UK COVID-19 PUBLIC INQUIRY

MODULE 2

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

I. INTRODUCTION

1. Dismissal, disbelief and denial characterise the enduring experience of the Long Covid Groups (LCGs). They welcome this Inquiry as a much-needed forum to understand how decisions made in response to the pandemic have left almost 2 million people suffering from the debilitating and disabling long-term harm of Long Covid. Underpinned by the principles of transparency and openness, this Module of the Inquiry is the sole statutory vehicle the public can look to for answers; it is the only place the bereaved and the survivors of the virus can hope the Government will be held to account for the decisions it took, and the way in which they were taken.

2. The LCGs came to the Inquiry with six framework questions that sought to get to the heart of their central concern - whether the suffering of nearly 2 million people with Long Covid was avoidable.[1] They seek to understand if common sense prevailed: whether long-term injury was a consideration in the pandemic response and whether the public's health really was of primary importance to decision-makers. This Closing Statement looks back and pieces together the picture of Long Covid that has emerged from the evidence. These submissions first examine whether long-term sequelae were foreseen, before considering the vacuum of understanding within which patient advocacy groups were forced to mobilise. They then consider what decision-makers were advised upon and knew about Long Covid before exploring whether this knowledge was translated into the UK Government's pandemic response in three core areas: epidemiological surveillance and reporting; public communications of the risk of Long Covid and decision-making on the imposition and lifting of NPIs. We conclude by looking ahead to where lessons could be learnt, and recommendations can be made to prevent similar avoidable suffering in the future.

[1] The Long Covid Groups, Joint Opening Statement for Module 2, 26 September 2023 § 6.

3. The Inquiry has heard voluminous evidence that this was a Government beleaguered by dysfunction; one that Alex Thomas, describes as a "*chaotic government system with competing power sources, unclear lines of responsibility, and ultimately poor decision making."*[2] The structural issues of a central Government were described as a "*bomb site,"*[3] with frail decision-making structures and weak leadership criticised for flip-flopping and trolleying, where "*important decisions…taken outwith Cabinet*"[4] which exacerbated the inadequacy of the response to Long Covid. The backdrop of Government dysfunction and opacity is reflected in the Government's approach to engaging with the Inquiry, epitomised by the difficulties in obtaining full and frank disclosure of their WhatsApp records. These submissions have sought to focus on the decisions made rather than the insalubrious conduct brought to light through the Inquiry investigations. Nonetheless, their conduct provides significant context for the attitudes of the leaders of Government who held the responsibility for the nation's wellbeing in their hands.

4. These submissions focus only on the period under investigation by the Chair, January 2020 to February 2022.[5] However, the Covid-19 pandemic is ongoing. Adults and children continue to suffer from long-term harm from Covid-19.[6] Several of the concerns raised by the LCGs during the relevant period, still have relevance today – there is an urgent and immediate need for the Inquiry to provide recommendations on the need for ongoing surveillance of the prevalence of Long Covid, public communications about the risk of Long Covid and on the importance of Covid-safe mitigation measures in times of high Covid-19 prevalence.

II. "THE ONLY WAY TO PREVENT LONG COVID IS TO PREVENT COVID-19"

5. "*The only way to prevent Long Covid is to prevent Covid-19*": These words have been repeated within this Inquiry as a defence for failing to consider Long Covid so often it has become a Government mantra.[7] For those who developed Long Covid, it is a bitter reminder of the Government's failure to control the transmission of Covid-19. The Government approach to Covid-19 has not been characterised by a desire to prevent injury to health. Instead, the Government has tolerated high levels of transmission of Covid-19, has been reluctant to introduce and maintain preventative measures which

[2] [9/79/9-13].
[3] [15/107/9].
[4] [20/13/12-25].
[5] UK Covid-19 Inquiry, Module 2 Outline of Scope.
[6] [INQ000272244]; [INQ000272174]; [INQ000272161]; [INQ000272226].
[7] [30/20/14-18] [30/94/2-5] [30/120/5-8] [31/171/12-14] [19/131/10-18].

could reduce transmission and prioritised short-term economic health over public health. The result was that significantly more people developed Long Covid than there should have been.[8]

FAILURE TO MINIMISE THE SPREAD OF COVID-19

6. High prevalence of the virus was permitted from the outset. Professor Tom Hale reported to the Inquiry that this was a costly strategy: "*So the long experience of managing infectious disease of all kinds shows very clearly that because such diseases tend to spread in non-linear and, in the case of Covid-19, rapid fashion, early interventions, when prevalence is low, are critical to restrain further spread."*[9]

7. The adoption of influenza plans absent any other framework for responding to the pandemic led to tolerance of high rates of transmission of Covid-19 in the assumption that nothing else could be done. In stark divergence to other countries, the UK maintained a plan to ride out the pandemic through a 'one wave strategy.' Although witnesses to the Inquiry have distanced themselves from the herd immunity strategy, this appeared to be the intended objective of the UK Government even though this meant a significant number of people would be affected by Covid-19. Key decision makers were indifferent to the costs of high prevalence of transmission of Covid-19 until it threatened to overwhelm the NHS. Sir Simon Stevens saw this as the wrong approach *"I personally do not think solely viewing the amount of Covid through the lens of whether or not there are NHS beds to cope for severely ill patients is by itself the right lens…the right question is: how do you control the increase in the numbers infected."*[10]

8. The rapid abandonment of community testing was one of the casualties of acceptance of high rates of transmission of Covid-19.[11] It meant that people no longer knew if they had acquired Covid-19 and could not easily demonstrate that their symptoms were linked to acute Covid-19 when they developed Long Covid; this impeded receiving a diagnosis and accessing care and led to inadvertent transmission of the disease.[12]

9. The delay in imposing the first lockdown was another consequence of these strategies. Many witnesses have confirmed that by 13 March 2020 there was a broad realisation

[8] [INQ000272181].
[9] [7/80/8-17].
[10] [17/42/19-25/43/1-3].
[11] [3/99/7-20] [6/156/2-6] [15/150/9-13] [7/103/8-23].
[12] [9/97/15-19].

that a lockdown was necessary; it took another 10 days for the UK Government to impose that lockdown. The delay is not readily explained. It is now accepted that minimising levels of transmission of Covid-19 is better in the long-term. Despite those early lessons, the UK Government seemed no better prepared for the second wave. There was a needless delay in imposing a second lockdown as the Government permitted high levels of transmission of Covid-19. Advice on the need for early national interventions to limit transmission went unheeded. Instead, ineffective strategies such as tiering were relied upon which created an "*epidemiological levelling up*" of the virus.[13] The leadership of Government resisted imposing nationwide interventions until there was no alternative.[14] The consequence - more people were infected with Covid-19 and went on to develop Long Covid than in the first wave.

10. By early 2021, the picture was no better. Matt Hancock agreed that cases were high then due to Government policies.[15] The Government continued to tolerate high levels of transmission of Covid-19 and this position became entrenched in Government strategies in Summer 2021 labelled "High Prevalence Strategies."[16] Professor Edmunds told the Inquiry that transmission in the UK was higher at this time than comparator countries in Western Europe, and attributed this to the failure to implement measures such as mandatory mask wearing, encouraging vaccine passports and vaccinating children.[17] High prevalence marked the Government's approach throughout which demonstrated a failure to minimise the spread of Covid-19, resulting in an inevitable failure to prevent Long Covid.

PREVENTATIVE MEASURES

11. Active resistance to implementing preventative measures undoubtedly contributed to the transmission of Covid-19. Three important examples were in relation to recognising airborne transmission of Covid 19, the use of PPE and guidance on wearing facemasks.
    a. **Airborne Transmission:** The evidence demonstrates an inexplicable reluctance to recognise the epidemiological data that showed that Covid-19 spreads through airborne transmission. Professor Catherine Noakes, Chair of the EMG, said that *"from a precautionary basis, it would have been appropriate to indicate that aspects like ventilation mattered, early on."*[18] Matt Hancock admitted that it was

[13] [25/114/19-25/114/23]; [INQ000273553/68].
[14] [19/112/9-23].
[15] [30/16/7-30/16/25].
[16] [INQ000092058].
[17] [13/146/20-13/147/17]; [13/146/11-13/146/19].
[18] [13/17/25/18/1-2].

clear by summer 2020 that airborne transmission was more important,[19] and yet, contrary to advice in January 2021 the Government continued to rank aerosol transmission as the least important of the three modes.[20] This resulted in the public not understanding that improved ventilation and the use of HEPA filters could minimise the risk of harm to their health. Matt Hancock accepted that *"with hindsight"* a more precautionary approach should have been taken and that a lesson for the future was to assume good ventilation should be part of infection control.[21]

b. **PPE:** The Government did not ensure there was adequate PPE for healthcare workers. The lack of PPE and other safety measures in workplaces was widely reported by frontline workers who went on to acquire Covid-19 and Long Covid.[22]

c. **Face Masks:** The lack of PPE had a knock-on effect on decisions made about advice for the community use of face coverings, effectively 'PPE' for the wider public. After SAGE changed their advice to recognise there was sufficient evidence to recommend community use of cloth face masks in April 2020, there was a delay in Government issuing guidance to this effect. Professor Stephen Riley confirmed there was no scientific reason not to advise using face masks in enclosed community settings in April 2020.[23] Professor Sir Peter Horby stated that the main downside to encouraging the use of face masks, was that it might divert masks from healthcare workers who need it most.[24] Matt Hancock suggested that guidance encouraging the use of face masks was *"self-indulgent and dangerous"* as there were not enough masks available.[25] Policy seemed to be driven by the availability of physical stock, not the promotion of public health. Internally, there was recognition that the UK Government was slow to change its position, reacting only when the Scottish Government issued guidance on face masks.[26]

ECONOMIC HEALTH WAS PRIORITISED OVER PUBLIC HEALTH

12. A defining feature of the Government's response to the pandemic was that it prioritised short-term economic health over public health. This proved to be a false economy:

[19] [30/95/7-30/96/10].
[20] [INQ000146632/45-46].
[21] [30/96/12-23].
[22] [3/119/18-25/1201-2].
[23] [11/81/16-20].
[24] [12/208/2-5].
[25] [INQ000102697/33].
[26] [INQ000048313/53].

Professor Hale's research found that countries which maintained a low level of spread had a better outcome in economic performance as well as the number of deaths and general health impact.[27] The leadership of Government however did not arrive at that same conclusion. In March 2020, a decision to announce a "Stay at Home" order in London was delayed because of the potential impact on financial markets.[28] Sadiq Khan criticised this decision for not recognising "*the link between the health of individuals and the health of the economy."*[29]

13. The Eat Out to Help Out scheme has also been heavily criticised as an expensive initiative which encouraged transmission at a time when the Government could have better spent the money to support those who were no longer able to work due to the virus. HM Treasury, the architects of the scheme continued to resist measures which would actively limit transmission of Covid-19 and strongly opposed a second lockdown.[30]

14. While there was a resistance by the leadership of Government and HM Treasury to introduce NPIs out of concern for economic harm, there was no equivalent concern for the economic costs to individuals, even when economic support would achieve the added benefit of limiting transmission of Covid-19. The Government was repeatedly advised that increased financial support to facilitate self-isolation would limit transmission of Covid-19.[31] Yet this vital support was not prioritised.[32] This resistance to economic support for people affected directly by Covid-19 was replicated in the lack of planning for economic costs of Covid-19 itself and the need for financial support for people affected by Long Covid. The economic harm of Long Covid is addressed separately below.

15. These decisions by the UK Government illustrate that the lead-up to the first lockdown was only the beginning of the pandemic response. Once the package of NPIs which came to be known as 'lockdown' were first imposed in March 2020, there were ongoing decisions to be made about how long those measures needed to be kept in place, how to release the measures and how to revisit decisions in light of developing scientific knowledge about the virus. There was no possibility of there being a 'one wave' only and the response to the pandemic was required to evolve as further waves arose; it was plainly going to require cross-government coordination over many years.

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[27] [8/103/12-23].
[28] [INQ000221436/21].
[29] [26/39/10-26/40/14].
[30] [13/131/7-13/132/3].
[31] [7/29/21-7/30/7]; [10/168/19-10/169/4]; [17/17/20-17/18/24].
[32] [5/53/3-9]; [26/111/5-12]; [26/141/18-19]; [26/188/2-10].

III. EVIDENCE ON LONG COVID AND DECISION-MAKING

1. LONG COVID WAS FORESEEABLE AND WAS FORESEEN

16. Long-term sequelae from viral infections were known before Covid-19. Professor Brightling and Dr Evans opined that Long Covid "*was foreseeable to us before the pandemic, because we were aware of what had happened with SARS-CoV-1 and it was even more apparent early on in the pandemic that this would be a potential problem.*"[33] Professor Brightling's understanding of SARS CoV-1 gave him cause to believe that a novel coronavirus would cause long-term sequelae.[34] Such was their appreciation of that risk that by March 2020, they immediately prepared a funding proposal to monitor the potential impact of long-term sequelae in hospitalised patients in a study that became known as PHOSP.[35]

17. This risk was also understood and anticipated by the Government's Chief Medical and Scientific Advisors. Professor Sir Chris Whitty, Sir Patrick Vallance, Professor Jonathan Van Tam and Dame Jenny Harries all accept that long-term sequelae or post-viral syndromes were "*well established"* and were "*a possible outcome of Covid-19."*[36] In contrast to how they described the understanding of acute Covid-19, Chris Whitty and Jenny Harries caveat the accepted understanding of long-term sequelae by saying the extent and nature of the long-term sequelae of Covid-19 could not have been predicted. The same caveat applies equally to the understanding of the impact of acute infection however - the extent and nature of how acute infection from Covid-19 would manifest were equally unknown before 2020, yet the Government's advisors did not rely on this to justify delays in recognising its impact. The evidence clearly demonstrates that the long-term health impacts from the virus were considered secondary or peripheral when compared with the exclusionary focus placed on the impact from acute infection.

18. Early discussions of the risk of long-term sequelae by senior decision-makers were not translated into action. Dominic Cummings, Chief Advisor to the Prime Minister and Matt Hancock recalled warnings from Chris Whitty and, in Dominic Cummings' case, also Patrick Vallance about the potential for long-term consequences of Covid-19 in early 2020.[37] Their foresight of long-term sequelae arising from Covid-19, as with other

[33] [9/91/1-10].
[34] [9/91/17-23].
[35] [9/90/22-24] [9/93/15/94/22].
[36] [INQ000251645/207]; [INQ000269203/135]; [INQ000273807/169]; [INQ000238826/203].
[37] [15/143/19-25] [INQ000273833/1].

coronaviruses including SARS and MERS was echoed by the Academy of Medical Sciences in their Report for Winter 2020/21 published in July 2020,[38] and by the NHS in a briefing note dated August 2020.[39] A CMO commissioned literature review of long-term health impacts of Covid-19 also expressly considered "*relevant findings from long-term follow up of SARS and MERS patients,"* as they are similar diseases which "*may offer insight into the long-term sequelae for Covid-19."*[40] It was apparent that Covid-19 was likely to produce similar long-term sequelae to other coronaviruses.

19. These documented concerns about the impact of long-term sequelae, commissioned from within Government in Summer 2020, did not expand decision-makers' focus to recognise the virus' impact on long-term morbidity. Long Covid was both foreseeable and foreseen, yet decision-makers chose to overlook the known risk it posed.

2. THE UNIQUE ROLE OF PATIENT ADVOCACY IN RECOGNISING LONG COVID

20. The LCGs have played a key role in raising awareness of the long-term impact of Covid-19. Professor Brightling said that there wasn't recognition of Long Covid until "*Patients really got together as one voice to really advocate for what we know now as Long Covid, indeed actually defined Long Covid and a number of different charities that now exist that got together in those early months, May and June of 2020."*[41]

21. Scholars consider that Long Covid may be the first illness to be identified through patients finding one another on social media *'it moved from patients, through various media, to formal clinical and policy channels in just a few months. This initial mapping of Long Covid…demonstrates how patients marshalled epistemic authority."*[42] It is extraordinary that it took the voices of patient advocates, mobilised by their common suffering, to recognise a foreseeable illness.

22. The LCGs' members are patients, parents and carers, who were forced to become advocates to fill the vacuum in public information on the long-term effects of the virus that they were experiencing first-hand. In early 2020, the prevailing message about Covid-19 was that it was a short, acute illness which was likely to be mild for the majority of people.[43] There was no public knowledge or communication about long-term sequelae,

[38] [INQ000211967/24].
[39] [INQ000205638/3].
[40] [INQ000292636/8].
[41] [9/97/15-22].
[42] [INQ000249034].
[43] [INQ000249034/2]; [INQ000182380/5/4]; [INQ000064510/11].

or its potentially debilitating and disabling impact on long-term health. As further reports of those long-term effects emerged in social and published media in April and May 2020, there was still no recognition or confirmation from central Government of the long-term effects of the virus.[44]

23. The Government's failure to recognise the impact of long-term sequelae left people confused and isolated, unable to understand the persisting and debilitating symptoms that they, or those they cared for, were suffering from. The LCGs provided not only solace, solidarity and support, they also advocated for recognition of their illness to help the many others who were suffering in isolation without support.[45]

24. The calls for recognition began in Spring 2020 and gathered momentum through social media. Long Covid Support and Long Covid SOS started campaigns on Twitter and other social media in May and July 2020.[46] These campaigns were supported by written letters to MPs in June 2020,[47] followed by a direct letter to the leadership of Government and key advisers on 3 July 2020.[48] A further letter was sent to Jeremy Hunt, Chair of the Health & Social Care Committee on 28 August 2020 requesting that their concerns be heard.[49] Long Covid Kids joined their number in September 2020 as parents grew increasingly concerned about the debilitating long-term illness gripping their children.[50] LC Kids published a film in October 2020, "*Our Unhappily ever After*"[51] to raise awareness that children were also being affected by Long Covid and describing how profoundly life-changing and disabling their suffering was.

25. The LCGs were not alone in calling for public recognition of Long Covid. Layla Moran, MP and Chair of the APPG on Coronavirus, published an open letter to Boris Johnson in the British Medical Journal (BMJ) on 23 September 2020 after he failed to respond to her private letter to him on 23 August 2020. She asked the Government to publicly recognise Long Covid and to start collecting and publishing regular figures on the number of people living with Long Covid.[52]

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[44] [INQ000249034/2]; [INQ000064510/11].
[45] [INQ000280195]; [INQ000280196]; [INQ000280197]; [INQ000272250]. [INQ000272218]; [INQ000272230].
[46] [INQ000280196/7-8].
[47] [INQ000280197/5-6].
[48] [INQ000238582].
[49] [INQ000248911].
[50] [INQ000280195/5].
[51] [INQ000272195].
[52] [INQ000308723]. [INQ000308739].

26. By Summer 2020, there was a crescendo of voices advocating for the Government to validate and recognise the suffering caused by Long Covid. The LCGs warned that when the UK suffered a second wave of infections, the number of people with Long Covid would also grow. They called for:

    a. **Recognition** by Government leaders that people were suffering from Long Covid, and more would go on to suffer from it;[53]

    b. **Incorporating Long Covid into decision-making** since there was "*very little focus on the part of government on the ongoing very poor health of potentially hundreds of thousands of people…"* ;[54]

    c. **Awareness of the Economic Impact of Long Covid** to ensure there was economic support and social safety nets as well as education to support employees to have staged returns to work.[55] Long Covid was a matter for *"an economy which is already facing an existential struggle: large numbers on long-term sick leave will significantly impact the workforce as it emerges from furlough;"*[56] and

    d. **Recognition of the Disproportionate Impact of Long Covid** on socially and economically marginalised communities.[57]

27. Yet their voices were not heard, and their advocacy was not heeded. Most of their letters were either unanswered or re-directed to other departments, revealing a vacuum of responsibility for the prevention of Long Covid within Government. Only NHS England offered to meet to discuss issues arising from treatment for Long Covid. This led to LC SOS and Long Covid Support being invited to participate in the Long Covid Ministerial Roundtables from October 2020. There was no other response from Government (save for a letter from PHE redirecting them to DHSC).[58]

28. The Devolved Administrations of Wales and Scotland showed a markedly different attitude by acknowledging their concerns in written letters of response.[59] The WHO also took a different approach to the UK Government and invited LC SOS patient advocates to a meeting on 21 August 2020 which led to Dr Tedros Ghebreyesus, Director of WHO, calling for recognition of Long Covid internationally *"(I have) heard loud and clear that*

[53] [INQ000248911].
[54] [INQ000238582/2].
[55] [INQ000248911/2].
[56] [INQ000238582].
[57] [INQ000248911/2].
[58] [INQ000272236/1].
[59] [INQ000272236/3-6].

Long Covid needs recognition, guidelines, research and ongoing patient input and narratives to shape the WHO response from here on."[60]

29. By 1 September 2020, the WHO had updated the international classification of disease emergency codes for Covid-19 to include 'post-covid conditions' recognising that Long Covid was a clinically diagnosable illness directly caused by infection from Covid-19.[61] Domestically however, the UK still had not formally recognised Long Covid or communicated the impact that longer-term sequelae could have on long-term health.

30. The Government was not responsive or adaptive; it did not react to the groundswell of patient advocacy; it did not acknowledge concerns raised by fellow MPs and it failed to follow in-step with the WHO's understanding of the virus. Instead, the Government maintained a blinkered approach focussing solely on the impact of acute infection to steer decision-making without consideration of long-term morbidity.

3. LONG COVID WAS KNOWN BUT NOT RECOGNISED

3.1 Awareness of Long Covid in the Scientific Community

31. Long Covid is an illness identified through patient advocacy, but it should not have been. There was a growing awareness of Long Covid emerging from within Government's scientific advisory groups that should have been acted on far before patient advocacy was required to mobilise.

32. On 28 April 2020, the first reports of long-term sequelae of Covid-19 were raised in SAGE meetings. SAGE even noted that there was a "*possible Kawasaki-like syndrome"* in children with a probable link to Covid-19, recognising the possibility of long-term illness manifesting in children.[62] SAGE emphasised the importance of cohort studies of Covid-19 survivors to understand the long-term effects. On 7 May 2020, SAGE confirmed the existence of long-term health sequelae "*such as persistence of extreme tiredness and shortness of breath for several months"* and the importance of monitoring those impacts in long-term cohort studies.[63] The agreed actions were for NERVTAG to consider a broader clinical syndrome definition and its use. Chris Whitty was also noted as linking

[60] [INQ000238544]; [INQ000238544].
[61] [INQ000308707].
[62] [INQ000146629/186].
[63] [INQ000146629/215].

this to a long-term cohort study. Yet the concerns raised within the scientific advisory community were not addressed by decision-makers.

33. Matt Hancock said that it was during April 2020 that he became aware of post-viral fatigue due to public discussion, and that by May he became aware of the term Long Covid emerging because people shared anecdotal experiences which resonated with his own experience of his mother suffering from Long Covid.[64] Boris Johnson was also aware of anecdotal experiences as he shared an article about prolonged symptoms of Covid-19 with his close advisers, Matt Hancock, Chris Whitty, Patrick Vallance, Dominic Cummings, Simon Case and Lee Cain on 17 May 2020.[65] However, he could not recall receiving any advice in response to this article. It appears, once again, that indications of long-term impacts were considered and still disregarded.[66]

34. From the outset, decision-makers considered Long Covid as a treatment issue, rather than a debilitating risk requiring prevention. The only focus on Long Covid by summer 2020 was as a treatment issue for post-hospitalised patients. Matt Hancock explained that as he became aware of Long Covid, he pushed for action ensuring that there was guidance for post-hospitalised patients published on 5 June 2020, followed by the announcement of the PHOSP-COVID Study on 5 July 2020.[67] On that day, the NHS launched the online Your Covid Recovery website.[68] The Agenda of the first Ministerial Roundtable on Long Covid held on 31 July 2020 and the resulting actions illustrate that Long Covid continued to be seen as a matter for research and treatment without any attempt being made to address prevention and communication of its risk.[69] Given that transmission of Covid-19 was ongoing, the Government accepted that people would suffer long-term harm as a natural outcome of the virus, without consideration of prevention of harm.

35. This cannot be attributed to a lack of information about Long Covid. The Academy of Medical Sciences' report "*Preparing for a challenging winter 2020/21*" was endorsed by SAGE in July 2020 and warned of an increase in Covid-19 requiring the NHS to prepare for those who suffered from Covid-19 and from post-viral sequelae.[70] By September 2020, there was sufficient information about Long Covid for guidance to be published first

[64] [INQ000273833/2]; [30/19/16-25].
[65] [INQ000102087]; [INQ000102085].
[66] [32/160/3-10].
[67] [INQ000273833/2].
[68] [INQ000205651].
[69] [INQ000094257]; [INQ000070625].
[70] [INQ000211967/25].

in the BMJ in August 2020,[71] and then by PHE in September 2020.[72] The WHO had also updated the International Classification Disease Emergency Codes to clinically recognise Long Covid as an illness.[73] In October 2020, the first NIHR Review into Long Covid was published,[74] and DHSC was sufficiently assured of the severity of Long Covid to invest £10 million into research and treatment of Long Covid.[75] There was a significant volume of information, research and clinical advice being disseminated on Long Covid by Autumn 2020, albeit it was not shared with the public (see further below).

3.2 Awareness of Long Covid in Government

36. The failure to consider Long Covid in decision-making cannot be attributed to a lack of awareness within central Government. The LCGs had written to Boris Johnson and his close advisers from July 2020 asking for recognition of Long Covid and for recognition of the risk of Long Covid in children in October 2020.[76] Others were warning of the need to consider Long Covid in the response to the pandemic including Members of Parliament, a group of experts, Independent SAGE, and the Royal Society's SET-C Group (Science in Emergencies Tasking: Covid-19) Group who provided a paper to SAGE and UKRI on Long Covid.[77]

37. Within Government, Matt Hancock, and Sir Patrick Vallance were advising that Long Covid was a relevant consideration. On 8 September 2020, the same day that Matt Hancock gave evidence to the Select Committee on Long Covid, he also advised Cabinet about Long Covid.[78] On 13 October 2020, Patrick Vallance advised Cabinet that an argument against shielding only the elderly, was that many young people were being hospitalised or suffering from Long Covid which the CMO's office also confirmed with No.10.[79] SAGE's further advice on segmentation also warned that the long-term effects of Covid-19 were a relevant consideration against the viability of the strategy.[80]

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[71] [INQ000223054]; [INQ000252609/13].
[72] [INQ000272238].
[73] [INQ000252609/14].
[74] [INQ000058418].
[75] [INQ000273833].
[76] [INQ000238582]; [INQ000280195/5].
[77] [INQ000056575/47]; [INQ000249682]; [INQ000249746]; [INQ000308723]. [INQ000308739].
[78] This is not reflected in Cabinet Minutes but is noted in Sir Patrick Vallance's diaries for the same date [INQ000273901/166].
[79] [INQ000088996/8]; [INQ000071115].
[80] [INQ000074986].

4. LONG COVID WAS DISREGARDED

38. Against this backdrop of foresight, advocacy, evidence and understanding, there was a clear reluctance amongst key decision-makers to recognise Long Covid, combined with an unwillingness to factor it into decision-making. The evidence before the Inquiry points to three main reasons for this:
    1. Boris Johnson was dismissive of Long Covid;
    2. The Government was not agile in responding to emerging evidence;
    3. Long Covid was an inconvenient truth.

4.1 Dismissal of Long Covid

39. Boris Johnson's attitude to Long Covid undoubtedly had an impact on the failure to consider Long Covid in decision-making. Decision-making was concentrated in the Prime Minister who was ultimately responsible for steering the Government's response.[81] Boris Johnson admitted that it took him "*some time to recognise that Long Covid was a serious condition."*[82] He thought *"Long Covid is not a thing."*[83] In oral evidence, he said that calling Long Covid *"Bollocks"* and describing it *"like Gulf War Syndrome"* was a shrouded plea for advice; that he was trying to "*get my officials to explain to me exactly what the syndrome was."*[84]

40. Boris Johnson's claims that his disparaging remarks were a call for advice do not withstand scrutiny:
    a. In October 2020, he scrawled *"BOLLOCKS"* on a box grid which summarised the findings of an NIHR report on Long Covid commissioned by Chris Whitty.[85] The grid summarised the findings of the report which included scientific and clinical data on long-term sequelae. Boris Johnson dismissed the findings of the report without requesting to see it in full.[86]
    b. Long Covid was repeatedly raised with Boris Johnson by October 2020 by his advisors, but there is no evidence that he requested advice, rather that he dismissed Long Covid without further consideration.[87]

[81] [31/18/15-31/19/18] [31/21/9-17] [33/6/2-16].
[82] [INQ000255836/191].
[83] [INQ000165938].
[84] [31/169/6-31/170/17].
[85] [INQ000251910/9].
[86] [32/162/16-24].
[87] [INQ000273901/213,245]; [INQ000146633/4]; [INQ000165938/1].

c. Imran Shafi said that he referred to Long Covid in a Note he prepared in January 2021 "*largely to sort of try to raise awareness again of the issue and to try to create space for the Chief Medical Officer to further advise the PM."*[88] Boris Johnson's advisers were also afraid that if Boris Johnson was given advice in the form of a written note from the CMO's office there was a risk of *"getting a reaction from the Prime Minister that wouldn't be helpful."*[89] This suggests that the issue of Long Covid had been raised with the Prime Minister in the past but that there remained concerns about how to effectively persuade him of its existence.

41. In his witness statement, Boris Johnson said that "*in late May 2021, I requested a note from Chris on Long Covid"* and we know this was provided soon thereafter.[90] The written statement does not say that he asked for advice any earlier than this. It was only when pressed in oral evidence that he came up with the suggestion that he had been asking for advice prior to this. If he had asked for advice any earlier, he would have received it as quickly as he did after his request in May 2021.

42. Although the NIHR evidence on Long Covid should have been sufficient to inform Boris Johnson that Long Covid warranted concern (not least because Chris Whitty led NIHR), Chris Whitty chose not to provide formal advice on Long Covid to the Prime Minister until June 2021. Chris Whitty's delay in advising on Long Covid cannot be readily explained given that the NIHR had research available from September 2020 and further written advice had been prepared by the CMO's Office in February 2021 for this very purpose.[91]

43. According to Chris Whitty, it was "*not his job*" as Chief Medical Officer "*to disabuse even senior political leaders of things which I'm not convinced they fully understand where I don't think it's material to the public health outcomes."*[92] He said it was only important to ensure that the Prime Minister knew about Long Covid "*if it would have made a difference to decisions that the Prime Minister himself had to take.*"[93]

44. Chris Whitty's remarks are both internally and externally inconsistent. It is unclear why Chris Whitty saw advising on the existence of long-term effects of the virus as beyond his remit, when he was readily providing advice on the acute impact of the virus. When Chris Whitty did finally present Boris Johnson with advice on Long Covid in Summer

[88] [14/200/1-8].
[89] [14/200/21-14/201/11].
[90] [INQ000255836/192].
[91] [INQ000072752]; [INQ000292630].
[92] [24/138/6-13].
[93] [24/138/14-23].

2021, he was persuaded that Long Covid was relevant to decisions taken in 2021 since he advised "*there is a large enough problem to be concerned about over and above mortality and hospitalisation."*[94] The same rationale applied to decisions taken in 2020, particularly in tackling the second wave, and should have prompted him to advise on Long Covid as soon as it was known of.

45. Indeed, Chris Whitty recognised in his statement that the indiscriminate risk of Long Covid to otherwise healthy people of all ages was relevant to strategies developed in response to the pandemic and has admitted that there was a delay in recognising that risk, "*The fact we did not recognise that Long Covid would be a significant part of the disease burden of Covid-19 early in the pandemic has however had important practical implications...recognising that the syndromes that make up Long Covid were something which could occur at any age….made us more cautious of the effects of Covid-19 in young and otherwise healthy adults as the pandemic progressed."*[95]

46. Chris Whitty's approach to Long Covid as not being a relevant consideration for decision-making in response to the pandemic in 2020 is also externally inconsistent and in direct contradiction with the views of Patrick Vallance who did assess that Long Covid was a relevant consideration. Between September to October 2020 Patrick Vallance advised first No.10 then Boris Johnson and Cabinet that Long Covid was one of the reasons that segmentation and the Great Barrington Declaration proposals would not work.[96]

47. Even without Chris Whitty's advice, there was enough information available by October 2020 for Boris Johnson to understand that Long Covid was a significant policy issue to be tackled, alongside mortality and hospitalisation rates.[97] Boris Johnson's inexplicable dismissal of Long Covid should not have endured in the context of widespread, vocal concern about Long Covid and substantive advice on its impact to decisions being taken.

4.2 The Government was not flexible in responding to emerging evidence

48. The Government machinery was slow to recognise and respond to new evidence as it affected Long Covid. When reports of the long-term impacts of Covid-19 emerged in April and May 2020, there were no requests from central Government for advice from SAGE and NERVTAG on Long Covid until many months later. Similarly, the bodies within

[94] [INQ000251916/3].
[95] [INQ000251645/207-208].
[96] [INQ000273901/159]; [INQ000088996/8].
[97] [INQ000273901/166].

Cabinet responsible for preparing advice for Cabinet and the Prime Minister did not immediately incorporate advice on the long-term impacts of Covid-19.

49. The Covid-19 Task Force (CTF), formed in Summer 2020 to prepare advice for the Prime Minister and Cabinet,[98] was aware of the risk of Long Covid.[99] Yet, they only put together advice on the potential impact of Long Covid in April 2021.[100] Simon Ridley suggested that the paper on Long Covid was prepared in April 2021 as more information became available since the ONS had started publishing data on Long Covid.[101] In sharp contrast to the delay in preparing the CTF paper on Long Covid, a parliamentary paper on the short and long-term effects of Covid-19 was published on 7 September 2020.[102] While all members of Cabinet would have had access to this information, the lack of similar advice on long-term consequences of Covid-19 being presented directly to Cabinet by the CTF illustrates that early evidence of Long Covid did not inform decisions made by Cabinet Office and the Prime Minister. Early advice should have been prepared on information available at the time and updated as further information and data was obtained.

50. There was also a delay in considering Long Covid in the main advisory bodies responsible for providing scientific and technical advice to the Government on Covid-19: SAGE and NERVTAG. The first detailed discussion about evidence on Long Covid in SAGE took place in February 2021,[103] and the first commissioned paper was presented only in July 2021.[104] The former was nine months after the first reports of long-term sequelae were noted in SAGE meetings in May 2020,[105] and five months after Cabinet Office had indicated that there was interest in commissioning SAGE to look into long-term health impacts of Long Covid in September 2020.[106]

51. Similarly, NERVTAG only considered Long Covid in passing on 18 September 2020 when Professor Brightling was invited to present his work on PHOSP studying post-hospitalised patients.[107] Having raised Long Covid of their own initiative,[108] and received affirmation from DHSC that it would be helpful for NERVTAG to consider Long Covid,

[98] [19/132/4-19/133/19].
[99] [19/133/17-19].
[100] [INQ000292660].
[101] [19/132/12-19/133/4].
[102] [INQ000238654].
[103] [INQ000146629/526-527].
[104] [INQ000223056].
[105] [INQ000146629/215].
[106] [INQ000112675/4].
[107] [INQ000120446/3].
[108] [INQ000120434/10].

DHSC then confirmed that they were content to follow the work that Professor Brightling was doing and did not request further advice from NERVTAG on Long Covid.[109] This discussion took place months after the first reports of paediatric hyper-inflammatory syndrome were noted in May 2020,[110] and patient reports of long-term symptoms of Covid-19 in community managed cases were noted in social and printed media.[111] Professor Sir Peter Horby accepted in oral evidence that Long Covid "*wasn't raised until quite a lot later*" in NERVTAG.[112]

52. Various explanations were put forward for the delay in SAGE providing advice on Long Covid. Dr Stuart Wainwright thought that as SAGE was a short-term mechanism, he would have expected Long Covid to be covered by DHSC and PHE.[113] Professor Kamlesh Khunti thought the delay in SAGE discussing Long Covid was because "*there wasn't any evidence that one could change anything in terms of Long Covid"* and they still didn't know enough about Long Covid.[114] He also agreed that Long Covid was one of the reasons that Covid-19 could not be allowed to spread unchecked and was a relevant factor to take into account when assessing the need for non-pharmaceutical interventions.[115]

53. Professor Brightling in his review of the minutes of SAGE noted that "*there was really very little time spent on thinking about the long-term consequences until coming into 2021."* In his opinion there was a missed opportunity to consider Long Covid earlier because of the focus on acute episodes and vaccines. He opined that if there had been data available from activated hibernating studies, then there would have been earlier reports coming into SAGE about the progress of those studies.[116] Professor Brightling's view undeniably comes closer to the heart of the problem that there was exclusive focus on the acute impacts of Covid-19 meaning that the long-term impacts were overlooked.

54. The delay in considering Long Covid in SAGE and in NERVTAG was driven as much by the lack of interest in central Government as it was by external constraints in data. There was no demand for advice on Long Covid from SAGE when reports of the long-term effects of Covid-19 began to emerge in April and May 2020.[117] However, advice on the

[109] [INQ000120445/3].
[110] [INQ000220211/8]; [INQ000109339].
[111] [INQ000249034].
[112] [12/221/3-4].
[113] [8/33/23-8/34/18].
[114] [7/52/9-20].
[115] [7/62/1-24].
[116] [9/121/16-9/122/13].
[117] [8/34/20]-[8/35/10].

long-term impacts of Covid-19 was necessary to understand the potential impact of the virus on the population as a whole.

4.3 Long Covid was an Inconvenient Truth

55. The evidence has revealed an unwillingness amongst decision makers to consider and accept risks that would derail decisions designed to move the UK back to 'business as usual' mode. In Summer 2020, there was strong resistance from Boris Johnson and Rishi Sunak to imposing further lockdowns due to perceived risk of further damage to the economy.[118] The Government needed to prepare for a resurgence in transmission of Covid-19 and yet was reluctant to take necessary measures which would effectively control transmission of the virus. Boris Johnson was keen to pursue strategies which would allow business as usual to continue and avoid further lockdowns. He considered *"letting it rip"* and entertained proposals from the Great Barrington Declaration Proponents as well as segmentation. Following advice against these proposals, the Government implemented a tiering strategy which essentially amounted to an *"epidemiological levelling up"* of the virus across the UK.[119] The reluctance to take early measures to limit transmission of Covid-19 by resisting calls for a circuit breaker or national NPIs resulted in high transmission of Covid-19 amongst the general population.[120]

56. Professor Carl Heneghan was forced to accept in oral evidence that the risk of significant numbers of people suffering from serious long-term sequelae, including the young, flawed the rationale for not imposing restrictions.[121] Yet there was no mention of Long Covid in the Great Barrington Declaration and Carl Heneghan could not say if it was taken into consideration when putting forward the proposal, which suggests it was not.[122] Those who did take Long Covid into account argued against any proposal which amounted to 'letting the virus rip' through the population or allowing it to spread unchecked amongst the younger population and other unknown vulnerable.[123]

57. Boris Johnson's expressions of disbelief and denial of Long Covid as a medical condition exemplified central Government's resistance to accepting what was an inconvenient truth – that Covid-19 posed a risk to all. It was preferable to ignore Long Covid than to consider

[118] [INQ000088301]; [INQ000089917].
[119] [INQ000229666]; [INQ000273553/68].
[120] [INQ000238826/131-132]; [22/120/19-22]; [24/65/8-21].
[121] [13/182/5-18].
[122] [13/184/22-13/185/6].
[123] [22/122/1-5]; [25/90/9-17].

it in the response to the pandemic. To the limited extent that it was considered, it was for symptom management after the event without thought of prevention.

5. The Double Dismissal of Long Covid in Children

58. The Inquiry may find there was a dismissive approach taken to children generally, noting that the Government Strategy was *"incoherent, and as a result children were often overlooked, and there were even occasions where it felt that (the Government) was indifferent to children's experience during Covid"* such that *"it was very clear that there was no one at the Cabinet Table who was taking Children's best interests to those decisions."*[124] Children with Long Covid suffered the double disadvantage of being disregarded within the pandemic response and suffering injury from the virus with the associated consequences for their health, life and education. There is also a knock-on effect on their caregivers and households.

59. Early public health statements from the CMO suggested that Covid-19 posed only a minimal risk to children.[125] This meant parents were left without direction and affected families unsupported and needed to advocate for recognition of the impact of Long Covid on their children. Sammie McFarland describes becoming an involuntary advocate for children with Long Covid *"In the first year of the pandemic, Long Covid Kids had to demonstrate that children and young people also suffered from Covid-19…we therefore spent the first year evidencing the impact of Covid-19 infection and Long Covid on children and young people using lived experiences."*[126]

60. Dr Evans has said that whilst it is less common for children to have severe disease, Long Covid is still prevalent in a significant number of children. Professor Brightling agreed saying *"although the number of children are considerably fewer than adults that's still a substantial proportion when you're then thinking about your own children or other family members. It's really important to those children and their parents."*[127] The ONS statistics as at March 2023 estimated there are 53,000 children between the ages of 2 and 16 living with Long Covid for at least 12 months.[128] Children with Long Covid are often too unwell to attend school regularly; their illness deprives them of the ability to play, do sports or undertake other activities that were previously a part of their daily lives.[129]

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[124] [4/33/25-4/34/3]; [4/43/10-12]
[125] [INQ000070434].
[126] [INQ000280195/8].
[127] [9/119/5-9].
[128] [INQ000272181].
[129] [INQ000272183].

61. Long Covid devastates the course of children's lives and disrupts their development. Despite being presented with evidence of this occurring, there was no explicit recognition of Long Covid in children by central Government. Members from LC Kids attended the Long Covid Ministerial Roundtables from early 2021 raising concerns about the impact of Long Covid in children and calling for its recognition and public awareness campaigns for its prevention. In July 2021, LC Kids were still advocating for the mere recognition that children could get Long Covid. They wrote to Sajid Javid saying *"we urge you to consider the lived experience of children with Long Covid, and early evidence from researchers when creating policy,"*[130] but this did not result in public recognition of paediatric Long Covid.[131]

62. Children are still unprotected from Covid-19 since vaccine coverage was not extended to minors without a known vulnerability. Professor John Edmunds noted that many Western European countries had higher levels of vaccine coverage in younger individuals because they had started vaccinating them: *"So I remember at the beginning of term, September of 2021, at that time France […] roughly speaking about 80% of their kids had -- secondary school age children had had one dose and about 50% had two doses, we hadn't even started vaccinating our children*"[132] Children and younger people were left exposed and unprotected whilst uninformed of the risk of Long Covid to their health.

6. LONG COVID WAS NOT FACTORED INTO DECISION-MAKING

63. The disregard for Long Covid translated into decision-making that overlooked the suffering of those with Long Covid. Decision makers did not begin collecting data on long-term sequelae until called upon to do so by patient advocates. Even once available, they did not incorporate data on Long Covid into the datasets provided to primary decision-makers. Public communication of the risks of Covid-19 were focused on the impact of acute infection. There was no central Government communications strategy to inform the public of the risk of Long Covid.[133] Decisions taken on releasing measures failed to consider the indiscriminate risk of Long Covid and consequently accepted high prevalence of Covid-19 in the community without keeping Covid-safe mitigation measures in place.

[130] [INQ000272152].
[131] [9/119/11-13].
[132] [13/147/11-17].
[133] [28/144/11-28/145/4].

6.1 The Overlooked Metric of Long-Term Morbidity

64. The failure to recognise Long Covid resulted in a failure to incorporate long-term sequelae into early surveillance systems and a subsequent delay in collecting and monitoring data on the prevalence and impact of Long Covid. The Government's Chief Scientific and Medical Advisors have retrospectively suggested that Long Covid could not have been foreseen because the extent and severity of long-term sequelae of the disease was not known. However, as with all impacts felt from a novel virus, the only way for the severity and nature of long-term sequelae of a novel virus to be understood, is for it to be actively monitored. This did not happen.

65. Professor Sir Peter Horby describes the UK's surveillance as some of the best epidemiological tools available anywhere in the world yet the UK did not have a hibernating study ready to monitor long-term sequelae.[134] Professor Brightling and Dr Evans explained that foreseeability of long-term sequelae from SARS-CoV-2 was extrapolated from existing knowledge of SARS-CoV-1, MERS and other post-viral syndromes.[135] ISARIC, one of the key tools used to measure and monitor the impact of Covid-19 was developed in 2012 for MERS-CoV. Professor Horby, who was Executive Director of ISARIC, explained that the organisation worked extensively on SARS and MERS for decades, yet this experience of a previous coronavirus with documented long-term sequelae did not result in a hibernating study to monitor the impact of protracted symptoms of Covid-19.[136] Professor Horby has described this as *"an omission… it could have been done and we intend to do that in the future."*[137]

66. The omission of long-term sequelae from ISARIC's monitoring study was discussed at SAGE 29 on 28 April 2020 when the importance of cohort studies of Covid-19 survivors was reiterated during a discussion on whether ISARIC was sufficient or whether an additional longitudinal research was required *"UKRI to review whether ISARIC cohort studies following discharged Covid-19 patients are sufficient and to identify any additional longitudinal research required,"* but ISARIC was not adapted at this point.[138] No reason has been given to explain why prolonged symptoms were not monitored. Instead, Professor Horby has explained that it was not until late Summer 2020, several months after SAGE 29, that ISARIC started to engage on Long Covid. It did so by engaging *"with*

[134] [INQ000226562/44].
[135] [INQ000280198/5].
[136] [INQ000226562/4].
[137] [12/222/5-9].
[138] [INQ000146629/186].

the Long Covid survivors group… they were co-developers of the Long Covid protocol, which we have established and is – data is being collected on that."[139] Even the initial monitoring of long-term sequelae, key to understanding the long-term morbidity caused by the virus, required patient advocacy to activate it.

67. In addition to understanding the nature of long-term sequelae, prevalence data assists decision-makers to determine the incidence, risk profiles and a necessary third dimension to the overall assessment of severity of pandemic harm. The ONS Covid-19 Infection Survey (CIS) designed in April 2020 as the main study to monitor prevalence of Covid-19 in the UK did not initially monitor reports of long-term sequelae.[140] Despite a consultative process in designing the CIS Survey and SAGE 29 separately emphasising the importance of cohort studies of Covid-19 survivors, this was not explicitly incorporated into the original ONS survey. LC Support gave evidence to the APPG on Coronavirus on 5 August 2020 explaining that in the absence of data on Long Covid, the UK was mis-assessing the impact of the pandemic by overlooking the significant impact of Long Covid."[141]

68. Sir Ian Diamond explained that the CIS Survey was easily adapted, yet the ONS were not asked to measure Long Covid until a formal request from No.10 was sent on 25 September 2020.[142] There is no evidence to explain why data on the prevalence of Long Covid was not asked to be collected until the eve of the second wave. Notably, two days before the request, Layla Moran's letter to Boris Johnson was published in the BMJ asking that Long Covid be counted.[143] Unaware of the request, LC SOS had contacted ONS directly on 16 October 2020 asking them to count Long Covid and publish statistics on Long Covid as a measure of impact of the pandemic.[144] As with ISARIC, the ONS went on to collaborate with the LCGs to refine the questions on the CIS study.

69. There was a further delay in collecting data on Long Covid in children. In October 2020, LC Kids' co-founder Frances Simpson had written in the BMJ about the importance of counting Long Covid in children.[145] On 23 December 2020, several months after the ONS began considering how to include Long Covid in their data capture, LC Kids wrote to

[139] [12/221/12-16].
[140] [INQ000146629/165].
[141] [INQ000249062].
[142] [6/92/3-25]; [INQ000268012/18].
[143] [INQ000308723].
[144] [INQ000272223].
[145] [INQ000272196].

Chris Loder MP sharing their advocacy film "*Our Unhappily Ever After"*[146] to evidence the need to count Long Covid in children and the hospitalisation rates for children with Covid-19.

70. The failure to monitor the nature and prevalence of long-term sequelae of Covid-19 left decision-makers with a gap in data; in their understanding of the virus and in their assessment of the severity of the pandemic's harm.

71. Perversely, even once data began to be collected, it was not provided to decision-makers. In addition to ONS data, the DHSC began producing a Long Covid Dashboard in February 2021.[147] Whilst the ONS datasets and the DHSC's dashboards may have been available to central Government on request, their data on Long Covid did not feed into the main Covid-19 Dashboard prepared for decision-making. The main Covid-19 Dashboard focused on the impact of acute infections alone, giving an incomplete picture of the severity of pandemic impact. No good reason has been given to explain why Long Covid was excluded.

72. Simon Ridley said that the absence of data on Long Covid in the Covid-19 Dashboards did not mean that Long Covid was not factored into decision-making.[148] However, he could not explain why the ONS data on Long Covid first published in December 2020 and then regularly from April 2021 did not feature in the main Covid-19 Dashboard. Chris Whitty advised Boris Johnson in June 2021 that Long Covid was a *"large enough problem"* to be considered in addition to hospitalisation and mortality. Yet this measurable impact was not communicated to Boris Johnson or included as a third metric in his Dashboard.[149]

73. Indeed, by July 2020, the Home Office, DHSC, GAD and ONS had improved their analytic methods to capture morbidity in their modelling.[150] Their joint analysis classified morbidity as a Category A direct health impact of Covid-19 in public health terms and modelled quality-adjusted life-years (QALYs) to find that survivors of Covid-19 are likely to need critical care, including cognitive, physical and mental health impairments. Although key departments across Government had recognised that Long Covid is a Category A direct health impact in line with mortality and hospitalisations, this did not prompt Cabinet Office

[146] [INQ000272195]; [INQ000272219].
[147] [INQ000283413]; [INQ000205648] [INQ000273823].
[148] [19/134/9-19/135/25].
[149] [INQ000251916/3].
[150] [INQ000268012/29]; [INQ000074959].

or No.10 to adapt their thinking or seek to expand the data available to them to include Long Covid in advice informing decisions.

74. Even now, data on the prevalence of Long Covid is not being collected and reported on the Covid-19 Dashboard, or by the ONS in the new *Winter (2023) Coronavirus (Covid-19) Infection Study: estimates of epidemiological characteristics.*[151] Whilst the ONS new Winter (2023) CIS includes some questions on Long Covid, it is expressly not designed to estimate the prevalence of Long Covid in the general population. Decision makers continue to have only a distorted picture of pandemic harm that focuses on the impacts from acute infection, deaths and hospitalisations, as the only consequences of concern.

6.2 *Public Communication of Long Covid - The Unused Tool of the NPI Toolkit*

75. Described by Boris Johnson as *"incredibly important… in the end, the most important tool we had to deal with the virus*,"[152] the value of public communications as an NPI has been unanimously championed by decision-makers. Matt Hancock referred to communications as a very important NPI,[153] whilst Christopher Wormald described it as *"advice to the public on how to behave"* and so a "*non-pharmaceutical intervention designed to stop the virus."*[154] Chris Whitty similarly agreed that effective and timely communication plays a crucial role in managing a public health crisis.[155] Public health communication was an important part of the Covid-19 response in the UK, so much so that Lee Cain described it as *"driving a huge amount of the Government machine."* However, there was no driving force propelling public communication on Long Covid.[156]

76. Sir Simon Stevens clarified the two distinct forms of public health communications that Long Covid requires. The first is *"public messaging for people who might be experiencing what came to be known as Long Covid so that they were able to come forward and engage with services."*[157] This is signposting access to treatment and care for those who understand they are suffering from Long Covid. The second, and less well understood

[151] England Summary, the Official UK government website for data and insights on coronavirus (Covid-19). https://coronavirus.data.gov.uk/ ; Winter Coronavirus (Covid-19) Infection Study: Estimates of epidemiological characteristics, 21 December 2023 https://www.gov.uk/government/statistics/winter-coronavirus-covid-19-infection-study-estimates-of-epidemiological-characteristics-england-and-scotland-2023-to-2024/winter-coronavirus-covid-19-infection-study-estimates-of-epidemiological-characteristics-21-december-2023
[152] [31/75/5-9].
[153] [30/118/22-30/119/1].
[154] [17/109/5-8].
[155] [24/123/14-17].
[156] [15/19/13-14].
[157] [17/70/18-21].

form, is preventative communication that explains that the virus causes prolonged symptoms beyond acute infection, which can be damaging to anyone's long-term health. That is *"the Government talk about the risks of Long Covid as a way of trying to encourage people to take action to limit the spread of the virus."*[158]

77. Dr Evans explained that preventative communication of the indiscriminate risk of Long Covid is *"an important public health message."* She underscored the need for distinct public messaging on Long Covid by distinguishing its indiscriminate nature from the narrower risk profile of acute Covid and made plain that people need to know that *"actually anyone can develop Long Covid. So anyone that's contracting the infection can end up unfortunately with this very prolonged illness."*[159]

78. The evidence demonstrates that the limited public health communications on Long Covid were focused on signposting information resources for Long Covid, to the detriment of raising awareness of the risk of Long Covid and promoting its prevention among those who were told that they were not at risk from Covid-19 infections. Indeed, the two appear to be confused and even conflated by senior decision makers. Lee Cain and Professor Sir Christopher Wormald identified NHSE as the operational lead for the response to Long Covid and pointed to NHSE's resources, such as the (i) Your Covid Recovery website, (ii) the NHS five-point plan and (iii) the NICE guidelines as sources of communication on the risk of Long Covid.[160] However, none of these resources communicate the indiscriminate risk of Long Covid to the public, namely that Long Covid could affect any person. They provide general information on recovery, announce the creation of treatment clinics and offer clinical guidance to assist medical practitioners determining the care needs of patients. There was a mistaken conflation of communication of treatment sources, with communication of the risk of Long Covid from infection.

79. Sir Christopher Wormald continued to suggest that DHSC and NHSE's understanding of the risks of Long Covid were communicated through NHSE's publications, which conflicted with his latter delineation of Government responsibility for Long Covid.[161] He explained that the responsibilities across the DHSC, Cabinet Office and NHSE varied in relation to Long Covid: The DHSC's role was to consider the strategic implications for

[158] [17/70/23-25].
[159] [9/116/4-9].
[160] [INQ000369657/6]; [15/77/11-25].
[161] [INQ000369657/6].

policy and to commission and fund research through NIHR.[162] NHSE was responsible for designing treatment services for Long Covid, and the Cabinet Office's Covid-19 Taskforce was to consider Long Covid when making decisions on interventions. Using Christopher Wormald's own demarcations of responsibility for Long Covid,[163] public communications of the risk of Long Covid should have fallen within the purview of (i) the DHSC when considering the strategic implications Long Covid had on policy and (ii) the Covid-19 Taskforce when considering interventions to minimise the spread of Covid-19. Yet the reality from the evidence is of a disjointed patchwork of communication with neither body assuming the responsibility for creating a public health communications strategy on the risk of Long Covid.

80. Central government messaging was that only the vulnerable and elderly were at risk; Covid-19 would be short, mild and flu like. For a cohort of people that was not true. The sole communications product on the risk of Long Covid was one video and accompanying press statement produced by DHSC in October 2020.[164] Whilst Christopher Wormald agreed that *"if the one video had been the one thing that had happened"* it would not have been sufficient public health messaging, he nonetheless maintained that there was "*an awful lot of other activity on Long Covid from when it became apparent after the first wave that this was going to be an important thing for the country and for its sufferers."* However, he was unable to point to any other examples of public health communication campaigns by DHSC of the risk of Long Covid. Christopher Wormald's assertion that "*there had been UK Government messaging up to 22 June 2021 on the new and emerging nature of Long Covid"* refers to the one DHSC video, which was neither sufficient nor effective as a public health campaign.[165] This accords with the evidence of Sajid Javid admitting that, in his recollection, there was no communications campaign on the risk of Long Covid.[166]

81. The absence of public health messaging on Long Covid meant people who did not consider themselves to be vulnerable or otherwise at risk did not know that they could suffer serious illness and adverse consequences from infection. Professor Rubin said the absence of public health messaging would lead to lower levels of protective behaviour.[167] The Government knew that another cohort, that is the otherwise healthy adults and children (the "unknown vulnerable" according to Professor McLean), could develop long-

[162] [INQ000369657/7].
[163] [INQ000369657/7].
[164] [INQ000283375].
[165] [INQ000369657/6].
[166] [28/144/11-28/145/4].
[167] [12/115/14-12/116/4].

term harm from infection but did not communicate to the public that Covid was not always short, mild and flu like.[168]

82. When asked about the near three-month delay from noting that awareness of Long Covid needed to be raised in July 2020 to launching the video in October 2020,[169] both Matt Hancock and Christopher Wormald suggest that greater caution and understanding were required before communicating the risk of Long Covid.[170] The approach to communicating Long Covid should have followed Lee Cain's epithet on public communications *"not making the perfect the enemy of the good"* by issuing timely, adaptive messaging as soon as the risks were known,[171] akin to the WHO's approach which recognised Long Covid in August 2020 while still pursuing further research into it.[172]

83. There were no slogans, public health messages or campaigns built by DHSC or Cabinet Office around the single video to ensure the risk of Long Covid was understood by the public. There were only brief, ad-hoc mentions which lacked cohesion and failed to clearly communicate the pervasive risk posed by Long Covid. Boris Johnson did not warn the public in his many press conferences once about the long-term harm.

84. Lee Cain extolled the virtues of press conferences as a valuable tool for public communications saying, *"those press conferences alone, you know, we're looking at 10 million people watching every single evening, huge numbers."*[173] There were only four mentions of Long Covid in all the press conferences of which the first (and only one in 2020) was in October 2020.[174] There were no attempts made to use this powerful vehicle to communicate the risk of Long Covid to the public. Chris Whitty accepted, on reflection, that *"if I were to re-run the press conferences …I would have made an earlier mention of Long Covid…just to acknowledge that there was Long Covid would have been a useful thing to do. I think the acknowledgement would have been helpful at an earlier stage in public."*[175]

[168] [25/90/13-16].
[169] [INQ000070127].
[170] [INQ000369657/5]; [30/21/13-23].
[171] [15/44/1-6].
[172] [INQ000238544].
[173] [15/82/12-22].
[174] [INQ000064571/4]; [INQ000064592/1]; [INQ000064608/7]; [INQ000183994].
[175] [24/142/6-24].

85. There was a wholesale absence of preventative messaging from central Government on the indiscriminate risk of Long Covid. Lee Cain complains of a general practice of government departments acting as *"communication fiefdoms in their own right,"*[176] which were apparently remedied by the Covid-19 Communications hub responsible for coordinating Government messaging. However, when asked about communication of Long Covid, Lee Cain said it was not a primary focus of his work because it was an issue that would have been led departmentally or by the NHS. This answer lacks coherence and demonstrates that no entity took responsibility for communicating the risk of Long Covid to the public, it "*fell between the cracks.*" Not even Lee Cain knew *"where the full responsibility would lie."*[177]

86. Chris Wormald drew attention to the lacuna in central Government communication when referencing the Long Covid Oversight Board's meeting of 22 June 2021. He accepted that *"The Long Covid policy team considered that people want one source of information which would sign-post them to more detailed content"* and in doing so, also accepts that there was no *"joined up, cross-Government"* central messaging on the risk of Long Covid. There is no evidence that this concern was ever remedied.

87. The omission in central Government communication was tacitly accepted by Simon Ridley who suggests that there was some nebulous reference to Long Covid by the Cabinet Office, *"there was a lot of communication about the potential risks to Covid albeit we weren't discussing Long Covid in and of its – by that label."* A discussion which fails to refer expressly to Long Covid cannot be termed clear and intentional communication of the risks where Simon Ridley acknowledges the importance *"that people know their – the risk they could face from catching Covid-19."*[178]

88. Also of concern, Matt Hancock said that whilst he had not seen the amount of cross-government communication, he used his own media appearances and social media to discuss Long Covid as a substitute. However, an individual Minister's social media account cannot in any event supplant cross-Government public health messaging on the risk of long-term health harms and demonstrates a complete failure of understanding of the need for clear, consistent, timely messaging from central Government on the risks of Long Covid.

[176] [15/79/4-16].
[177] [15/81/7-23].
[178] [19/131/2-9].

89. As understanding of the manifold symptoms of Covid-19 grew, this failed to be reflected in public communication and official guidance on symptoms for Covid-19 was not updated until April 2022. The inadequacy of public communication compounded the Government's delayed recognition of Long Covid and has left individuals unaware of what they were suffering from. It contributed to the medical community's protracted dismissal of patients presenting with prolonged symptoms, and exacerbated sufferers' feelings of isolation, powerfully expressed by LC Support in a letter to Jeremy Hunt on 28 August 2020.[179]

90. Patient advocates had to fill this void. For example, not only was there no public awareness campaign for parents to understand that Long Covid posed a risk of harm to their children, but guidance on symptoms experienced by children were not updated to include paediatric Long Covid. In addition to their ongoing advocacy, LC Kids therefore published graphics in August 2021 to raise awareness of symptoms experienced by children, which were missing from Government's guidance.[180]

6.3 *Long Covid, The Forgotten Factor in Decision-Making*

The Impact of the Failure to consider Long Covid in 2020

91. The impact of Long Covid in adults and children and its distinct, indiscriminate risk profile, were important factors to be accounted for in strategy development in response to the virus' transmission.[181] Professor Kamlesh Khunti said that Long Covid should "*absolutely"* be one of the factors considered in assessing the need for NPIs.[182] Sir Patrick Vallance confirmed that Long Covid was "*definitely flagged"* to decision makers and it was a "*real issue*."[183] Anne Longfield said that Long Covid "*is very real, it's a reality for families, it has a devastating impact on children and families and needs to be much more part of not only the debate but also the policy making decisions."*[184]

92. Had the risk of Long Covid been considered by decision-makers in 2020, less time would have been spent investigating strategies which encouraged uncontrolled transmission of Covid-19 such as segmentation and the Great Barrington Declaration proposals. Boris Johnson's comments at the time displayed a belief that young and otherwise healthy people would be otherwise unaffected by Covid-19 which influenced the strategies that

[179] [INQ000248911].
[180] [INQ000272178]; [INQ000248911]; [INQ000272218].
[181] [25/90/2-17]; [22/126/1-13].
[182] [7/61/25-7/62/24]; [7/61/25-7/62/24].
[183] [22/127/18-22/1228/8].
[184] [4/42/16-20].

he considered at the time.[185] In contrast, the then First Minister of Scotland, Nicola Sturgeon, made clear that Scotland considered the risk of long-term harm to health from Covid-19 to the unknown vulnerable was a relevant factor in declining to follow a shielding strategy.[186] Her evidence further emphasised that Long Covid was a relevant consideration in decisions about NPIs.[187] She described one of the differences of opinion between the UK Government and the Scottish Government being "*over what level of virus it was acceptable or sensible to 'live with' before vaccines/ treatments were widely available. The Scottish Government's position – in light of the serious health harm that the virus was capable of causing, including long Covid – was that we should seek to suppress it to the lowest possible level. The UK Government did not always seem to agree with this."*[188]

93. The injury to health caused by Long Covid also came with an accompanying economic cost.[189] The Office for Budget Responsibility (OBR) in their Economic and Fiscal Outlooks warned of spending implications as a result of Long Covid first in November 2020,[190] and again in March 2021."[191] This assessment reflected the concerns of the LCGs who asked the Government to ensure there was economic support and social safety nets for people affected by Long Covid.[192]

94. Clare Lombardelli agreed that there was an economic effect for people suffering from Long Covid in terms of labour market activity. She also said that information on the economic impact of a significant number of people suffering from Long Covid would have been shared with the Treasury when they became aware of it.[193] Yet the economic costs of Long Covid, along with the other direct costs of Covid-19, did not feature in HM Treasury advice or that from Cabinet. Rishi Sunak admitted that "*generally the impact of Covid on the labour market was mis-estimated…"* due to the predominant fear of significant unemployment which did not manifest in the end.[194] Rishi Sunak accepted that Long Covid was one of the factors relevant to the rise to date in economic inactivity and scarring.[195] The failure to recognise the direct costs of Covid-19 skewed the Treasury

185 [INQ000273901/150, 190, 230, 234].
186 [INQ000103173].
187 [INQ000339033/90].
188 [INQ000273749/3].
189 [[INQ000272241]
190 [INQ000114451/121].
191 [INQ000114450/136].
192 [INQ000238582/2-3]; [INQ000248911].
193 [18/55/21-18/56/10].
194 [33/205/8-21].
195 [33/204/3-25].

focus who were reported to be against further lockdowns in 2020.[196] Earlier action by the Government should have been taken to limit transmission of what became a deadlier second wave and which undoubtedly caused more people to develop Long Covid.

The Impact of the Failure to Consider Long Covid in Decision-Making in 2021

95. The Government's failure to properly consider Long Covid continued well into 2021. Boris Johnson continued to doubt the medical evidence behind Long Covid until mid-2021 when Sir Patrick Vallance recorded, "*he isn't very persuaded by Long Covid.*"[197] It was only in June after receiving written and oral advice from Professor Sir Chris Whitty that Mr Johnson accepted the evidence supporting Long Covid and that it was "*not exactly Gulf War Syndrome then.*"[198]

96. There are two conclusions to be drawn from his delayed acceptance of Long Covid. The first is that Boris Johnson did not consider Long Covid in the plans to remove Covid-19 measures of Covid-19 in the first half of 2021. The second was that in Summer 2021, when planning strategies (High Prevalence Summer) in response to high rates of transmission of Covid-19, Boris Johnson had accepted the evidence on Long Covid but he continued to disregard it when making decisions in response to the pandemic.[199]

(i) Spring 2021

97. In January, LC Support wrote to all MPs ahead of a Parliamentary Debate on Long Covid asking the Government to recognise that Long Covid was impacting a significant number of people and preventing them from engaging in economic activity. They asked for more to be done to prevent Long Covid by making "*Long Covid part of the narrative,*" communicating the diversity of symptoms of Covid-19 and considering Long Covid in early intervention with antiretrovirals. They also asked for more support for people with Long Covid who were no longer able to work.[200] That month, LC SOS wrote an open letter to the Prime Minister asking that the Government make "*Long Covid a primary consideration in your policy decision making for lifting restrictions.*"[201] Running up to the first parliamentary debate on Long Covid on 11 January 2021, LC Kids wrote to MPs as part of the Parents United Against Unsafe Schools campaign.[202] They raised concerns

[196] [INQ000226497/68].
[197] [INQ000273901/659].
[198] [INQ000251916]; [INQ000251917]; [INQ000251918].
[199] [INQ000092058].
[200] [INQ000248900].
[201] [INQ000238583].
[202] [INQ000283396]

about the risk of Long Covid in children and young people and provided a briefing to MPs on the need for resources to be provided to make schools safe when lifting measures.[203]

98. Their concerns were well-founded. On 22 February 2021, the Government published the Spring Roadmap which set out the plan for releasing restrictions.[204] On the day before publication, Boris Johnson reviewed the draft Roadmap and sent a number of questions to his advisors. The last question was "*Do we really believe in Long Covid? Why can't we hedge it more? I bet it is completely gulf war syndrome stuff."*[205] Imran Shafi shared the questions before a meeting the same day shortly before the Roadmap was signed off.[206] While there had been text on Long Covid discussed with the CMO's Office on 18 February 2021,[207] the published Roadmap did not refer to Long Covid and made only passing reference to the long-term consequences of Covid-19.[208] There was no reference to the now oft-repeated mantra that "*no Covid-19 meant no Long Covid."* This omission is significant not least because Matt Hancock wrote formally to the Prime Minister on 14 February 2021 to warn that lifting restrictions too quickly risked serious illness occurring "*with Long Covid and hospitalisation rates."*[209] In February 2021, Dame McLean queried the ethics of knowingly allowing more people to be infected.[210] In March 2021, Dr Ben Warner wrote *"infections up=Long Covid."*[211] He said it was clear that "*we did know about Long Covid … and that even if we don't see deaths then Long Covid is obviously another thing to bear in mind*."[212] Boris Johnson's comments by WhatsApp show that as the Government prepared for the release of restrictions, Long Covid was again dismissed.

99. The decisions taken during this period did not promote the safety of children in schools or consider the role of schools in the transmission of Covid-19.[213] On 12 April 2021 LC Kids wrote to Matt Hancock with Safe Ed for All urgently demanding that Covid-safe mitigation measures be put in place in schools.[214] This included calls for improved ventilation, mandatory mask mandates, social distancing and the encouragement of remote learning where feasible. A similar letter was sent by LC Kids to Gavin Williamson

[203] [INQ000272147].
[204] [INQ000089798].
[205] [INQ000214216/52].
[206] [INQ000226334/9].
[207] [INQ000072826].
[208] [INQ000089798].
[209] [INQ000153728].
[210] [INQ000063400].
[211] [INQ000264429/16].
[212] [18/199/12-15].
[213] [INQ000272175].
[214] [INQ000272150].

on 4 May 2021 as part of the ongoing campaign by Parents United Against Unsafe Schools.[215] The letter called for the *"safe re-opening of schools"* which required basic mitigation measures to remain in place to prevent a repeat of the harm caused by *"the previous full re-opening of schools in September"* 2020. Later that month, there was explicit agreement between the DHSC, PHE, NHS and DfE that messaging in schools needed to be adapted to assist children experiencing long-term symptoms from infection with Covid-19.[216] Despite this, there was no messaging on Long Covid to make schools safer for children.

(ii) Summer 2021

100. In July 2021 LC Support, LC SOS, and LC Kids wrote to Sajid Javid, urging him to take into account the impact of Long Covid when making decisions in response to the pandemic. [217] They warned that the high rates of transmission of Covid-19 were likely to lead to increased numbers of people suffering from Long Covid. They said:

> "*Long Covid has not only been ignored in policy making decisions, and barely mentioned in the roadmap out of lockdown – it has been almost completely absent from the government's public messaging. The population are now being asked to take responsibility for their own safety and "exercise good judgement" but due to this communications failure many do not realise the extent of risk they are taking when exposing themselves to this virus."*[218]

101. By Summer 2021, the UK Government was aware that there were high rates of transmission of Covid-19. The public announcement on the move to Step 4 of the Roadmap recognised that the pandemic was not over and a third wave was underway but made no explicit reference to the risk of Long Covid despite the incidence of Covid-19 remaining "*high and rising*."[219] In contrast to the position presented to the public, a Covid-O Ministerial briefing noted *"Long Covid cases will increase, creating an increased burden on individuals and the health system.*"[220] Cabinet were aware that there were high rates of transmission and that at least 3 million young adults between 18 to 30 years were unvaccinated and unprotected.[221]

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[215] [INQ000272151].
[216] [INQ000283448].
[217] [INQ000248931]; [INQ000238584]; [INQ000272152]; [INQ000272191].
[218] [INQ000238584].
[219] [INQ000055233].
[220] [INQ000092536].
[221] [INQ000089048/11-12].

102. Long Covid was a known risk which even Boris Johnson had accepted by this time. Yet decision-makers did not raise concerns about the likely harm Long Covid would cause amongst the younger, unvaccinated population and ongoing risk even if vaccinated. Instead, the Government accepted the high prevalence of Covid-19, knowing it would cause more people to suffer from Long Covid. Sajid Javid admitted that Long Covid was an accepted trade-off for releasing restrictions on social distancing.[222] This trade-off is explicitly recognised by decision makers and in advice (see for example Covid Operations Committee papers and Covid Task force papers) at the time which recognised that high rates of transmission would result in increased incidence of Long Covid.[223] Sajid Javid notes from a Long Covid Ministerial round table record "*Long Covid Dashboard 23/9...should focus on prevention/costs rising/how do we prevent/keep same where you ca*n."[224] However, no effort was made to put Covid safe mitigation measures in place to minimise transmission of Covid 19 and there was no public health campaign.[225]

103. There was no substantive plan to prevent high incidence of Long Covid through NPIs to change the behaviour of those who mistakenly believed that Covid posed no significant risk to them, such as public health communications, ventilation, masks or other Covid-safe mitigation measures. Data from the ONS illustrates the sharp escalation of cases of Long Covid from June 2021.[226]

104. Further, although the growing impact of Long Covid on the workforce was recognised, there was no corresponding proposal on mitigations for that impact.[227] At an earlier meeting of Covid-O on 5 July 2021, the minutes recorded concern that Long Covid should not be used "*loosely"* as Personal Independence Payment Claims "*had reached an all time high."*[228] Even after it was added to the agenda, Long Covid was an inconvenient truth which decision-makers chose to ignore. There was no plan to support people with Long Covid, and the only minutes recording discussion on the subject discouraged recognition of Long Covid.

The Impact of the Failure to Consider Long Covid in Decision-Making in 2022

105. On 10 February 2022, LC SOS issued a press statement warning against the uncontrolled spread of Covid-19 in the community without precautionary measures in

[222] [28/142/13-25].
[223] [INQ000067095]; [INQ000092058]; [INQ000055219]; [INQ000055599]; [INQ000063973]..
[224] [INQ000274058/21].
[225] [28/142/19-28/144/23].
[226] [INQ000292765/7].
[227] [INQ000092058/2].
[228] [INQ000092025/7].

place.[229] They stated that previously healthy and economically active people would be affected by a debilitating long-term illness for which there were no effective treatments. LC SOS and LC Kids issued a joint statement on 21 February reinforcing these concerns including removing free testing, contact tracing and surveillance, legal requirements to self-isolate and financial support for those that are required to isolate.[230]

106. Sajid Javid explained that in February 2022 when the Government published their plan 'Living with Covid-19' he considered it would be "*irresponsible to disarm*" against Covid-19.[231] As HM Treasury were unwilling to continue funding necessary measures he tried to redistribute funds from DHSC to maintain some protections in place.[232] However, on 21 February 2022, the Government announced that free testing would end on 1 April 2022 and people who tested positive were no longer required to isolate from February 2022. Further by April 2022, there would be no formal advice for people to stay at home if infected with Covid-19.

107. Sir Patrick Vallance's diaries suggested that some within Cabinet had opposed further measures on Covid-19 as it was compared to a "*common cold."*[233] They also suggest the lead-up to finalising "Living with Covid" was contentious;[234] some ministers opposed even "*mild caution about people still wearing masks*" while HM Treasury was described as "*totally against continued spend on Vx (unbelievable!!!)* [sic]*"*[235] Other ministers were still repeating the idea of "*let it rip' + get it over + done with."*[236]

108. Despite the persistent advocacy of the LCGs and regular meetings with ministers at the Long Covid Ministerial Roundtables, Long Covid was still not a consideration by the UK Government in their haste to claim that the pandemic was over. The lack of free testing for Covid-19 meant a return to the early days of the pandemic where there was inadequate surveillance and people with persisting long-term symptoms of Covid-19 struggled to secure a diagnosis in the absence of a positive test confirming initial acute infection of Covid-19. Boris Johnson's response to questions at the Press Conference about how people could exercise personal responsibility without free testing exposed his

[229] [INQ000238611].
[230] [INQ000238612].
[231] [INQ000309523]; [INQ000302485/40].
[232] [INQ000302485/40].
[233] [INQ000273901/540, 554].
[234] [INQ000273901/573-580].
[235] [INQ000273901/571,573].
[236] [INQ000273901/564].

attitude to Covid-19: he referred to Covid-19 as "*relatively mild*" with low levels of mortality. He did not acknowledge the ongoing risk of Long Covid.[237]

109. Long Covid continued to be a risk which was at best ignored by Government who dismissed Covid-19 as no different to a common cold, and at worst quietly accepted as a trade-off when easing restrictions. There was a reasonable middle ground which the Government should have taken. Instead of accepting the long-term ill-health and disability of adults and children, the Government could have approached decisions to ease restrictions armed with data on the impact of long-term morbidity as a measure of pandemic harm and used this to take informed steps to maintain simple Covid-safe measures while relaxing the strongest 'lockdown' measures. The public needed to be informed of all the risks that Covid-19 still posed to them. Long Covid is an additional, distinct factor to be considered in decision-making around NPIS, in addition to the impact of acute Covid.

IV. LOOKING FORWARD

110. The Inquiry has heard ample evidence on the Government's dysfunction: of its weak leadership, its inconsistent approach to taking decisions and the inadequacy of its decision-making structures for a pandemic. These systemic and structural failures need to be remedied first and foremost. In addition to resolving the over-arching structural form of Government, the LCGs propose substantive recommendations on key areas that impact Long Covid.

RECOMMENDATIONS REGARDING COVID-19 PANDEMIC

111. The lessons to be drawn from the Government response to the Covid-19 pandemic do not apply only to a potential future threat, they have immediate relevance. The UK effectively 'disarmed' against Covid-19 in February 2022, but the virus and new variants continue to circulate now. People are still developing Long Covid following infection, and sometimes only after reinfection. There are lessons to be learnt from *the ongoing Covid-19 pandemic* which can have an immediate impact. They require preventative and supportive measures to be put in place:

Preventative Measures

112. Preventative measures should be reintroduced to prevent people developing Long Covid:

[237] [INQ000064608].

a. There is an urgent need for an immediate **nationwide communications campaign** advising the public that Long Covid is (i) a debilitating and disabling long-term illness (ii) caused by infection from Covid 19 and (iii) has an indiscriminate risk profile, meaning that all adults and children are susceptible to it, even if they have recovered from previous infections. Communications on Long Covid should be shaped to encourage protective behaviours amongst the public to minimise the general transmission of Covid-19 in a reasonable manner. The LCGs have had to fill this gap, one example is by self-funding a Digi-Van to circulate through London's streets during the course of the Inquiry hearings explaining the risk of Long Covid to the general public. This, and their other awareness-raising activities, doesn't supplant the need for a Government communications strategy.
b. The ONS should immediately resume collection of **data on the prevalence of Long Covid** to assist the general public and decision makers with understanding it's risk.
c. **Covid-safe mitigation measures** should be reintroduced in public buildings, especially schools and healthcare settings. This includes measures such as: Air filtration and improved ventilation in all public buildings to improve the indoor air quality; adequate and ongoing provision of PPE in healthcare settings to protect the long-term health of medical staff and patients; and adequate and ongoing provision of Covid-19 tests in the community to support protective behaviours and assist in identifying Covid-19 infection for diagnostic and care purposes.

Supportive Measures

113. There is a need for measures to be introduced to provide support for those still suffering from Long Covid:

a. Long Covid causes workplace absenteeism, loss of earnings and labour market inactivity.[238] A **package of economic support** must be made available for individuals who have suffered economic losses due to Long Covid.
b. Long Covid causes absences from schools and interference with education. **Guidance and support** should be offered to education providers to assist them to make reasonable adjustments for students who need support accessing education.
c. The Inquiry heard evidence from the BMA and the TUC about the profound impact Long Covid has head on health care workers but the IIAC has still not reached a

[238] [INQ000292660].

decision on **the designation of Long Covid as an occupational disease**.[239] In addition to the above, the Chair should refer to the Government/IIAC urgent question of Long Covid being designated an occupational disease so that healthcare workers can access financial support.

RECOMMENDATIONS FOR A FUTURE PANDEMIC

114. Recommendations on how long-term sequelae can be built into a pandemic response hold significant potential to learn from the avoidable suffering of those with Long Covid. The LCGs have identified four broad categories from the Covid-19 pandemic which could assist with the Chair's final recommendations for ***future pandemics***:

a. Surveillance systems should be in place from the outset, for example in the form of sleeping studies. These should identify and monitor data on the impact of longer-term sequelae so that long-term health implications can be recognised early on. This data should feed into modelling for long-term sequelae to assist decision makers with a fuller picture of the severity of pandemic harm.

b. The long-term health consequences of a novel virus (including its socio-economic impact) must be factored into decisions made in response to the transmission of the virus and included in assessments of the necessity for NPIs and PIs, as they may have a different risk profile to acute infections and add to the burden of the disease.

c. Decision-makers should take a preventative approach and provide clear, timely and consistent public messaging on the long-term consequences of infection throughout a pandemic. Public health communications on the long-term consequences of the infection should be kept under review and updated as further information becomes available to raise awareness of the risk of long-term consequences to encourage protective behaviour, and signpost available treatment resources.

d. Adult and child patient voices should be involved from an early stage of any pandemic response, in a way that accommodates children's participation, to ensure that policies are responsive to people's needs.[240]

V. CONCLUSION

115. The picture of Long Covid painted from the evidence is a damning one. On the one hand, the evidence shows that long-term sequelae were both foreseeable and was foreseen by senior decision-makers. Building upon this foresight, was a growing

[239] [3/118/14-25]; [4/64/7-17].
[240] [INQ000249018/23].

understanding of the nature of long-term sequelae within Westminster and the scientific advisory channels that fed into the Government decision-making. Decision-makers' approach to Covid-19 maintained a blinkered focus on the impact of acute Covid, and relegated consideration of the long-term impact of Covid as peripheral, even non-existent. This left patients who were suffering from the foreseeable effects of long-term sequelae to advocate for recognition of their own suffering.

116. The myopic focus on acute Covid-19 drew an artificial separation between the direct impact of acute infections from the impact of long-term illness from infection of Covid-19. Government used the two metrics of hospitalisations and deaths to inform their understanding of the severity of the pandemic's impact; this placed the impact of long-term morbidity out of sight and left decision-makers with a distorted sense of the severity of the pandemic's impact when making decisions. Data collection and monitoring of Long Covid only began when urged upon by patient advocates. Even when collected, the data did not factor into the CRIPS, Dashboards and other tools that decision-makers relied upon primarily.

117. Patient advocates also called for public messaging of the risk of Long Covid but these calls were not heeded because Long Covid had been silo-ed as a treatment issue, with no regard for its prevention. The Inquiry has heard clear evidence that despite Long Covid posing an indiscriminate risk to adults and children, it was not factored into decision-making around the imposition of and easing of measures. The Government failed to warn individuals and parents that anyone could suffer from long-term harm. People did not know to protect themselves from this known risk; they mistakenly believed that Covid would be short, mild and flu like for those that were not elderly or previously identified as clinically vulnerable. Instead of maintaining Covid-safe mitigation measures in schools and other public places when easing wider measures, Covid-19 was allowed to spread uncontrollably.

118. The long-term health of the population was needlessly sacrificed. The answer to the LCGs' central question is clear from the evidence: the ongoing suffering of nearly two million adults and children with Long Covid was avoidable, and should have been avoided.

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SANGEETHA IENGAR
SHANTHI SIVAKUMARAN
JANE RYAN
BHATT MURPHY SOLICITORS