by patients who went on to advocate for recognition, surveillance and care. The UK’s healthcare system was unprepared and reactive to their advocacy, rather than proactively responding to the newly vulnerable population suffering from the long-term health impacts of disease.

3. The creation of a body of people with long-term, often disabling health impairments has exacerbated existing inequalities, as well as created new health inequalities.[1] Every Story Matters (‘**ESM**’) has documented how many of those with LC experience significant long-term health impairments: some report loss of mobility and are “*now a wheelchair user,*” others say they were “*unable to return to work or my normal life.*” ESM also recognises that “*many…said they feel like they have been forgotten by the healthcare system and wider society, and that no one cares any more.*[2] Children have told the LCGs about a loss of their childhood: *‘many of us are in bed a lot of the time, it can be boring, annoying, frustrating and tiring and we miss our friends. We miss feeling well.’*[3] The LCGs

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[1] [INQ000370954/62] § 8.6.
[2] [INQ000474233/188]; [INQ000474233/186].
[3] [INQ000370954/44] § 5.2.

call for the Inquiry to make findings that will inform better provision of healthcare for those currently suffering from LC, and recommendations for the future response to the long-term health impacts of a future, as yet unknown, pandemic.

4. This opening statement addresses the following ten issues: (i) the ongoing impact of LC, (ii) the importance of patient advocacy, (iii) the failure to warn the public, practitioners and patients of the risk of LC in adults and children and young people (**'CYP'**), (iv) building understanding of LC, (v) diagnosing and responding to LC, (vi) the inconsistent provision of dedicated LC services (vii) health inequalities, (viii) preventative measures for LC, (ix) the disproportionate impact on LC on HCWs and (x) inadequate occupational protections for HCWs with LC. It sets out the findings of fact that the LCGs invite the Inquiry to make and the 22 recommendations that the LCGs say follow from those findings. These are necessarily preliminary observations only and will be refined as the evidence emerges.

II. THE ONGOING IMPACT OF LC

5. LC has a devastating impact on individuals' long-term physical, mental, social, educational, family and financial wellbeing.[4] ESM has documented how LC has limited adults' daily activities including the ability to work and earn an income.[5] CYP with LC have been unable to attend school, interact with friends or participate in their usual hobbies and extracurricular activities; they have lost their childhoods to the disease.[6] There is an additional financial strain on the healthcare system, as dedicated funds must be allocated to care and support for patients suffering on a long-term basis. Coupled with the direct financial cost, the healthcare system is also managing the significant loss of capacity from the disproportionate impact of LC on HCWs. This cost to the individual and to the healthcare system inevitably triggers a third, wider financial cost borne by the national economy.[7] The UK healthcare system's failure to adequately promote and protect public health from LC has adversely affected the social and economic fabric of the country, with LC continuing to affect the lives and livelihoods of 2 million adults and CYP, and counting.[89]

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[4] [INQ000370954]; [INQ000474233/186].
[5] [INQ000474233/186 - 7].
[6] [INQ000370954/50] § 5.17.
[7] Cambridge Economics, *"New macroeconomics insights on the impacts of Long Covid in the UK"* Available online at: https://www.camecon.com/macroeconomic-impact-long-covid-uk/
[8] The latest Winter Coronavirus (Covid-19) Infection Study data from the ONS demonstrates that as of March 2024 an estimated 2 million people in the UK were reporting Long Covid symptoms. Available online at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/selfreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland/november2023tomarch2024

6. LC is indiscriminate and everyone is at risk of developing LC from acute Covid-19 infections. The current, unchecked transmission of Covid-19 will inevitably increase the numbers of the people who suffer from LC and its associated harms.

III. THE IMPORTANCE OF PATIENT ADVOCATES IN THE RESPONSE TO LC

7. **Patient Advocacy led to the recognition of LC in adults and CYP:** awareness of protracted symptoms of Covid-19 in adults first emerged as a result of patients sharing their stories, symptoms, and prolonged suffering through social media and through the LCGs advocacy campaigns.[10] There were further delays in the recognition of paediatric Long Covid and throughout 2020 it was left to patient advocates to dispel the myth that CYP could not suffer harm from Covid-19.[11]

8. **Patient advocates were in regular dialogue with decision makers in the UK's healthcare system on the care and support needed for adults and CYP with LC, but many critical issues they raised did not translate into effective or adequate care and support on the ground:** the LCGs participated in monthly Ministerial Roundtables on LC and the NHSE LC Taskforce, as well as in regular meetings with NHSE, which created direct routes of constructive engagement with NHSE and the DHSC.[12]

   Recommendations: (1) patient advocates' role in the recognition of and response to LC should be formally acknowledged;[13] (2) future pandemic responses should incorporate patient advocates into the healthcare response from an early stage.

IV. FAILING TO COMMUNICATE THE RISK OF LC

9. **Practitioners, patients and the public have not been adequately warned about the risk of LC:** communication on LC was and remains reactive and sparse despite the well documented risks. This undermined public understanding of the risk of LC, damaged healthcare service delivery and undermined patient confidence in the healthcare sector's ability to meet LC care needs. None of the relevant public bodies in England accept responsibility in their evidence to the Inquiry for

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[10] [INQ000249034]; [INQ000370954/11-12] §§3.1-3.3.

[11] [INQ000370954/46] § 5.6.

[12] [INQ000320227].

[13] [INQ000283415/2].

disseminating clear and timely public health information on the risk and symptomology of LC,[14] leaving a communication vacuum. To date, there has been only one public health video campaign to inform the public of the risk of LC, despite the Cabinet Office, NHSE, and PHE all having recognised the risk of LC by September 2020.[15] Alarmingly, there has been no equivalent public health campaign on the ongoing, debilitating harm that LC has on CYP, despite there being over 55,000 children suffering from LC in England and Scotland alone.[16] The public silence on paediatric harm has resulted in a widespread, harmful misunderstanding that Covid-19 has no impact on CYP.[17]

10. **The ongoing provision of information to the public on LC symptomology and signposting access to services, has been sporadic, delayed and thereby ineffective.[18]** For example, the December 2020 NHSE patient-facing leaflet for those isolating at home failed to refer to LC, as did the April 2021 updated leaflet.[19] The August 2021 leaflet referred only in passing to LC, without any further advice.[20] The NICE rapid guidelines on the long-term effects of Covid-19 recognised that LC symptoms and existing health inequalities make it harder for LC patients to access services and advised that additional information and support for LC sufferers should be made available.[21] Production of guidance was left to individual LC clinics, resulting in inconsistent and often ineffective information about LC services.[22] Patients were also directed to Your Covid Recovery app to access services, which has been criticised for being "*unfit for purpose*" as *"an online screening tool cannot be the gatekeeper to these support services."*[23]

11. **Internal communication of clinical information to HCWs on the growing understanding of LC, and guidance on how to assess, diagnose, refer and care for patients with LC, was ineffective.** The NHSE did not properly train HCWs on the risks of LC. Neither did NHSE comply with its own guidance on LC clinics to *"cover communications to general practitioners, hospital doctors, registered nurses, pharmacists."*[24] For example, despite NHSE being aware by late September that GPs did not have advice on how to respond to LC, it was the RCGP that plugged this information gap by producing e-learning modules and *'top tips'* on LC.[25] Even with these resources, NHS staff

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[14] [INQ0000485652/228] §§837, 840, 842, 843 and 855; [INQ000409251/37] §150; [INQ000410867/164] §431; [INQ000436880/3] §1.5.6.

[15] [INQ000071192]; [INQ000071194].

[16] The latest ONS statistics (released on 25 April 2024, relating to a period from November 2023 to March 2024) show that there are currently an estimated 55,801 children in England and Scotland (defined as 3 to 17 years old by ONS) who have Long Covid and have had symptoms persisting for at least 12 weeks. Available online at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/adhocs/2101selfreportedlongcovidenglandandscotland

[17] [PHT000000033/16] p. 63 l. 20 – 25]; [INQ000370954/49] §5.12-5.15.

[18] [INQ000283482]

[19] [INQ000470524]; [INQ000470513].

[20] [INQ000470542].

[21] [INQ000339283].

[22] [INQ000470502/5] §23.

[23] [INQ000226564/82]; [INQ000370954/36 - 39] §§4.10 – 4.19.

[24] [INQ000283377].

[25] [INQ000205639/2]; [INQ000205645] .

reported feeling ill-advised on how to respond to LC which chimes with patient experiences of being disbelieved and dismissed.[26]

Recommendations: (3) There is an urgent need for public information on the ongoing risk of LC for patients and carers, and better internal clinical communication to healthcare professionals on responding to LC. (4) Effective communication systems need to be crafted and put in place for any future pandemic.

V. THE HEALTHCARE SYSTEM: BUILDING UNDERSTANDING OF LC

12. **LC was foreseeable and yet the healthcare system was unprepared**: the existing healthcare infrastructure was not ready to respond to significant numbers of people suffering from long-term ill-health and disability. Pandemic plans for the healthcare sector did not include planning for data collection of long-term sequelae, or any adaptive pandemic procedures for primary and emergency care to deliver services.[27] A systematic review of the LC patient experience found access to NHS care to be *"complex, difficult and exhausting… other qualitative data highlighted patients having to seek and create their own care pathways". '*[28]

13. **Research into LC has been insufficient and delayed, having an adverse effect on clinical care:** understanding the nature of the long-term sequelae of a novel virus is the cornerstone to providing responsive healthcare services to meet care needs, yet research into LC has been insufficient and delayed such that *"Long Covid remains a glaring blind spot in our knowledge, that urgently needs to be filled."*[29] There has been a corresponding adverse impact on clinical care for LC. Research needs to be embedded in clinical care from the outset. This might have led to "*earlier recognition of Long Covid*" instead "*clinical care followed the research.*" There was the potential to "*learn more quickly what services for Long Covid are effective and therefore what should be provided at scale.*"[30]

14. Research into LC suffered from an initial over-focus on hospitalised patients and there has still not been any equivalent sized research call for non-hospitalised sufferers of LC.[31] The substantive scope of the funding calls for research have also been insufficient: there was an initial failure to recognise the need for research into potential therapies for LC until patient advocates called for it, and there

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[26] [INQ000058981/4]; [INQ000370954/14] §3.5.
[27] [INQ000474283/23] §57-69.
[28] [INQ000421758/12] §24.
[29] [INQ000421758/4] §4.
[30] [INQ000421758/41] §§126-127.
[31] [INQ000292630/1].

has been no further funding call for research into therapeutics since 2021. No paediatric biomedical studies have been conducted in the UK but evidence from adult clinical studies cannot be extrapolated to decide policy and services for CYP with Long Covid, leaving a lacuna in medical knowledge. The scale of the funds allocated have also been insufficient when compared internationally.[32]

Recommendations: (5) there needs to be a more focused and better-funded approach to research into LC, specifically paediatric LC and the use of therapeutics to manage LC symptoms; (6) the distinct disease burden on CYP should be recognised and investigated, without comparison to adults; (7) research into long-term sequelae should be funded at the start of any future pandemic, at the same pace as research into the acute form of any novel virus.

15. **Data Surveillance:** effective surveillance systems and patient registers are "*the first step towards dealing with Long Covid*", yet in the early stages of the pandemic, the NHSE and PHE did not have systems in place for the collection of data on the long-term symptoms of Covid-19.[33] Systems were slow to be created, and were then inadequate. The LCGs have consistently called for data gathering on LC to inform research into the condition, policy making and public health resource planning.[34] DHSC recognised the need for NHSE to gather data on LC in September 2020 (the same month that WHO published ICD codes for post-covid conditions), but the only reliable data that NHSE has been able to collate and publish is service user data from the LC clinics, which does not inform prevalence of LC or quantify demand to plan for services.[35] The self-reported ONS CIS study was relied on instead to fill the gap in prevalence data. However, limited data gathering has affected understanding of LC including its impact on health inequalities.[36]

16. There was a paucity of data: (i) the NHSE and PHE did not have in place systems for the coordinated and systemic collection of data on the long-term symptoms of Covid-19; (ii) the NHSE Covid-19 data store which informs "*strategic decision-making by senior NHS England officials*" was not developed to gather data on LC and NHSE and DHSC;[37] (iii) there was and continues to be poor and inconsistent use of SNOMED codes for LC (which were only introduced between December 2020

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[32] [INQ000421758/9] §§15-19.
[33] [INQ000370954/30] §3.34.
[34] [INQ000283396/2].
[35] [INQ000292632/3]; [INQ000283407]; [INQ000283438/29]; [INQ000283413/2].
[36] [INQ000421758/32] §91.
[37] [INQ000283410]; [INQ000409251/98] §400; [INQ000283397/1]; [INQ000226520/6].

to March 2021)[38], and (iv) Alternative proposals by NHSE did not appear to materialise or took a long time to establish e.g. the LC Self-monitoring tool, and the NHSE National Patient Registry.[39]

17. There has been no publicly recorded data on prevalence since the ONS Winter Infection Study was closed in March 2024 and UKHSA's published Covid-19 data dashboard does not acknowledge LC.[40] It is unclear how the NHSE is modelling for current and future demand for LC services in the absence of ONS data (which was still relied on in the 2022 NHS Plan for estimating future demand on LC services).[41]

Recommendations: (8) integrated data systems should plan for surveillance of post-infectious sequelae;[42] (9) data gathering on prevalence and impact of LC should be resumed on a continuous basis and published monthly.

VI. THE HEALTHCARE SYSTEM: DIAGNOSING AND RESPONDING TO LC

18. **Primary care is typically the front line of healthcare response for LC sufferers, yet it lacked the preparedness, resilience and resources to respond to the demands of the pandemic.**[43] Pandemic preparedness guidance across the four nations was focused on an influenza pandemic scenario and did not specifically address adapting primary care needs for patients suffering long term, leaving practitioners to scramble to redesign and adapt service provision during the pandemic.[44] Further, there was a lack of awareness of the risk of long-term morbidity from a novel virus in the medical profession. These systemic failures meant the LCGs' ongoing experience of primary care has been and remains one of dismissal and disbelief, which has unnecessarily delayed patients obtaining a clear diagnosis of LC.[45]

19. The general lack of awareness of LC was exacerbated by the policy and practical obstacles presented by the pandemic. Primary care was principally conducted through tele-services which made it difficult for clinicians to assess key physiological indicators such as the degree of breathlessness,

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[38] [INQ000421758/32] § 91]. [INQ000283458/13].

[39] [INQ000238590/8]; [INQ000283408]; [INQ000283410].

[40] ONS *'Self-reported Coronavirus (Covid-19) infections and associated symptoms, England and Scotland: November 2023 to March 2024.'* Available online at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/selfreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland/november2023tomarch2024#:~:text=During%20wave%204%20(ending%207%20March%202024)%2C%20long%20COVID,been%20%22limited%20a%20lot%22

[41] [INQ000238590/17].

[42] [INQ000421758/39] §115.

[43] Professor Edwards Draft Report § 81.

[44] Professor Edwards Draft Report §§63-69.

[45] [INQ000370954/11] Section 3; [INQ000381156] §30 ; [INQ000226564/82].

and prevented clinicians from relying on physical tests such as ECGs.[46] Issues with testing (i.e. the decision to restrict access to community testing of adults on 12 March 2020, digital exclusion and limits on children's access to testing) meant many sufferers were unable to link their symptoms to infection with Covid-19, and were consequently disbelieved.[47] The NHS also failed to update the list of adult symptoms associated with Covid-19 until April 2022, out of step with official guidance from PHE and the WHO,[48] and did not inform the public of paediatric symptoms of Covid-19 in line with developing evidence.[49] This made it even harder for individuals to persuade primary care professionals that their protracted symptoms were related to Covid-19 infection. These obstacles forced the majority of LC patients to manage their symptoms at home alone, turn to the support of charities or pay for private medical care.[50] The foundational role of primary care as part of the *"whole pathway"* of LC care was overlooked.[51]

20. **These systemic issues permeated primary, secondary and community healthcare – care procedures and pathways were not responsive to, or adapted to accommodate, the healthcare needs of LC.** The NHS 111 service failed to provide information relating to suspected LC so individuals were often left unaware that they were suffering from LC after seeking advice.[52] The majority of LC sufferers who contacted NHS 111 were told to stay at home, forcing them to manage their symptoms on their own.[53] The Ambulance and Emergency response was equally ill-equipped as LC was not factored into triage or escalation of care guidance. HCWs were unsupported and under-resourced to escalate care.[54]

Recommendation (10) LC healthcare should be considered holistically, incorporating primary, secondary and emergency care into its design; (11) pre-pandemic plans should cover primary and community care response to the acute and long-term sequelae of a novel virus.

21. The Inquiry has heard evidence in other Modules that CYP were *"often overlooked"* and that the Government *"was indifferent to children's experience during Covid,"* a failure which is most evident for paediatric LC.[55] The reluctance to consider that Covid-19 could have an impact on CYP led to a further delay in recognising, diagnosing and responding to paediatric LC by creating suitable child-specific care pathways. As with adult sufferers, CYP with LC and their parents were routinely

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[46] Professor Edwards Draft Report at §§118-119; [INQ000366258].
[47] [INQ000356273/2,6]; [INQ000366254]; [INQ000224589]; [INQ000320233].
[48] [INQ000320241].
[49] [INQ000370954/47] § 5.9.
[50] INQ000255837] at § 10; [INQ000370954/68] §10.2.
[51] [INQ000060080/2]; [INQ000366262/16].
[52] [INQ000410473] entry for 26.10.20; [INQ000410473].
[53] [INQ000370954/12] §3.3.
[54] [INQ000252598]; [INQ000499523/18]; and [INQ000499523/27].
[55] M2 Transcript [4/33/25-4/34/3]

disbelieved, but this was compounded by: (i) the lack of information on the risk of Covid-19 to CYP, (ii) the absence of data on the impact of the virus on CYP, (iii) the delay in developing a clinical case definition and paediatric model of care, and (iv) the failure to commission timely research into paediatric impacts of the virus.[56] *"At best, an adult framework was being applied to paediatric problems,"* at worst, CYP with LC were entirely overlooked.[57] Dedicated CYP Hubs were created in England but were sparse. Dedicated clinics in Wales, Scotland or Northern Ireland were either absent or slow to be established.[58]

Recommendation (12) CYP need accessible, dedicated child-centred services which can provide age-appropriate assessments, care and support.

VII. DEDICATED LONG COVID SERVICES

22. **Across the four nations, patients experienced significant inconsistency in access, approach, interventions and use of specific therapies**: each of the four nations took a different approach to providing LC care "*and externally appeared to be uncoordinated across the nations.*"[59] Many of the LCGs' experiences would have been avoided by having a pre-planned approach to creating specialised services for the assessment and care of people who suffer from long-term symptoms of the novel virus.[60]

23. The following factors should inform the provision of assessment, care and support services for LC:
    a. **Dedicated services led by senior specialist clinicians who are able to prescribe, with the support of a multi-disciplinary team including doctors** are essential given the complex, multi-system nature of LC. Structuring services in this way is "*clinically and cost effective*" and ensures care is provided in a service which enables learning within and across teams and prevents multiple speciality referrals. Regrettably this "*gold standard*" is not available across the four nations.[61]
    b. **Consistency in standards and services** should be realised across and within the four Nations to ensure health equity. Only 16% of LC sites are reported to offer the highest level of service in terms of complexity of assessment and available intervention.[62] As the clinics' clinical and

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[56] [INQ000320272]; [INQ000320273]; [INQ000283420/21]; [INQ000066583]; [INQ000238545/12].
[57] [INQ000370954] §5.5.4.
[58] [INQ000421758/16] §36.
[59] [INQ000421758/42] §127.
[60] [INQ000421758/43] §135.
[61] [INQ000421658/42] §§128,131; [INQ000485702/7] §17 ; [INQ000283459/18-22].
[62] [INQ000421758/34] §98.

cost effectiveness is evaluated through health-related quality of life assessments, (EQ5D-5L and C19-YRS), standardisation of assessments is important for data gathering.[63]

c. **Self-help online resources** do not replace the need for individualised assessments and advice from qualified medical professionals. Those who most need health and care services are the "*least likely to be able to use digital health services.*"[64]

d. **Pathways to dedicated services should be clear and accessible.** Barriers to access for LC services have arisen from GPs not knowing about LC or LC services; LC patients not knowing how to access support and referrals being made to alternative pathways.[65] Some LC services refuse to accept LC patients who do not meet a certain severity threshold, so that such patients fall in the gap between services.[66]

e. **Dedicated funding for LC** is critical to the effective running of services. Before dedicated funding was provided, access to NHSE Services for LC was variable and depended on "*clinician enthusiasm.*"[67] In Scotland, health boards were not provided with any central funding allocation resulting in LC services being overwhelmed and unable to meet demand. Sustained central funding for LC care in England will prevent services disintegrating. In Scotland, Wales and Northern Ireland, the absence of dedicated funding means there is no certainty on the healthcare that will be available.[68]

24. There was a need for clear leadership and support within the public health services to coordinate an early, collective approach. In Northern Ireland and Scotland, where there was no guidance on the provision of LC services for the first year, a variety of models were introduced creating a postcode lottery for LC patients and unsustainable pressures on effective services.[69] In England, there has been no update on the July 2022 NHS Plan for improving Long Covid services despite the growing numbers of people developing Long Covid.[70]

25. Aside from the National Evaluation of LC Service Outcomes (which only measures patient outcomes across all services), there is no independent review or oversight of the LC Services to address unwarranted variations and the CQC does not have a specific programme of inspections of LC

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[63] [INQ000320289/2] ; [INQ000421758/34] §100.
[64] [INQ000224589/5]; [INQ000356269].
[65] [INQ000470552/4].
[66] [INQ000370954/40 – 41].
[67] [INQ000421758/26] §73.
[68] Expert report [INQ000421758/13,38] §§27,28,31,110,112.
[69] [INQ000485702/2] §2; [INQ000421758/28].
[70] ONS, Self-reported Coronavirus (Covid-19) infections and associated symptoms, England and Scotland: November 2023 to March 2024 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/selfreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland/november2023tomarch2024#:~:text=Of%20those%20who%20self%2Dreported,(ending%207%20March%202024).

services.[71] In Northern Ireland, the Regulation and Quality Improvement Authority has not inspected LC Clinics.[72] In Wales, six monthly reviews of LC Services were implemented to identify points of concern and a similar approach could usefully be adopted across the four nations.[73]

Recommendation: (13) a skeleton protocol should be prepared which will bring together a panel of experts with knowledge of long-term effects of a novel virus to respond to a future pandemic. This should include patient participation and academic researchers. There should also be a core service specification which can be adapted according to the characteristics of a novel virus;[74] (14) current LC Services should be well-funded beyond 2025 and a comprehensive review carried out to identify and remedy inconsistencies in access and standards of services provided.

VIII. HEALTH INEQUALITIES

26. LC exacerbates pre-existing inequalities while simultaneously creating health inequalities. Socio-economic inequalities contribute to higher rates of LC in economically deprived areas.[75] Inequalities in terms of access to care and support also arise from multiple and intersectional barriers including age, digital literacy, language barriers and different health seeking behaviour.[76] Women are at higher risk of LC but have reported their symptoms being dismissed or misdiagnosed as menopause or mental health conditions.[77]

27. Recognition that pre-existing inequalities were risk factors for Covid-19 led to LCGs raising these concerns at Ministerial Roundtables on LC in October and December 2020.[78] NHSE agreed to put equality and diversity at the centre of the NHSE Five Point Plan and subsequent Long Covid Plans "*embedded*" equality and diversity issues and committed to record and publish diversity data.[79] Understanding of health inequalities is hindered by limited data on ethnicity and socio-economic

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[71] [INQ000471158/172] §500.
[72] [INQ000421798/33] §115.
[73] [INQ000421758/35] §101.
[74] [INQ000421758/39] §117.
[75] [INQ000231669] (M2 disclosure); [INQ000421758/29, 32] §§79, 87,91; Shabnam et al, Socioeconomic inequalities of Long COVID: a retrospective population-based cohort study in the United Kingdom https://journals.sagepub.com/doi/10.1177/01410768231168377 ; Health Equity North, Navigating the Long Haul: Understanding Long Covid in Northern England.
[76] [INQ000421758/32] §92; [INQ000366262/10]; [INQ000235290/10]; [INQ000224575/3]; [INQ000319639/25] §78.
[77] [INQ000366262/10].
[78] [INQ000058536/2]; [INQ000205646/2].
[79] [INQ000485652/275] §1054; [INQ000112676].

backgrounds.[80] Nonetheless, there continues to be significant unwarranted geographical variation in access to services and the most deprived areas are significantly underserved.[81]

Recommendations: (15) services should be designed, implemented, and reviewed for their effectiveness at addressing and reducing health inequalities.

IX. PREVENTATIVE MEASURES

28. Research has confirmed that vaccines reduce the likelihood of developing LC and may have a therapeutic effect on LC, yet there is no public awareness campaign to explain this additional preventative impact of vaccination.[82] Individuals who have developed LC are still at risk of harm from future SARS-CoV-2 infections. As research is ongoing in this area, the precautionary principle should be applied and people with LC should be immediately offered the vaccination as a priority group.[83]

Recommendation: (16) In the absence of curative treatments, LC should be reconsidered as an indication for vaccine prioritisation and vaccinations and boosters should be made more widely available to prevent new cases of LC.

X. THE DISPROPORTIONATE IMPACT OF LC ON HEALTHCARE WORKERS

29. **HCWs are disproportionately impacted by Covid-19, and in turn by LC.**[84] Infection prevention and control ('**IPC**') measures were and remain inadequate, allowing widespread transmission of Covid-19 which increased the incidence of LC amongst HCWs. This led to and continues to contribute a foreseeable reduction in staffing capacity across the four nations, which inevitably impeded healthcare service delivery.

30. **IPC and PPE guidance was and continues to be inadequate for preventing the transmission of SARS-CoV-2.**[85] IPC Guidance in force at the early stages of the pandemic did not recognise the role of airborne transmission when prior experience and knowledge of similar pathogens, specifically

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[80] [INQ000421758/32] §91.
[81] [INQ000370954/68] §10.3.
[82] [INQ000236459]; [INQ000283448/1] ; [INQ000280198/20] §4.5.
[83] [INQ000421758/41] §125.
[84] [INQ000283436/1], [INQ000300548], [INQ000474276/35,43] §§84,110.
[85] [INQ000477304/114] §260; [INQ000409574/51] §127.

SARS-CoV-1 and MERS which are known to be airborne, should have guided early understanding of SARS-CoV-2.[86] Even as the evidence base developed so that by the end of September 2020, "*there was moderate certainty evidence*" to "*justify precautionary measures being taken*" to prevent airborne transmission, IPC guidance was not adapted to recognise the significance of airborne transmission. It was only in April 2022, that the new NPICM contained limited recognition of the role of airborne transmission but aerosol generating procedures ('**AGPs**') were, and are still, unjustifiably distinguished from non-AGPs.[87]

31. The ongoing resistance to recognising the significance of airborne transmission directly impacted guidance on the use of respirators and improved ventilation in healthcare settings.[88] These were affordable, proportionate measures which should have been embedded in IPC guidance from the early stages of the pandemic. Guidance also should have addressed the increased risk that ill-fitting respirators posed to ethnic minorities and women. At present there are still no general recommendations in place for wearing respirators in hospital settings; and current HTM Guidelines for ventilation are "*no longer fit for purpose.*"[89]

Recommendation: (17) all relevant guidance and guidelines should be urgently reviewed to recognise the significance of airborne transmission of Covid-19 and clearly recommend the use of respirators in all healthcare settings and improved ventilation and introduction of air cleaning devices in public buildings.[90] (18) a multi-disciplinary approach should be taken in a future pandemic response,[91] and the precautionary approach should inform IPC Guidance as the evidence base for the novel virus is developed.

XI. OCCUPATIONAL PROTECTIONS FOR LC

32. **There was a failure to systematically produce risk assessments in the healthcare system, in breach of employers' statutory legal duties to protect HCWs.** There is an ongoing legal duty on all employers to make *"suitable and sufficient risk assessments'"* of the risk of exposure to a substance hazardous to health, and to identify the steps needed to control this risk.[92] Surveys across the four nations show that risk assessments were nevertheless not updated to account for the

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[86] [INQ000273913/20] §§56-67; [INQ000410867] §110.
[87] [INQ000474276/59,108] §§144, 310.
[88] [INQ000474276/83, 109] at §314.
[89] [INQ000474276/106] §303.
[90] [INQ000474276/106] §302.
[91] [INQ000474276/112] §332(i).
[92] Regulation 6 of the Control of Substances Hazardous to Health ('**COSHH**') Regulations 2022 and Regulation 3 of the Management of Health and Safety at Work Regulations 1999 ('**MHSW**').

additional hazards posed by Covid-19, after it was classified as a Hazard Group 3 biological agent.[93] The Cabinet Office had acknowledged the disproportionate impact of Covid-19 on HCWs, yet in express contradiction of existing legal duties to protect health and safety, the February 2022 Government guidance announced that it would remove employers' responsibility to consider Covid-19 in their risk assessments, leaving employees without information as to the risk of Covid-19 in their workplace.[94] Simultaneously workplace guidance has become less protective. The guidance in place as of March 2023 no longer requires testing for Covid-19 for individuals experiencing respiratory infection symptoms and permits HCWs to return to work even when they have tested positive. [95] This increases the risk of the transmission of Covid-19 to everyone in healthcare spaces.

33. **The disproportionate impact of LC on HCWs was (i) not accurately captured in the picture painted by RIDDOR reporting or any other systematic data collection and was (ii) exacerbated by RIDDOR under-reporting which led to inadequate occupational adjustments and financial support.[96]** Covid-19 saw systematic under-reporting under RIDDOR across the four nations.[97] As of October 2023, only 36 RIDDOR reports relating to LC were received. This is inconsistent with other published data including statistics showing that the risk of infection to HCWs was six times that to the general population.[98] Instead of taking a precautionary approach, HSE continues to mis-categorise Covid-19 as a *'significant'* rather than *'serious'* risk under its EMM, overlooking the disabling, long-term health impact that LC has on the working population. This categorisation has meant there are fewer investigations into RIDDOR reports and a reduced use of Notices to improve workplace risk controls.

34. Even in the absence of clearly reported data from RIDDOR, by early Autumn 2020, the DHSC, NHS and the Secretary of State were all aware that a significant number of HCWs were already suffering from LC and by early 2021 LC as an occupational disease was recognised as an '*emerging policy issue'*.[99] Despite extensive discussion about the prescription of LC as an occupational disease between DHSC, HSE, NHS Resolution, DWP, BEIS and IIAC,[100] LC is still not prescribed as an occupational disease, which is out of step with several other countries, and severely limits the occupational protections that HCWs with workplace-attributed LC can avail of.[101]

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[93] [INQ000269869] §3.31.
[94] [INQ000086652/25] §60 ; [INQ000283436] ;[INQ000250961].
[95] Managing Healthcare Staff with symptoms of a respiratory infection or a positive Covid-19 test result, 31 March 2023 https://www.gov.uk/government/publications/covid-19-managing-healthcare-staff-with-symptoms-of-a-respiratory-infection/managing-healthcare-staff-with-symptoms-of-a-respiratory-infection-or-a-positive-covid-19-test-result.
[96] [INQ000475580] §134; [INQ000417579]; [INQ000474217/9] §8.1.
[97] [INQ000192256/3]; [INQ000400723/29] §104; [INQ000119177/4]; [INQ000477304/125] §289.
[98] [INQ000477304] § 288.
[99] [INQ000283397/7]; [INQ000283402/7]; [INQ000283404/2]; [INQ000249042]; [INQ000283383/4.
[100] INQ000283383/4]; [INQ000283390]; [INQ000283421]; [INQ000283437]; [INQ000283466]; [INQ000283476].
[101] [INQ000272149/8]; [INQ000320283].

Recommendations (19) risk assessments should continue to include the risks posed by Covid-19, as required by statute; (20) HSE guidance should encourage employers to accurately report Covid-19 occupational infections and cases of LC under the RIDDOR regulations; (21) the IIAC should be urged to review prescription of LC as an Occupational Disease for the purposes of access to Industrial Injuries Disablement Benefit; (22) the system for RIDDOR reporting and its accompanying guidance needs to be improved for future pandemics, to ensure there is a system in place to accurately report occupational disease.

XII. CONCLUSION

35. A future, different, pandemic is difficult to predict, and it is possible that the long-term consequences of infection "*could be the primary driver of mortality, morbidity and broader societal impacts.*"[102] The lessons to be learnt from the LCGs experience should inform proper planning for the healthcare system to be ready for the long-term health impacts of any future disease. It must also prompt immediate changes to the healthcare system to remedy access to care for those currently suffering from LC. The LCGs look to the Inquiry to ensure that the systemic failures that characterise the LC healthcare experience are learned from.

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[102] [INQ000421758/40] §120.