Witness Name: LCG
Statement No.: 1
Exhibits: LCG2/1 - LCG2/96
Dated: 30 May 2025

UK COVID-19 INQUIRY

WITNESS STATEMENT OF
THE LONG COVID GROUP

We, the undersigned on behalf of the Long Covid Core Participant Group, will say as follows: -

INTRODUCTION

1.1 I, Sammie McFarland, am the Chief Executive Officer and co-founder of Long Covid Kids.

1.2 I, Dr Mark Faghy, am the co-vice chair of Long COVID Physio.

1.3 I, Lucy Moore, am the chair of Long Covid SOS.

1.4 I, Natalie Rogers, am a founding trustee of Long Covid Support.

1.5 Together we represent the Long Covid Core Participant Group ("LCG"). We make this composite statement in response to the Inquiry's Request for Evidence under Rule 9 of the Inquiry Rules 2006 dated 12 July 2024.

1.6 We have provided a statement in accordance with the Inquiry's request addressing the impact of Long Covid on patients and healthcare staff in the

United Kingdom between 1 March 2020 and 28 June 2022 ("the relevant period").

1.7 This statement is broken down as follows:

1.8 Annexes:

1.8.1 Chronology of advocacy for recognition of Long Covid (LCG2/01 - INQ000516979)

1.8.2 List of the articles or reports published or contributed to by the LCG, or evidence that the LCG has given to Select Committees regarding the development of TTI policies. (LCG2/02 - INQ000516980)

The Long Covid Group

2. The LCG is comprised of the four above-named organisations. Together, our organisations represent the interests of almost two million adults and children who are the surviving victims of Covid-19 infection, who continue to suffer life-changing illness and/or disability following SARS-CoV-2 infection. All website and social media figures in the following paragraphs are correct as of 14 May 2025:

2.1 Long Covid Kids ("LCK") was established in September 2020 by a group of families whose children became victims of Long Covid. LCK supports, represents and advocates for children and young people living with the ongoing symptoms of Covid-19/Long Covid. This includes the families/caregivers and education and health professionals working with them. LCK supports over 11,000 families and has over 28,000 X (previously known as Twitter) followers and almost 6,000 Instagram followers. In October 2021, LCK became the first registered charity advocating for families, children and young people living with Long Covid and related illnesses anywhere in the world. Long Covid Kids Scotland ("LCK Scotland") is separately registered in Scotland and provides advice and support to approximately 300 families in Scotland.

2.2 Long COVID Physio ("LC Physio") was formed in November 2020 to connect physiotherapists and allied healthcare professionals living with Long Covid through social media. LC Physio provides free educational resources and advocates for the safe rehabilitation of Long Covid sufferers. LC Physio has 25,100 X (previously known as Twitter) followers, a website with more than 30,000 monthly page views, a peer support Facebook group with 535 members and an online video series watched more than 1 million times across all social media channels.

2.3 Long Covid SOS ("LC SOS") was established in June 2020 as a volunteer-run patient advocacy and campaign group. LC SOS advocates for recognition, research and rehabilitation for people impacted by Long Covid. LC SOS has over 26,000 X (previously known as Twitter) followers; 20,800 Instagram

followers and approximately 6,400 individuals have signed up to the website. LC SOS became a registered charity in May 2022.

2.4 Long Covid Support ("LC Support") began as a peer support Facebook group in May 2020, registering as a charitable company in May 2021. Membership of the Facebook support group grew quickly and there are now 67,800 members globally. LC Support also has a Facebook page with 26,000 members. LC Support has over 30,000 X (previously known as Twitter) followers and over 21,000 Instagram followers. LC Support provides support and information to sufferers of Long Covid, and campaigns for equitable access to high quality healthcare, employment and welfare rights and research into treatment for Long Covid.

3. Our organisations were established within the first year of the pandemic to advocate for recognition of Long Covid, for better public messaging around its risk, for the implementation of Covid-safe preventative measures, and for access to healthcare systems. We did so by documenting the long-term harm and disability caused by Covid-19 and shared this evidence-based information with decision-makers to advocate for change. Our organisations are mostly led by people with Long Covid or carers of those with Long Covid. Most of us have not recovered when compared to our pre-infection health and continue to experience health impairment more than three years after infection.

Long Covid

4. Long Covid is a patient derived term; it was patient advocacy that was instrumental in the formal recognition of Long Covid as a clinical illness. (Perego and Callard, How and why patients made Long Covid, Social Science & Medicine Journal, published on 7 October 2020) We use the term 'Long Covid' as an umbrella, patient-led term to encapsulate long-term illness caused by infection from Covid-19. We note that 'Post Covid-19 Syndrome' has been used by bodies such as the NHS to refer to the condition of Long Covid. We find this term inappropriate and harmful. The word 'post' creates an artificial fracture between infection and what follows. Our experience of Long Covid is that for many people there is no clear delineation of symptoms between the acute phase and the period that follows; the initial illness

has not resolved and Long Covid is not merely an after-effect of acute Covid-19. Similarly, use of the word 'syndrome' is suggestive of an illness of an uncertain aetiology rather than one rooted in infectious disease. We perceive this term as stigmatising and minimising. We urge that the patient-derived term Long Covid is used instead.

5. As set out above our groups were formed to advocate for recognition of Long Covid. We have explained our role in ensuring that Long Covid was recognised and responded to in our statements to the Inquiry in Modules 2 and 3 and have included chronology of that advocacy in the Annex to this statement.

6. In our evidence to this Inquiry in previous modules, we have explained that the evidence demonstrates that the risk of long-term sequelae of Covid-19 was foreseeable. We have also explained that after reports from people with Long Covid in social media, and the formation of our groups, it was clear that by Summer 2020, there was sufficient information and awareness that a significant number of people infected with Covid-19 were developing Long Covid.

Test Trace and Isolate ('TTI') system

7. As a group we have suffered the long-term devastating impact of infection from SARS-CoV-2. We understand that the ambition of TTI systems was to identify infected individuals, or groups of individuals, through testing, and to trace their contacts as early as possible. Potentially infectious contacts are then encouraged or obliged to reduce interactions with other people (to self-isolate), thereby reducing the overall transmission of the disease, and in turn, the overall prevalence of Long Covid in the community. Preventing acute infections of Covid-19 would in turn prevent Long Covid. The Long Covid Groups have engaged with decision makers throughout the pandemic including the UK Government, Devolved Nations, NHSE, WHO and others about the failures of their test, trace and isolate systems which increase the prevalence of, and suffering caused, by Long Covid. We have set out below a chronological list of our advocacy. Our concerns arose from the

inadequacies of the TTI systems and the failure to consider the long-term impacts of Covid-19 when decisions were made about those systems.

8. Our concerns about the TTI systems are broadly divided into:

    i. lack or absence of community testing for Covid-19;
    ii. inadequate communications about the full spectrum of symptoms of Covid-19;
    iii. discouragement of testing in the workplace;
    iv. absence of public health messaging on Long Covid;
    v. inadequate financial support for isolation.

9. These concerns are expounded upon below:

Access to testing for Covid-19

10. We support and encourage widespread access to testing for Covid-19. Limited Access to tests for Covid-19 has had a profound impact on how straightforward it is to be diagnosed with Long Covid which we set out in more detail below. We are concerned that the TTI system, instead of facilitating access to tests, stopped community testing on 12 March 2020 at a critical point in the pandemic.

11. Even then, there was limited capacity for those who had access to testing in the NHS. Lindsey, an LCP member reports:

"At this point (early 2020) NHS healthcare workers could access covid tests but general population testing was unavailable. I immediately contacted work to ask for a covid test but they failed to provide one. By the time public tests were finally available I tested negative. This caused me many problems as we didn't know for sure whether I had had covid and at times caused difficulty accessing services for my son and I as we didn't have a covid positive test. Once antibody testing became available to NHS staff I again asked my employer for an antibody test as having the presence of antibodies would have allowed me to prove I had had covid. Again,

despite asking repeatedly, work failed to provide me with one." [LCG2/03 - INQ000356270/36]

12. When community testing was resumed in May 2020, there continued to be barriers to accessing Covid-19 tests including shortages of tests, discouragement of workplace testing and a lack of accurate public health information about the known symptoms of Covid-19 and risks of Long Covid. We wrote to key decision makers about the importance of making Covid-19 tests freely available for people and other related concerns on many occasions as set out in the chronology below. When testing did become available again in May, those who had been trying to have their illness recognised since March were retrospectively testing. Unsurprisingly, this resulted in them receiving negative test results, consequently they had inaccurate information on their medical records.

Children and young people

13. We were also concerned that there were barriers to children accessing tests and the impact of transmission on children and young people. Long Covid Kids has repeatedly sought to engage with Government, healthcare providers and schools. Harm to children from Covid-19 infection has been consistently overlooked and public messaging about the risks of Long Covid to children has been dismissed despite the Government being presented with evidence of the devastating impact on some children.

14. LCK members include families where children were not able to access tests and this had adverse consequences as it made the diagnosis of Long Covid difficult as they could not show a positive test. LCK advocated for testing as a measure to assist diagnosis and prevent transmission, particularly when vaccination was not available for children and is now no longer available for children under the age of 12 years old unless they are clinically extremely vulnerable.

15. For much of the pandemic, children have had higher exposure to COVID-19 from being in school or pre-school settings, often with minimal measures in place to protect them. Testing was never made available to primary school children, unlike in other European countries (e.g., Austria), where accessible testing (e.g. saliva tests) for young children was prioritised. On 26 January 2021 members of Long Covid Kids gave evidence to the APPG on Coronavirus [LCG2/04 - INQ000272149]. LCK raised concerns that the Government had not communicated that children can suffer long term harm from infection, about aerosol transmission and about safety measures in schools. It is our view that schools and educational settings failed to adequately protect children from contracting Covid-19 and therefore, develop Long Covid because they failed to implement adequate mitigation measures like test trace and isolate.

16. As of March 2023, the NHS general advice for parents and guardians of children who may be having Covid –19 symptoms is: *"If your child has mild symptoms such as runny nose, sore throat or mild cough, and they feel well enough, they can go to school or childcare."*

17. This advice may potentially result in children attending school whilst positive for Covid-19, possibly transmitting Covid-19, as well as children developing Long Covid.

Communicating Covid-19 symptoms

18. Understanding the symptoms of Covid-19 was a key public health issue that was essential to knowing whether to test or not. SAGE 34, which met on 7 May 2020, noted "*the importance of the public understanding Covid-19 symptoms for testing and tracing to work.*" [LCG2/05 - INQ000512740]

19. Through patient advocacy, we highlighted from an early stage of the pandemic, that Covid-19 presented with multiple different symptoms beyond a fever, cough and change of taste or smell. The Centers for Disease Control and Prevention ("CDC") had an extensive symptoms list which more accurately reflected the symptoms of acute Covid-19 whereas the NHS symptoms list was not updated until after free testing was ended in April 2022 [LCG2/06 – INQ000516895 (Covid-19: UK adds

sore throat, headache, fatigue, and six other symptoms to official list | The BMJ April 2022) and LCG2/07 - INQ000516902: BBC Article: Coronavirus symptoms: UK adds loss of smell and taste to list, 18 May 2020)]. The NHSE has so far not given a reason to explain why the list of symptoms associated with Covid-19 were only updated in April 2022, despite developing evidence that the official guidance was out of date. This undue delay meant several individuals did not know that their symptoms were attributable to Covid-19 and did not therefore think to test. [LCG2/08) – INQ000320241]

20. In addition, the only way to be able to access a free test was to present with symptoms published as consistent with Covid-19. However it was a concern to us, and we raised with decision makers that the symptoms of Covid-19 extended far more than the cough, fever, loss of taste or smell symptoms that were publicised.

21. The official advice that Covid-19 presents with a limited number of symptoms (fever, cough and breathlessness — latterly updated to include change in sense of smell) meant some people with atypical presentations were not tested early, or in some cases not tested at all [LCG2/09 - INQ000058418]. This failure to recognise the wide range of symptoms caused by Covid-19 adversely affected people accessing treatment and care as they were not believed to have Covid-19 if they did not have one of the three officially recognised symptoms. This in turn made it even more difficult to convince medical professionals that the long-term symptoms people were suffering from, were caused by SARS-CoV-2 infection. A further consequence, of this was that some people struggled to receive fit notes and if they did manage to receive fit notes, it did not attribute their ongoing symptoms to Covid-19, and for some people this in turn caused them issues with absence management procedures.

22. In children, Covid-19 presents differently to adults and yet the same published symptoms were used as the gateway to being tested. For example, researchers from King's College and ZOE analysed symptoms children recorded in the ZOE Covid Study App (https://health-study.zoe.com/post/long-covid-children) and stated

"Interestingly, the classic three symptoms required for an NHS PCR swab test were less common in children, with 40% reporting anosmia, 38% developing a fever, and 26% suffering from a cough."

Public health messaging on Long Covid

23. The LCGs are concerned that there has been a lack of public health messaging warning about the risk of Long Covid and about how to identify the symptoms of Long Covid [INQ000370954]. This has resulted in a lack of public awareness of those risks and misconceptions that Covid-19 is only of concern to those identified as at risk from acute infections of Covid-19. In fact, Long Covid carries an indiscriminate risk of harm as people who are not in the risk categories for acute Covid-19 infections are still at risk of developing Long Covid.

24. We are not aware of any public health messaging campaign warning the public of the risks of Long Covid, to date. There was one video by the DHSC in October 2020 which publicised Long Covid [LCG2/10 - INQ000283375] and the communications we have seen through the Inquiry seem to link raising awareness of Long Covid with behavioural compliance [LCG2/10 - INQ000283375; LCG2/11 - INQ000272221; LCG2/12 - INQ000390891] Ferrer R, Klein WM, Risk perceptions and health behavior. Curr Opin Psychol. 2015 Oct 1: 5;85-89. Doi:10.1016/j.copsyc.2015.03.012. PMID:26258160; PMCID: PMC4525709). However, this is not something that was addressed to us directly by any Government or healthcare bodies. The public simply have not been told of the risk of Long Covid and so often do not understand that their illness could be related to Covid-19 and so they should test.

25. We understand that effective messaging was a tool the Government used for behavioural compliance with TTI strategies. It is not clear to us therefore why given the indiscriminate risk of Long Covid to any adult or child, the UK Government decided not to raise public awareness of Long Covid to encourage behavioural compliance with TTI strategies when they were in place, and promote minimisation behaviours measures to manage the risk of Covid-19 when those strategies were inoperative.

26. Our concerns about the lack of communications about the risk of Long Covid also extend to the period when the UK Government abandoned efforts to limit transmission of Covid-19 from February 2022. When the UK Government and Devolved Nations' Governments took decisions to remove measures mitigating the risk of Covid-19 transmission, they did so in the knowledge that this would result in more people suffering from long term loss of health and disability from infection of SARS-CoV-2. For example, in July 2021 "High Prevalence Planning" policy documents explicitly acknowledged the risk of Long Covid (which includes risk to children as well as adults) but this did not prompt the introduction of measures to mitigate the indiscriminate risk of Long Covid. There was no co-ordinated public health messaging at the time that restrictions were removed, to warn the public, parents and carers of the risks of developing Long Covid. The Cabinet Office paper "High Prevalence Planning: Summer Response" dated 21 July 2021 [LCG2/13 - INQ00092058] refers to Test Trace and Isolate capacity and recorded "*Long Covid: What is the proposed strategy to address the cumulative impact of long covid on public and private sector workforce and what mitigations do DHSC/DWP have on sickness absence.*" Despite this acknowledgement of the risk of Long Covid, there were no public health messaging campaigns on the risks Covid-19 poses to otherwise healthy adults and children.

27. This remains the case even now, despite there being no Covid-safe mitigation measures in place. This ongoing failure to adopt a risk mitigation measure such as public messaging means that individuals were not and are not aware of the risk posed to them and those they cared for, and so could not adapt their behaviour to mitigate this accepted risk.

28. It remains a significant concern to us that the indiscriminate risk of Long Covid remains largely ignored. Further, it remains unknown what consideration (if any) the government gave to warn the public about Long Covid.

Adequacy of financial support for TTI

29. We are concerned that without adequate financial support for self-isolation, people who had low incomes or were in insecure work were in a precarious financial position. As Mr Rotheram, Mayor of Liverpool City Region, explained in his oral evidence in Module 2 on 27 November 2023: "*were choosing whether to stay home and get no pounds, no pence or take the chance they didn't have Covid and go to work.*" (Module 2 hearings, Day 26, 27.11.2023, p.188, l.2 – 1.10)

30. As Professor Sir Christopher Whitty, Chief Medical Officer of England, explained in oral evidence in Module 2 on 22 November 2023:

> "*it was far easier to self-isolate… if you were in a job which was in permanent employment… then if you were in a self-employed environment, which many people, particularly on lower incomes, were… it was essential that we took account of that, particularly given that some of the highest incidence of Covid was in areas of relative deprivation, where there were higher rates of people who were not in continuous employment and therefore covered by ordinary sick pay.*" (Module 2 hearings Day 24, 22.11.2023, p.145 l.9-l.21)

31. Part and parcel of an effective TTI system is the provision of financial support for isolation to those who do not obtain that support from their employer. The LCGs are concerned that the Government's failure to provide financial support demonstrates a failure in understanding the centrality of an effective TTI system in responding to a novel pathogen.

Occupational Exposure

32. Some jobs put people at greater risk of exposure to Covid-19 such as healthcare workers and teachers, yet in these jobs, testing was being actively discouraged.

33. It was the experience of some of our members who are healthcare workers that they were advised by their employer to turn off the contact tracing app whilst at work as otherwise they would receive notifications all the time. It is concerning to us that this type of practice to circumvent the efficacy of the TTI system was being encouraged by employers within healthcare settings.

34. This remains the position as at October 2024. Long Covid Physio asked on their membership group about the current position for testing. Members reported differing practices across the UK by healthcare based staff. For example a LCP member in Gloucestershire reported that staff were told they do not need to test and could attend work when positive for Covid-19 unless they were unwell; a LCP member in North Devon reported that there were no tests for staff which meant if you did not test you could continue to work, but if a staff member did test positive then they were told to isolate for 5 days; a member in a London hospital reported that Covid-19 was treated like any other illness so staff were required to stay home if poorly but could otherwise attend if positive; a member in West Suffolk reported that staff were encouraged not to test and no tests were provided to staff and that they were to remain home if unwell but could attend if positive; a member in Scotland said that they had been told testing was not recommended and that they should attend work if positive and well enough. The current guidance to healthcare staff (LCG2/14 – INQ000516854 Guidance Managing healthcare staff with symptoms of a respiratory infection or positive covid-19 test) states that "*most healthcare staff who have symptoms of a respiratory infection are no longer asked to test for Covid-19. Healthcare staff who test positive for Covid-19 are no longer required to have 2 negative lateral flow devices (LFD) tests for Covid-19 before they return to work*". Only staff providing direct care to inpatients who are severely immunosuppressed "*should*" take a LFD test if they develop symptoms of a respiratory infection in "*line with local protocols.*" It is LCP experience that testing even when working with immunosuppressed patients is inconsistent. LCP members feel unsupported and unsafe at work. The focus of the NHS policy completely ignores the risk of Long Covid despite the risk of Long Covid ending careers and severely damaging health, furthermore, the guidance is contrary to NHS guidance which states that you should avoid meeting people who are at higher risks of becoming seriously unwell, for 10 days after testing. There is no way of knowing who is at risk of becoming seriously unwell.

35. Healthcare workers in our membership report feeling anxious and concerned that they were, and continue to be, expected to work in the absence of free regular

testing. This contributed to the overall transmission of Covid-19 and in turn the prevalence of Long Covid.

36. As of March 2023, the general advice to anyone who may be having symptoms of Covid –19, provided on the NHS website is:

"Try to stay at home and avoid contact with other people if you or your child have symptoms and either

have a high temperature

Do not feel well enough to go to work, school, childcare, or your normal activities

You can go back to your normal activities when you feel better or do not have a high temperature."

37. This advice means that many people are returning to work whilst having Covid-19 therefore potentially spreading Covid-19 and increasing theirs and others risk to Long Covid. Furthermore, if a person does not have the financial resources to stay at home and isolate, they may return to work despite being positive for Covid-19.

Impact of failings in the TTI systems

38. The failings in the TTI system have had a devastating and long-term impact on people with Long Covid in that: (i) they failed to limit transmission of Covid-19 meaning more people contracted Covid-19 and went on to develop Long Covid and (ii) reliable testing proved to have significant consequences for the diagnosis and support made available to people with Long Covid, as well as limiting understanding of Long Covid through the knock on effect on data and research into Long Covid.

Failure to limit transmission

39. The failure to limit high transmission through measures, including test, trace and isolate strategies, meant many more people contracted Covid-19 and went on to develop Long Covid. In his written advice to the Prime Minister on 31 May 2021, the Chief Medical Officer ("CMO") Sir Chris Whitty said the best way to prevent Long Covid was to "*stop people getting COVID; no COVID, no Long COVID* [LCG2/15 -

INQ000251916]. However, we could not see evidence of this logic informing TTI systems.

40. We understand that the risk of post-acute sequelae of viruses was well known from previous viruses, and it was foreseeable that there would be a risk of people suffering from long-term sequelae of Covid-19 [LCG2/16 - INQ000280198]. Awareness of the risk of post-viral sequelae was documented in July 2020 in a report by the Academy of Medical Sciences *"Preparing for a Challenging Winter 2020/21"* [LCG2/17 - INQ000440246]. The report explicitly referred to the likelihood of post-viral sequelae from Covid-19 by reference to previous viruses including SARS-1, Chikungunya and Ebola. The risk of post-acute sequelae was also acknowledged in a Briefing Note on Managing the Long Term Effects of Covid-19 for Sir Stephen Powis dated 28 August 2020 [LCG2/18 - INQ000205638]. The briefing note states:

> *"A proportion of this group are expected to experience persistent or permanent physical health problems similar to the long term respiratory, musculoskeletal, and neuropsychiatric symptoms that have been described for other coronaviruses (Severe Acute respiratory Syndrome (SARS) and Middle Eastern Respiratory Syndrome (MERS)) which have parallels with post-acute Covid-19."*

41. As the risk of post-acute sequelae was well-known, we are concerned that the TTI systems failed to limit transmission of Covid-19 in the early stages of the pandemic, and that a decision was made to abandon community testing in March 2020.

42. We also are concerned that even as knowledge and recognition of Long Covid was growing in Summer 2020, this was not factored into decision making about TTI systems. The TTI system was still ineffective in Autumn 2020 and unable to effectively monitor and limit transmission of Covid-19.

43. In June 2021, as the Government prepared to remove restrictions and abandon strategies to prevent high transmission of the virus, the LCGs wrote to Sajid Javid, Secretary of State for Health and Social Care, raising concerns that the TTI system should not be completely dismantled because of the ongoing risk of Long Covid; see for example letter dated 6 July 2021 from Long Covid SOS (LCG2/19 - INQ000238584). This stated "*There may not be a perfect time to lift all restrictions,*

but the time is certainly not now. Transmission is increasing at a startling rate and 36% of adults are not yet protected with two vaccine doses. Infection levels in schools are now approaching those at the height of the second wave. We asked you to urgently reconsider the timing of the removal of all measures to mitigate the spread of covid-19."

44. The Office for National Statistics - Self-reported coronavirus (COVID-19) infections and associated symptoms, England and Scotland: November 2023 to March 2024, released on 25 April 2024,reported the following: an estimated 2 million (3.3%) people have Long Covid, including approximately 65,988 children. This is higher than the estimated percentage reported at the end of the UK-wide Coronavirus (COVID-19) Infection Survey (CIS) in March 2023 (2.9%, 95% confidence interval: 2.8 to 3.0%). Therefore 1.5 million people's day-to-day activities are affected by Long Covid symptoms, of those 381,000 people report that their ability to undertake their day-to-day activities had been *"limited a lot"*; 71.1% experienced Long Covid symptoms a year or more, 51.3% experienced long Covid symptoms for at least 2 years and 30.6% (approx. 600,000 people) experienced long covid symptoms for more than 3 years. (LCG/20 – INQ000370954)

45. It is evident that the high transmission of Covid-19, and the continued unmitigated transmission even now, is causing more avoidable incidents of Long Covid. Whilst vaccination has been shown to reduce the likelihood of developing Long Covid, the numbers of people suffering Long Covid are growing.

Impact of absence of testing on Long Covid

Diagnosis and treatment

46. Access to tests became an important marker for obtaining a diagnosis of Long Covid. The inadequacies of the testing systems impeded many non-hospitalised Long Covid sufferers from obtaining a confirmation of their Covid-19 infection, which proved to be an obstacle to obtaining a diagnosis of Long Covid and being referred into Long Covid healthcare pathways. Module 3 Long Covid Groups Witness

Statement (dated 28 November 2023) paragraphs 2.2 and 3.3 provide examples of case studies demonstrating that this was a systemic issue. [LCG2/20 - INQ000370954]

47. Medical professionals did not accept that presenting symptoms were caused by Covid-19 both because of the absence of a positive test result, but also because of the lack of recognition of symptoms beyond the three formally noted on the NHS website. Dr Evans, the Long Covid expert to the Inquiry explained in oral evidence in Module 2 on 13 October 2023, that the lack of community testing was expressly linked to the delay in recognition of Long Covid.(Module 2 hearings: Day 9, 13.10.23, p.93 l.15 – p.94 l.22 & Day 9, 13.10.23, p.97 ll.15-19)

48. We exhibit to this witness statement at LCG2/03 - INQ000356270; LCG2/21 - INQ000356271; LCG2/22 - INQ000356272 to LCG2/22 - INQ000356273 case studies of people suffering from Long Covid. These are case study summaries from our members and are provided to illustrate the range of problems people with Long Covid experience from the severity of their symptoms, to gaining access to adequate care and treatment. Below are examples extracted from the exhibited case studies:

- Case Study 2 [LCG2/03 - INQ000356270] an adult states "*Most likely initially infected through work, although this is not confirmed due to no testing outside of hospital […] As time has gone on some healthcare professionals know and understand more but others are still very dismissive and can't understand symptoms they can't see. On one A&E visit my stats were 90% and I was told 'ahh but you had Covid so that's fine'*."

- Case Study 4 [LCG2/23 – INQ000356273], an adult states: "*My initial symptoms were ear pain, fever and fatigue. PCR testing wasn't available to the general public at that time so I did not have a confirmed diagnosis of Covid-19. I self-isolated in my flat by myself for 10 weeks … During this time I was in contact with numerous doctors. As I did not have a positive test and I did not present with a cough, they were of the opinion that I did not have Covid. I was diagnosed with anxiety and depression and prescribed anti-depressants".*

49. Further we rely on the lived experiences of two of our members to illustrate the significance of widespread testing to their experience of suffering from Covid-19. We refer to:

- *FJ* said: *"Most likely infected through work although this is not confirmed due to no testing outside of hospital…It was only through the positive antibody test given for working for the NHS that I was able to prove I had Covid…* They state their symptoms include *"POTS, severe fatigue, recurrent chest infections, moderate to severe muscle aches… extremely limited mobility (now rely on someone pushing me in a wheelchair to get out.)"* [LCG2/03 - INQ000356270] Long Covid Physio, Case Study 2 (FJ).

- *GE* said *"…PCR testing wasn't available to the general public at that time so I did not have a confirmed diagnosis of Covid-19. I self-isolated in my flat by myself for 10 weeks.*" He explained that not having a positive test led to him being misdiagnosed: "*As I did not have a positive test and I did not present with a cough, they were of the opinion that I did not have Covid. I was diagnosed with anxiety and depression and was prescribed anti-depressants… I was sectioned and placed on a mental health ward for a month."* He was bed bound for 6 months, he developed deep vein thrombosis twice and is now on blood thinners [LCG2/24 - INQ000272244] LC Support, Case Study 4 (GE).

50. The Government's decision to stop community testing for Covid-19 on 12 March 2020 meant that a large number of people who developed Long Covid had no access to testing in the community. Those who went on to develop Long Covid had no positive test result on their records to link their symptoms to infection with Covid 19. [LCG2/25 - INQ000320233].

Access to Long Covid services

51. The lack of community testing created obstacles for people seeking care from the healthcare system. 92% of participants in a September 2020 survey of patients'

experiences with GPs undertaken by LC SOS were unable to show a positive PCR test when presenting with Long Covid [LCG2/26 - INQ000320234, GP Survey Report Long Covid SOS]. In surveys completed by LC Support "Long Covid Patient Experience Assessment Services Survey" in March 2021 [LCG2/27 - INQ000272247], 268 sought referrals to Long Covid services/clinics, of those 181 were refused referrals: 129 due to doctor being unaware that a Long Covid clinic was in the area, 31 respondents considered that GPs disbelieved them, 12 respondents stated GPs "*won't refer as not hospitalised/no positive test.*"

52. Of 70 that were referred to Long Covid services, 6 were refused an appointment on the basis that they were not hospitalised or did not have a positive test. A patient is reported as a saying

> "*Doctor agrees am post viral but as no Covid test won't refer. Think had it March 2020 when couldn't get test. NHS Sheffield CCG 20.04.21*"
>
> *"I made my GP refer me. They said won't be accepted as I have no positive test and I was not on ventilator or in hospital. I never heard any reply, it's been 3 months so I guess I was refused. NHS Tower Hamlets CCG 22.04.21"* [LCG2/27 - INQ000272247/48]

53. Whilst this sample is small it does show that despite the *NICE Covid-19 rapid guidelines: Managing the long-term effects of Covid-19* recommending that absence of a positive test should not be a barrier to either diagnosis or treatment or referral to Long Covid service - in practice it was. [LCG2/28 - INQ000238545] The decisions taken by the Government to restrict community testing had a devastating impact on the ability of people with Long Covid to access the services they needed.

54. The Long Covid Groups raised the impact of absence of testing with relevant decisions makers as we set out below.

Research on Long Covid

55. The lack of testing also affected clinical guidance and research. For example, WHO discussions about the case definition for post Covid-19 condition in children and adolescents record that there was a discussion about excluding children and young people that did not have a positive test despite the failures in testing both at the start of the pandemic and currently. Whilst the definition was in favour of a clinical finding of "probable" history of SARS-CoV-2 infection this highlights the problem of failing to have recommended, free and available testing [A clinical case definition for post Covid-19 condition in children and adolescents by expert consensus 16 February 2023 LCG2/29- INQ000320231/22].

> *"One component of the case definition that elicited vigorous discussion was whether the case definition should only apply to children and adolescents with laboratory-confirmed SARS-CoV-2 infection or whether those with "probable", clinical COVID-19 should also be included. The panel discussed if the available evidence regarding symptoms should still apply if a child with no prior positive diagnostic test developed symptoms of post COVID-19 condition."*

56. The absence of tests also prevented people from participating in research on Long Covid because a requirement of the studies was for infection to be confirmed. [Living with Covid-19, Second Review, 16 March 2021 by NIHR LCG2/30 – INQ000516869]. "*The importance of patient-partnered research in addressing long COVID: Takeaways for biomedical research study design from the RECOVER Initiative's Mechanistic Pathways taskforce*" reported:

> "*Many in the 'first wave' of the alpha coronavirus variant found themselves unable to participate in research due to stringent protocol criteria…, study time frames could not be changed to include early 2020 SARS-CoV-2-infected patients who did not have a positive antigen test result because testing was scarce at the time* " (LCG2/31 - "INQ000516870")

57. The exclusion of a willing cohort of research participants results in limited data on Long Covid and skewed research findings. The impact is felt keenly in research on Long Covid as the Briefing Note from NHS Test and Trace, Joint Biosecurity Centre on Long Covid dated 28 January 2020 [LCG2/32 - INQ000283403/4] reported:

"...more information is urgently needed to assess the burden of disease after illness. Whilst observational studies to date suggest the potential for considerable morbidity with COVID-19... if even a small proportion of those with COVID-19 experience symptoms long-term, given the numbers of people who have been, and will be, infected, this would still represent a considerable ongoing burden of disease."

58. On 8 February 2021, LC Support wrote to Lord Bethell, pleading for "urgent facilitation of recruitment for crucial trial, which – if successful – would not only prevent Long Covid, but also severe acute cases." They explained that they were contacted by FLARE trial who informed them that: "recruitment in the community is being hampered as the process to request Test and Trace contact details of positive cases is too slow. LC Support proposed: "Could obtaining Test and Trace contact details be urgently facilitated for early treatment trials whilst they are still cases to recruit?" [LCG2/ 33 - INQ000516872 – Email from member of LC Support to Lord Bethel dated 8 February 2021]. The response from FLARE clearly identifies that issues with the TTI were negatively impacting the progress of research into Long Covid.

Data and Surveillance

59. Limited access to tests also impacted data gathering. The lack of tests led to poor and inconsistent use of the SNOMED codes for Long Covid as GPs were less inclined to record patients' symptoms as diagnosed Long Covid where they were unable to conclusively provide a positive test result. This in turn, led to inaccurate patient records. This had an impact on the individual's ability to access Long Covid healthcare, and on public health service delivery as a whole as coded figures for Long Covid belied the actual prevalence of Long Covid amongst the general population.

60. A report prepared with the TUC LCS (Workers' experiences of Long Covid – A joint report by the TUC and LC Support, March 2023) raised concerns about surveillance stating that:

"However, an ongoing issue when analysing the disproportionate impact of Covid-19, is a lack of public understanding on what constitutes Long Covid, the difficulty in gaining a diagnosis, the range of symptoms people can experience and that some people would not have had a positive Covid-19 test due to the difficulties that many experienced in accessing tests at the start of the pandemic and the ending of free testing in 2022. This is likely to impact people's ability to report it accurately." [LCG2/34 - INQ000272240/22].

Impact of TTI on Long Covid and health inequalities

61. As of March 2024, the ONS reported in their latest Winter Coronavirus (COVID-19) Infection Study data that an estimated 2 million people in the UK were reporting Long Covid symptoms. The ONS have found a large increase in disability, and the impact this has on workforce attendance and job loss [LCG2/35 - INQ000238600]. Long Covid has created a cohort of newly disabled people, who include healthcare staff, teachers and social workers. This creates new health inequalities in addition to the exacerbation of previous health inequalities. Our members will have and continue to experience further health inequalities arising from the lack of access to care, inadequate care, treatment and support.

62. Our members highlight the debilitating impact of Long Covid, having previously been fit, active and healthy to having their health destroyed, unable to walk a few metres, some becoming wheelchair bound, being diagnosed with Postural Orthostatic Tachycardia Syndrome, problems breathing, fatigue and chest pains amongst other symptoms. As NHS England and NHS Improvement highlight patient experiences in their presentation to Asthma UK and British Lung Foundation "there is a total lack of understanding around Long Covid. For example, if you are fine or slightly unwell and recover in your 10 days…people understand this. However, being unwell it is more difficult to understand — but not to the point of hospitalisation — but still struggling to recover is, in my experience, difficult for people to understand." [LCG2/36 - INQ000270139/37]. Furthermore, this also highlights the difficulties faced with recognition and diagnosis of Long Covid and finding care and support resulting in further health inequalities.

63. In addition to the new class of disabled people referred to in paragraph 53 above, data from ONS showing that those in the most deprived quintile are 81% more likely to suffer from Long Covid as compared to those in the least deprived quintile (Office of National Statistics (ONS) (February 2023) 'Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK'). Long Covid data from the Department of Health and Social Care dated 14 April 2022 also supports that patients from the most deprived areas were disproportionally represented [LCG2/37 - INQ000193812]. Socio-economic inequalities contribute to higher rates of Long Covid in economically deprived areas.([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:/fjournals.sagepub.com/doi/10.1177/0141076823 1168377; Health Equity North, Navigating the Long Haul: Understanding Long Covid in Northern England.)

64. The pre-pandemic structural inequalities which resulted in those from minority ethnic, deprived and under-served communities being disproportionately affected by Covid-19 also follow through to those who suffer from Long Covid. Patients from such communities have found it even more difficult to convince healthcare professionals of the existence of their illness, and then struggled to access treatment and rehabilitation.

65. A study by Southampton University aims to raise awareness among black and minority ethnic communities [LCG2/38 - INQ000320290]. Under-reporting may demonstrate the adverse impact that the failure of public health communications about Long Covid had on health inequalities.

66. Research also suggests that more women experience Long Covid (Bai F, Tomasoni D, Falcinella C, Barbanotti D, Castoldi R, Mulè G, Augello M, Mondatore D, Allegrini M, Cona A, Tesoro D, Tagliaferri G, Viganò O, Suardi E, Tincati C, Beringheli T, Varisco B, Battistini CL, Piscopo K, Vegni E, Tavelli A, Terzoni S, Marchetti G, Monforte AD, 'Female gender is associated with long COVID syndrome: a prospective cohort study', Clin Microbiol Infect. 2022 Apr;28(4)). Healthcare misogyny means that women struggle to get access to services, especially services

that are proportionate for their needs. This has been no different when it comes to accessing services for Long Covid, and LC Support provided evidence to the DHSC 'Women's Health Strategy: Call for Evidence' in June 2021 [LCG2/39 - INQ000272255]. Our members report that their Long Covid symptoms have been dismissed or misdiagnosed as menopause or mental health conditions, which has been exacerbated by lack of a testing that could connect their symptoms back to being infected with Covid-19. Women have reported losing their job because of Long Covid and are therefore more likely to be financially impacted as a consequence of developing Long Covid.

67. Contract tracing dependent on an app may exclude some groups who suffer from digital exclusion. Healthwatch England's report [LCG2/40 - INQ000366258] raises important points about how a lack of digital skills, age, disability, poverty, a lack of trust and language barriers are all factors of digital exclusion that exacerbated inequalities during the pandemic, particularly in relation to access to healthcare. TTI systems that are wholly reliant on an app will exclude several cohorts of the population, and so be ineffective overall in managing transmission of Covid-19.

LCGs advocacy on TTI systems

68. On 28 August 2020, LC Support wrote to Jeremy Hunt, the former chair of the UK Health and Social Care Committee highlighting the impact of the failure to provide community testing on people with Long Covid [LCG2/41 - INQ000248911]:

> *"A large number of us served on the front line of the response to COVID-19, many of us in the earliest days of the pandemic. Our persistent, ongoing health challenges are distressing not only because they were avoidable, but also because far too many of our peers in the health and social care sectors are failing to respond with the care and support that we desperately need, because they do not have the information they need to provide the right responses now. Sadly too many of our UK members are reporting experiences of extremely poor, uninformed and dismissive responses from professionals in health and care sectors when we turn to them for help. This is not the fault of individuals,*

rather that the systems are failing us - when we try to access health care, social care and benefits - often because there is inadequate awareness about the thousands of us who have not received a positive test result or been hospitalised."

69. We asked for urgent action by way of research, public health messaging, employment support:

Diagnostic reliability - A positive test result (antigen - swab - or antibody) should not be used as an access point to services and care - nor should the lack of diagnostic test results be used to deny access - until the tests are refined and become more sensitive and specific. ***Most of us were not tested in the acute phase because we were instructed to stay at home (and so could not access tests, which were also in short supply at the time most of us were infected); we have had to manage our symptoms syndromically (by symptoms not tests).*** *A good proportion of us have since tested antibody negative and there are theories that Long Covid may be associated with a weak or abnormal immune response at the outset, as well as the growing understanding that antibody levels fade over time. We need more and better diagnostic capacity as the use of testing as a public health intervention grows."* (Emphasis added)

70. On 10 September 2020, Matt Hancock MP gave evidence to the Health and Social Care Committee. He acknowledged the existence of long-term symptoms of Covid-19 and that the impact of Long Covid can be debilitating for a long period of time. At the end of the hearing, Jeremy Hunt, the Chair of the Health and Social Care Committee asked Matt Hancock MP to send him a reply to our letter of 28 August 2020 [LCG2/41 - INQ000248911] and the points raised in it. Matt Hancock confirmed he had seen the letter the night before and would reply to it, which he did on 14 September 2020 though we have not seen that letter.

71. On 12 October 2020 Jeremy Hunt wrote to Matt Hancock stating that our main points had not been addressed, including that awareness of the "*risks of acquiring the complex long-term condition known as Long Covid."* [LCG2/42 - INQ000249042]

72. In October 2020, LCSOS presented a report highlighting from a survey of patients' experiences with their GPs to the Ministerial Roundtable [LCG2/43 - INQ000292639] on Long Covid. This stated [LCG2/26 - INQ000320234]:

> *"On average, as of 09/09/2020, the length of illness reported was 165 days which translates to approx. 5.3 months or 23 weeks. 68% of respondents were first taken ill in March 2020. 98.5% are still suffering symptoms.* ***Almost 92% did not receive a positive PCR swab test result, which we interpret as being due to the lack of community testing when the vast majority became sick.*** *Antibody testing achieved only 11.1% positive results which is likely related to limited availability and prevalence of false negatives. The majority, 86.7%, were not admitted to hospital."* (Emphasis added)

73. On 16 October 2020, LCSOS raised with ONS that as testing had resumed, there should be better access to data to assess prevalence of Long Covid:

> *"You may remember me sending out a plea for the number of people with Long Covid to be counted so that we have a more accurate figure than "Tens if not hundreds of thousands" (quote from Simon Stevens BBC News)...*
>
> *Getting a fix on the numbers is something I've become very interested in over the past few months. Clearly it is in constant flux as people recover and more unfortunately get sick and become a new long haulers but I think it would benefit everybody, especially the NHS, if we could have some proper data. It would also be useful for the DWP as the condition seems to prevent so many from being able to work. The #countlongcovid hashtag is pretty popular on twitter. Now that more people are being tested, an indication of the percentage sick for 1, 3, 6 or more months should help us arrive at more solid date."* (email from Ondine Sherwood, 16 October 2020 [LCG2/44 -INQ000272223])

74. On 16 October 2020, following the first Long Covid Ministerial Roundtable, LC SOS contacted the ONS about the urgent need to count Long Covid and its absence from the national Covid-19 statistics as a measure of the impact of the pandemic

[LCG2/44 - INQ000272223]. This led to meetings with the ONS on 29 October 2020, 12 February 2021 and 17 September 2021.

75. Separately, LC Support contacted ONS on 7 February 2021 [LCG2/45 - INQ000249020] and 12 February 2021 [LCG2/46 - INQ000248996] following a presentation from the ONS at the Long Covid Ministerial Roundtable on 29 January 2021. In these emails, LC Support raised concerns about the survey questions proposed by the ONS, stating that many people would not be aware of Long Covid, or consider themselves to be suffering from it. It was suggested that the survey questions should instead ask about the symptoms being experienced, and the length of time they were being experienced. This led to a meeting with the ONS on 16 February 2021.

76. This meeting was followed up with a further email from LC Support to ONS on 22 February 2021 [LCG2/47 - INQ000249021], again raising concerns about the phrasing of the survey questions and providing suggested questions:

> *"To reiterate, we are concerned at the phrasing of the question that presupposes a survey respondent knows that they have had Covid (let alone Long Covid). We suggest that more meaningful insights into the prevalence and impact will result from asking whether they have newly experienced any of the listed symptoms for a period of 4 weeks or more since March 2020 AND asking about the impact of these on their activities of daily living, work etc (and for how long)."*

77. On 1 April 2021, the ONS published its very first bulletin on Long Covid [LCG2/48 - INQ000320261]. In that release, it was estimated that 1.1 million people were experiencing Long Covid.[2]

78. On 7 February 2021, LC Support communicated with ONS about the list of Covid-19 symptoms being limited, we stated:

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[2] Office for National Statistics (ONS), released 1 April 2021, ONS website, statistical bulletin, Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 April 2021

"My sense is that a large proportion of people will remain unaware of ever having had Covid, let alone Long Covid, on account of the poor communication of the breadth of symptoms (even today, Googling "NHS covid symptoms" results in a page that lists only cough, fever and loss of taste or smell - with all the risks of unwitting spread that brings)." [LCG2/45 - INQ000249020]

79. This led to further consideration of the proposed questions for the ONS LC survey as set out in the below email on 22 February 2021 [LCG2/47- INQ000249021], which continues to show the inextricable link between the lack of testing and the TTI system's failure in that regard, and the paucity of accurate data on the prevalence of Long Covid:

"We are concerned that you only plan to direct the Long Covid question to those who have a positive PCR test. We feel it would be better to direct the question to all participants of the survey, for the following reasons:

1. *It is important to consider that PCR test reliability is time dependent and quickly declines. If a person was recruited into the study at say 2 weeks into their acute illness (who had not requested a PCR test at symptom onset because their symptoms weren't those on the limited NHS list of 3) that person would then test negatively and not be followed up for Long Covid symptoms:*
   https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-020-01810-8
2. *If this person was then given an antibody test, they may not necessarily test positive as not all people have a strong antibody response, instead they have a stronger T-cell response https://www.medscape.com/viewarticle/9460033.*
3. *If you only direct the Long Covid question at participants who swab tested positive 12 weeks prior to the 14th Dec 2020, no one included will presently have been unwell for longer than 5 months."*

80. Long Covid affects both adults and children indiscriminately and, as a result, on 23 December 2020, LCK wrote to Chris Loder MP [LCG2/49 - INQ000320273] to

advocate for greater accessibility for children requiring Covid-19 tests. This letter called for the NHS and GOV websites to be updated to reflect the widespread understanding of the symptoms that children with acute Covid-19 and Long Covid present with and to:

"***Ensure that Children can access Testing.. Remove the barriers that preclude children from accessing testing by updating the NHS and GOV websites to reflect the symptoms that children present with, and ask the government to release a clear campaign to promote this.***"

81. It went to state: "*It is now clearly evidenced that children spread and contract COVID in the same way as adults. Therefore they should be protected in the same way as adults.*" There was no response to this email.

82. On 9 January 2021, LC Support called on Members of Parliament to make tests available to any individual experiencing unusual symptoms in light of the emerging evidence that many people infected by SARS-Cov-2 experienced symptoms beyond the three cardinal symptoms publicly recognised by the NHS (fever, cough and loss of smell/taste). [LCG2/50 - INQ000248900] Access to a test was conditional on demonstrating specific symptoms, namely a cough, loss of smell or fever. Limiting the symptoms in this way meant that those experiencing other symptoms were prevented from accessing free tests. Covid was well known by this stage to transmit asymptomatically so this type of barrier to testing was ineffective and dangerous.

83. In January 2021, LCK and LC Support gave evidence to the APPG on Coronavirus on the failures of the TTI system [LCG2/51 – INQ000320252], [LCG2/04 – INQ000272149]. The APPG on Coronavirus published their report on Long Covid in March 2022, making a series of recommendations including a legal definition of Long Covid classifying it as a disability, proposing more effective care pathways for adults and children, and compensation schemes for key workers with Long Covid, as well as set out above finding that the Covid-19 mitigation policies in schools were inadequate.

84. On 12 January 2021, LC SOS wrote to the then Prime Minister copied to Matt Hancock MP, Jeremy Hunt MP, Professor Sir Christopher Whitty and Lord Bethell

published in the BMJ titled: "*The risk of Long Covid must be a primary consideration in policy decisions.*" [LCG2/52 - INQ000238538] The letter highlighted the need to consider the indiscriminate risk of Long Covid in policy decisions on TTI and non-pharmaceutical interventions (NPIs). This followed Prime Minister Boris Johnson's announcement on 4 January 2021 announcing the vaccination programme and the lifting of restrictions.

85. On 4 March 2021, LC SOS received a reply from the DHSC Ministerial Correspondence and Public Enquiries team. [LCG2/53 - INQ000238622]. The reply said that the Government was guided by SAGE and public safety was the Government's priority, it referred to the Government taking a "cautious" approach to easing lockdown. The response did not deal with the risk of Long Covid in policy decisions including about transmission, testing and surveillance.

86. Between February to April 2021. LC Support completed surveys of its members setting out the Patient Experience of primary care. [LCG2/28 – INQ000272247] The survey data was shared with the NHSE Taskforce [Minutes from the NHS Long Covid Taskforce 04 February 2021 - [LCG2/54 - INQ000320304]. This data demonstrated that lack of community access to testing was preventing sufferers of Long Covid from accessing care pathways. It found that 82% of respondents struggled to secure referrals since the publication of the NICE guidelines on post covid condition. For example, 128 sought referrals since 18 December 2020, 95 were refused due to disbelief or not being hospitalised or unawareness of long covid services, and of 4 that were referred to Long Covid clinics 3 were refused due to not having a positive test or not being hospitalised. The report explained that:

> "*Our calls for research fall into two main categories, both equally urgent: how to prevent new cases, and how to help the vast numbers who have Long Covid What can we do to prevent Long Covid, as well as severe acute cases and transmission? • Can we identify an early intervention to be taken soon after symptom onset to stop viral replication? (community, orally administered, low side effects, low cost, linked to Test & Trace)? How can we help those living with Long Covid?*"

87. On 24 February 2021, LC Support emailed the DHSC with evidence from the patient surveys and communications to ONS in order to advocate for the need to use TTI to identify early intervention and stop viral replication. [LCG2/55 – INQ000249048]. LC Support does not have a record of receiving a response to this email.

88. On 12 April 2021, with Safe Ed for All, LCK wrote to Matt Hancock MP, then Secretary of State for Health and Social Care, raising concerns about the risk of Long Covid and the need for Covid-safe mitigation measures in schools in the absence of widespread testing of children. [LCG2/56 - INQ000272150]. LCK did not receive a reply.

89. On 6 July 2021, LC SOS wrote another open letter to Sajid Javid, then Secretary of State for Health and Social Care ("SSHSC"), copied to Lord Bethell, Jeremy Hunt MP and Professor Sir Christopher Whitty following Prime Minister Boris Johnson's speech on 5 July 2021 setting out the government's plans to ease restrictions. [LCG2/19 - INQ000238584] No response was received. The open letter raised the following concerns:

> *"The need to avoid overwhelming the NHS has been given as the primary aim of the government's pandemic response. Unfortunately, continuing to allow SARS-CoV-2 to infect huge numbers of people – 27,334 new cases reported on 5 July 2021, with forecasts that daily rates could reach more than 100,000 – will have serious implications for the health service despite the lower levels of hospitalisation during acute infection. Thousands of predominantly young, active people are condemned to prolonged ill-health and disability every day. As well as putting considerable pressure on the NHS, their reduced capacity to work will further contribute to the impact long covid is already having on society…"*

90. On 8 July 2021, LC Support wrote to the SSHSC, urging that, when evaluating policy, he takes into account that *"the only way to prevent Long Covid is to prevent initial infection with SARS-CoV-2."* We set out findings of government funded and other studies of Long Covid which served as a grave warning of the need to prevent further cases. [LCG2/57 - INQ000248931].

91. The letter called for an updated list of acute symptoms of Covid-19 in adult and children, to allow more people to apply for PCR tests and in doing so, prevent unwitting transmission of Covid-19. LC Support urged the government to:

> *"Communicate an updated list of acute symptoms of Covid-19 in both adults and children to allow people to apply for PCR tests and to prevent unwitting spread, including taking account of the differing presentations of the Delta and new variants (e.g., Lambda).*
>
> *Recognise that children and young people develop Long Covid. If you expect a peak of c.100,000 infections per day, many of which will be among young people, it follows that tens of thousands of children and young people will develop Long Covid. This is an accumulative burden, considering many children and young people have not recovered from the first wave. As stated this week by the Chief Medical Officer, 'I think we will get a significant amount more Long Covid, particularly in the younger ages where the vaccination rates are much lower."*
>
> *Continue to publish daily reports of Covid-19 statistics and include reference to Long Covid: Long Covid is rarely mentioned in public messaging relating to the pandemic. Raising awareness of this will encourage vaccine uptake, safe behaviours and avoid the negative impact that serious long-term illness can have."*

92. On 9 July 2021, LCK wrote to Sajid Javid the then Secretary of State for Health and Social Care about paediatric Long Covid, they stated that "Children may have experienced asymptomatic, atypical or typical severity of their initial acute OCIV-19 illness. Members continue to experience chronic and disabling symptoms. [LCG2/58 - INQ000272152]

93. The letter called for urgent steps including to "*Update the list of acute symptoms of Covid-19 to reflect the new variants and specifically highlight the full range of symptoms that children present with to allow families to apply for PCR tests and*

prevent transmission" along with other mitigation measures including CO2 monitors, HEPA filters and face coverings in schools to prevent risk transmissions and reinfections. No response was received.

94. On 10 February 2022, LC SOS raised concerns again with the SSHSC about Covid-19 being allowed to spread with no precautionary measures in place, which condemned several hundreds of thousands previously health and economically active people, to debilitating long term illness. [LCG2/59 - INQ000238611]

95. In February 2022, LC SOS and LCK issued a press statement (joint statement from LC SOS and LCK in response to the Prime Minister's announcement on 21 February 2022 removing all Covid mitigation measures [LCG2/60 - INQ000231928]). This stated:

> "*Without free testing, contact tracing and surveillance we will be unprepared and unable to tackle future variants which may be more resistant to vaccines. Scrapping the legal requirement to self-isolate and support payments for those who do, leaves us with fewer tools available to fight the rapid spread of Covid-19, as SAGE have already warned*".

96. Regrettably as set out above the prevalence and impact of Long Covid was growing, and there continued to be inadequate monitoring of Covid-19 and Long Covid (see further below) through testing and data collection. It is the LCG view that free testing should have continued to efficiently monitor the prevalence of Covid-19, and by consequence Long Covid.

97. At the Ministerial Roundtable on Long Covid on 10 March 2022, LCK reiterated concerns about the need for the testing system to be more accessible for children. [LCG2/61 –INQ000193796]. Ms McFarland from LCK pointed out:

> "*how important it is that families know what is being done to provide more help and support for long COVID. However, children remain unprotected at school, with testing due to end this month, and no mitigations like improved air quality*

in place. Schools must be made safe to keep children in school and reduce potential health issues for all children."

98. On 11 March 2022, LCK wrote to Andrew Gwynne MP, Shadow Minister for Public Health, about their strategy to raise awareness of Long Covid in Children and forth coming visit to Downing Street by children living with Long Covid [LCG2/62 - INQ000272159]. We have set out below our particular concerns about children and young people.

99. On 21 September 2022, LC SOS wrote to Therese Coffey, about the need to take Long Covid into account. [LCG2/63 - INQ000238585] LC SOS called for:

"ongoing data monitoring and risk management… to understand and mitigate the impact of long covid."

100. No response was received.

Children and young people

101. From the outset of the pandemic, there has been a failure to have regard to the risk of infection, transmission between, hospital admission, death and serious long-term illness, care pathways and consequences in children. This negatively impacted children and young people's access to healthcare, the accessibility of suitable child-specific treatment pathways, public awareness, policy development, vaccine decisions, vaccine uptake and the general availability of support for children with Long Covid.

102. Paediatric post-acute sequelae of Covid-19 or Long Covid has been described as:

"complex, heterogenous, post viral condition involving multiple body systems and is likely attributable to several concurrent underlying physiological processes including damage from direct viral invasion, endovascular dysfunction and micro thrombosis, viral persistence and the development of auto immunity." (Yonts A Brugler. Pediatric Long-COVID: A Review of the Definition, Epidemiology, Presentation, and Pathophysiology. Pediatr Ann.

2022 Nov;51(11):e416-e420. doi: 10.3928/19382359-20220913-06. Epub 2022 Nov 1. PMID: 36343180.)

103. As set out above LCK were concerned throughout that paediatric Covid and Long Covid was initially not recognised at all and the barriers to testing and surveillance of paediatric Covid and Long Covid. We note that it was shown by random testing that prevalence tracks with school opening and closures [LCG2/64 - INQ000272175]. This does not mean that LCK advocated for school closures – rather we sought and advocated for clear public health policy that was consistent, whilst prioritising and protecting children and young people. This included access to appropriate testing for children.

104. For example, on 23 December 2020 LCK wrote to Chris Loder MP [LCG2/49 - INQ000320273] sharing our film *"Our unhappily ever after"* and raising other matters including the need to count Long Covid in children and the hospitalisation rates for children with COVID-19.

105. On 4 May 2021, LCK with others wrote to the Secretary of State for Education, Gavin Williamson, the Minister for Education in Northern Ireland, Peter Wier, the Cabinet Secretary of Education and Skills in Scotland, John Swinney, and the Cabinet Secretary for Education in Wales, Kirsty Williams urging that the four governments urgently apply effective mitigation measures in educational settings based on local infection rates. [LCG2/65 - INQ000272151]

106. In February 2021, UKHSA advised against testing in schools. The schools' infection survey showed lower PCR positivity in primary school children than secondary school however during many periods when schools were open the ONS repeatedly showed that whilst primary school children had lower infection rates than secondary school children they still had higher positivity than all adult age groups [LCG2/66 - INQ000272179].

107. In March 2021, schools re-opened with isolation guidance of cases and contacts and other measures like rapid testing.

108. In May 2021, the masking requirement in secondary schools was ended.

109. In August 2021, the Government announced an end to quarantine for contacts in cases for those under 18, changing definition of contacts and to schools contact tracing. It was a concern to LCK members and parents of children and young people who had developed Long Covid from infection. This decision was criticised in the article as *"no evidential basis for this step provided by UKHSA."* [LCG2/66 - INQ000272179]

110. On 4 May 2021, LCK wrote to the Secretary of State for Education about mitigation measures in schools as part of a campaign by Parents United [LCG2/67 - INQ000272151]. Parents United was a national voluntary organisation which emerged at the beginning of the pandemic. It is a support and advocacy group for households containing Clinically Extremely Vulnerable ("CEV") parents and/or children.

111. On 23 September 2021 LCK met with the SSHSC when he chaired a Ministerial Roundtable on Long Covid. We published a blog post about the meeting [LCG2/68 - INQ000272153]. This set out what had been discussed. This included that the symptom list on the NHS and GOV website needed to be updated (it was not in fact updated until April 2022). LCK emphasised that *"prevention needs to be the focus"* and that *"we need mitigation measure in schools to protect NHS resources and the long term health of children and families."*

112. On 2 November 2021, LCK issued a public statement in response to the release of the JCVI decision for children not being eligible for vaccination which stated *"Acute infection in children has been identified as different for children, even in JCVI's view, yet the symptom eligibility for testing has not been updated. We are still seeing Covid-19 infections in children and we know that this makes it harder to get support or a diagnosis of Long Covid."*

113. On 29 November 2021, LCK attended a meeting with Jeremy Hunt MP and highlighted that there needed to be urgent action protecting children, including vaccination [LCG2/69 - INQ000249053].

114. On the same date LCK published a blog "*What are the barriers to getting a Covid test for a child*" which highlighted that children infected with Covid 19 can be asymptomatic and atypical. [LCG2/70 - INQ000272178]. It explained that swabs can be too big for children's noses and that it can be difficult to hold and swab a child. It provided information for parents and carers about other symptoms beyond the three on the NHS site (fever, cough, loss of taste or smell) by reference to the CDC list of symptoms which was much broader.

115. On 22 February 2022, LCK wrote a joint letter with LCSOS raising concerns about the removal of all Covid measures (LCG2/60 - INQ000231928). ". Ms McFarland, founder of Long Covid Kids stated in the letter: "*We don't have the data to understand the impact of repeat infections on children and young people in their formative years; in truth we don't yet know how repeat infections will affect the long term health of the rest of the population.*"

116. On 1 April 2022, a cohort of children and young people with Long Covid delivered LCK's support guide to Downing Street [LCG2/71 - INQ000320277]. Each child represented 10,000 young people in this country who have been seriously impacted by the condition, and they had come from every corner of the UK with letters describing the toll this illness has taken on their lives. [LCG2/72 - INQ000272162]. The children made a number of requests to the Prime Minister including about being listened to, recognising the devastating impact of Long Covid on their health, education and lives and also called for mitigation measures in schools. For example E wrote:

> "*My name is E, I am 9 years old and in early September 2021 I tested positive for Covid. I caught covid in the second week of being back in school, I must've picked it up from someone in my class who was showing no covid symptoms but there were lots of "colds" going around. After three days my body was in extreme pain and I was unable to move. I lost the ability to use my left leg and my back, shoulders, neck and leg gave me so much uncontrollable pain….I ended up in hospital but the Doctors could do nothing with me and told me it was just covid and I would get over it. I didn't and I went to back to A&E several times before I was admitted for 13 nights in November…Although*

you think taking down covid restrictions is a good idea, I would disagree. Wearing masks protects you and others and is not a hard thing to do. Isolation is important as it stops the spread of covid and means less people will get infected, meaning less work for the NHS."

117. On 1 June 2022, LCK received a response from the DHSC, not the Prime Minister [LCG2/73 - INQ000272163].

118. On 28 June 2022 LCK followed up in writing to the Prime Minister by letter reflecting these videos [LCG2/74 - INQ000272165].

119. On 6 September 2022, LCK received a response from James Morris MP, then Parliamentary Under-Secretary at the DHSC, in which there is a brief acknowledgement of the letters written by LCK members but no concrete commitment to a change in policy. [LCG2/75 - INQ000272166]

120. Long Covid Kids members raised concerns with their local MPs. In April 2022, LCK raised concerns with Gavin Robinson MP to discuss the lack of Long Covid support for under 16s, lack of mitigation measures in schools and lack of testing in Northern Ireland. [LCG2/76 - INQ000272171].

121. A parent of LCK emailed Robin Walker MP raising concerns about safety measures in schools and received a reply on 14 November 2021 stating that secondary schools "*should also retain a small asymptomatic testing (ATS) site until further notice so they can offer testing to pupils who are unable to test at home."* [LCG2/77 - INQ000272197/11]

122. On 29 October 2021, a parent member of LCK emailed John Glen MP raising concerns about transmission in schools and *"unvaccinated children were sent to densely populated, poorly ventilated building with no masks, bubbles or contact tracing and expected to mix more widely than the vast majority of adults…. She wrote "Long Covid can be absolutely debilitating and there is a real danger that if case rates are as high as they are many thousands of our children could be trapped with an ME type illness restricting their lives and limiting their potential for years to come"* [LCG2/77 - INQ000272197].

123. On 25 November 2021, a response from John Glenn MP stated that on balance it was determined that the relative detriment to learning and to mental health posed by keeping children at home rather than in education was more severe than the risk posed by exposure to the virus. [LCG2/77 - INQ000272197].

124. In April 2022, free testing ended including rapid testing in schools. Long Covid Kids remain concerned that widespread transmission of Covid-19 unchecked continues to cause more children and young people to develop Long Covid.

125. On 31 December 2022, a LCK parent (the same parent member who wrote on 29 October 2021) wrote to John Glen MP raising concerns about testing being stopped along with other mitigation measures stating that:

> *"clean indoor air, masking, free testing, reporting results, isolating when sick and supporting people to isolate are all measures that work. Opening up schools with no mitigations has not caused less disruption. Pupil and staff absences are still high, people are still unwell and yet your current advice is absolutely shocking – where is the evidence that after 3 days (who is perhaps still testing positive) is not infectious? It's not there. Why is it not recommended that children test?"* [LCG2/77 - INQ000272197/27]

126. On 16 January 2023 John Glenn MP responded stating that:

> *"I agree it would be wrong to ignore the risks of allowing Covid-19 to re-emerge…. most will make a full recovery within 12 weeks for some people Covid-19 symptoms can last longer."* [LCG2/77 - INQ000272197/26]

127. On 1 September 2023, a parent raised concerns about testing being brought back into schools so that *"people know if they are infected and can protect others"* and ventilation in schools in relation to a parliamentary debate on Covid-19 in September 2023. The letter was acknowledged on 5 September 2023. [LCG2/77 - INQ000272197/39]

Ongoing concerns about the legacy of TTI

128. The concerns we have raised in relation to TTI strategies remain the same today: There are no free tests available for Covid-19; there is no publicly available data on new cases of Long Covid; no one is encouraged to isolate if they test positive for Covid-19; there are no public health communications campaigns warning about Long Covid.

129. Insufficient access to testing at the start of the pandemic continues to be relevant to those with Long Covid today. LC Support and LCK conducted a survey about the impact of re-infections on Long Covid which found that:

> "*Testing status changed markedly between the first and second infections because the majority of respondents were those who had their first infection in the first wave in the community for whom tests were not available*."

130. In the second infection cohort, 84% of respondents had a positive test either by PCR or LFT, up from 38% in the first infection cohort [Long Covid Reinfection Survey August 2022 [LCG2/78 - INQ0002722334/6].

131. The limitations of the Covid-19 testing system between 2020-2022 and the ending of free testing in 2022, has an ongoing impact on data, surveillance and response to the current Covid-19 pandemic. People living in poverty cannot afford LFTs. Furthermore, whilst CEV people still receive free tests so that they can claim antivirals they must collect them from pharmacies where staff may not be wearing masks as a mitigating factor, when previously tests used to be posted. The failure to accurately report Covid-19 testing and the ending of free testing in 2022, has an ongoing impact on data, surveillance and response to the current Covid-19 pandemic. Throughout the Inquiry the pandemic has been referred to in the past tense. This is incorrect. This repeated mistake has devastating consequences for people already living with Long Covid due to risk of reinfection. Further, the current unmitigated transmission of Covid-19 will continue to cause more avoidable cases of Long Covid in adults and children. This is an on-going public health matter which appears to continue to be largely ignored.

132. The decision to stop free testing, discourage testing in certain settings, and not mandate testing in certain circumstances, has significantly slowed down the UK's understanding about the impact and severity of the SARS-COV-2 pathogen.

133. We remain very concerned that the UK continues with inadequate data and surveillance having stopped testing requirements and the provision of free tests. Testing is an important first step to gathering data and maintaining surveillance of a virus. We note that the CDC in August 2024 has recommenced 4 free lateral flow tests for households in the USA [LCG2/79 – INQ00000]. The webpage states *"Order your 4 free at home covid-19 tests Every US household is eligible to order 4 free at home tests" a*nd test results are encouraged to be reported. It seems to us that the UK government has not learned any lessons to date, and we would invite the Inquiry to make urgent interim recommendations to readily provide access to free testing given the continuing risk of Covid-19 and Long Covid.

Future TTI systems

134. Finally, in relation to TTI systems, it is the LCGs experience that the UK Government's TTI was slow and chaotic. The UK could have been leaders in testing however, this was squandered when the UK Government decided to halt community testing in March 2020, which inevitably led to the abandonment of contact tracing.

135. It is our view that this resulted in the UK acting blindly, without data, and having to rely on people presenting in hospitals as a basis for understanding the virus. This failure of TTI also led to an over-focus on hospital transmission rather than social care transmission (though we would add community transmission overall), which contributed to the delay in recognising Long Covid.

Lessons to be learned

136. The LCGs respectfully invite the Inquiry to make the following recommendations:

136.1 The unmitigated spread of Covid-19 is an ongoing public health problem. It requires urgent attention through the re-introduction of sensible mitigation policies including test, trace and isolate as well as other measures such as adequate ventilation in healthcare settings, schools and other public buildings.

136.2 Review the approach to TTI by other countries who successfully implemented TTI.

136.3 Free tests for Covid-19 should be made available immediately. This would assist in the diagnosis and recognition of Long Covid, and aid individuals seeking access to Long Covid healthcare.

136.4 Testing should be encouraged and supported particularly in work places and education.

136.5 The Government should issue guidance advising employers to support workers self isolating when positive for Covid-19.

136.6 Financial support should be offered to those self-isolating.

136.7 Decision making on the management and maintenance of TTI systems must factor in the impact of long-term sequelae when assessing the public health cost of those decisions.

136.8 There needs to be ongoing surveillance of the prevalence of Long Covid by UKHSA and the public health agencies of the four nations, including healthcare services monitoring and recording data relating to post-infectious sequelae. [INQ000421758/39 §115] It would facilitate the surveillance and monitoring of Covid-19 in order that the UK Government can properly respond.

Statement of Truth

We believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false

statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: Personal Data

Sammie McFarland

Dated: 2.6.2025

Signed: Personal Data

Dr M A Faghy

Dated: 4.6.2025

Signed: Personal Data

Lucy Moore

Dated: 3.6.2025

Signed: Personal Data

Natalie Rogers

Dated: 2.6.2025