COVID-19 PUBLIC INQUIRY

MODULE 2:
JOINT OPENING STATEMENT

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

I. INTRODUCTION

1. The Long Covid Groups, Long Covid Support, Long Covid SOS and Long Covid Kids, make this opening statement to Module 2 of the Covid-19 Inquiry as representative organisations for nearly 2 million adults and children who have suffered from Long Covid.[1]

2. The pandemic and measures taken in response to it have touched us all. We have emerged from this global event with common, but also distinctly individual experiences of the suffering it caused. At the outset, the Long Covid Groups wish to acknowledge the pain suffered by the Bereaved Families who lost loved ones to Covid-19 and offer their condolences to them.

3. The term Long Covid was born from the Covid-19 pandemic, but the prospect of long-term post-viral illness was not unknown before this pandemic. As Professor Brightling and Dr Evans note in their report *"it was foreseeable that there was going to be long-term sequelae from Covid-19 extrapolated from previous coronavirus pandemics and previous knowledge of post-viral syndromes."*[2] A central question for the Inquiry to grapple within this Module is: **since Long Covid was foreseeable, why was it not foreseen?**

4. For those suffering with Long Covid, they went into the pandemic being told that they faced either a short acute illness, or, if vulnerable, would die. What they learnt through personal experience was that there was a third possibility: long-term illness resulting from Covid-19. Previously fit and healthy adults and children have suffered profound and lasting changes to their lives as they experience the continuing effects of the disease. For many affected people, Long Covid amounts to a disability under section 6 of the Equality Act 2010 as it has a substantial and long-term adverse effect on their ability

[1] As of September 2022, 2.3 million people were reported to have suffered Long Covid. The number of people with Long Covid fell to 1.9 million people on 5 March 2023. Ian Diamond [INQ000271436_0075] paragraph231-232.
[2] Brightling and Evans Draft report on Long Covid at paragraphs 7.1, 7.4.

to carry out normal day-to-day activities.[3] Many were frontline workers in the NHS who risked their health and wellbeing.[4]

5. Module 2 is the first Module in which the Long Covid Groups are represented as Core Participants. Their interest in participating in this Inquiry stems from their lived experiences and serious concerns during the pandemic that decision-makers overlooked their suffering and failed to have proper regard to Long Covid in both adults and children. This led to those suffering from Long Covid establishing their own grassroots organisations to advocate on behalf of people with Long Covid. As at March 2023, 1.9 million people (2.9% of the population) are suffering from Long Covid and they look to this Inquiry to understand why.[5] Of that cohort 69% had Long Covid for at least one year and 41% for at least two years; Long Covid symptoms adversely affected the day-to-day activities of 79%, with 20%reporting their ability to undertake day- to- day activities had been substantially limited.[6] Long Covid is not a few weeks of aggravating symptoms, but can be a profoundly life changing and disabling condition. This includes for children with Long Covid who, in their formative years, have suffered the generic harms of the pandemic coupled with disadvantages caused by the physiological harms of ongoing symptoms.[7]

6. The Long Covid Groups welcome this Inquiry as a critical arena in which to record the events which took place during the pandemic, the impact on people, and to identify potential lessons to be learnt. The Long Covid Groups' hope is that Module 2 will answer six core questions pertinent to the ongoing suffering of people with Long Covid:

1) What decision-makers' understanding of long-term sequelae and Long Covid was;

2) What was the role of patient advocacy in the recognition and response to Long Covid;

3) Was there data collection and modelling of Long Covid;

4) Was the prevalence and the risk of Long Covid taken into account when decisions, like the imposition and then easing of non-pharmaceutical interventions, were adopted;

5) How - and to what extent - did decision makers warn the public about the risk of developing Long Covid and take the disease into account in public health communications; and

6) Whether nearly 2 million people suffering from Long Covid today was avoidable?

[3] See for example *Anrude v Advisory, Conciliation and Arbitration Service (ACAS)* (ET, 23 March 2023) Case Number 2207635/2021 at paragraph 14 where the Respondent accepted that Long Covid met the definition of disability within section 6 of the Equality Act 2010.

[4] ONS data from March 2022 shows that the prevalence of Long Covid is higher in those working in healthcare than in the general population. BMA, '*The Impact of the pandemic on the medical profession,"* BMA Covid Review 2, [INQ000118475_0009]; and BMA, ""Over-exposed and under-protected: the long-term impact of Covid-19 on doctors," cited in FEHMO submissions of 27 October 2022 at paragraph 5.

[5] [INQ000271436_0075] paragraph 232.

[6] [INQ000271436_0075] paragraph 233.

[7] See further Letters to Boris Johnson by and from Long Covid Kids, Sammie McFarland, Long Covid Kids Impact Statement at paragraph 49; and exhibits SM/24[INQ000_] (not yet disclosed).

7. A pandemic spreads with such force that that there can be no one individual action which can limit the risk from an emerging disease. Instead, we are dependent on the responses of Government decision-makers to manage and communicate that risk to us and take appropriate actions to mitigate our collective suffering. Only decisions taken at a Government-wide level and cascaded down to the local level can choreograph our individual movements, decisions and actions in order to mitigate the direct and indirect impacts of the pandemic.

8. The UK Government's response to this pandemic was not a case of the leadership rising to the challenge. Tested in challenging circumstances, the UK Government failed to deliver. The experience of those suffering with Long Covid - the surviving victims of the pandemic - illustrates that the harm caused to people by the pandemic was not a central concern of the Government. This resulted in Government decision-makers dismissing and minimising the experience of those with Long Covid; taking decisions which allowed Covid-19 to spread, directly increasing the prevalence of Long Covid; and failing to take Long Covid into account when implementing measures during the pandemic. A government which put people at the forefront of its thinking could not, and would not, have followed this approach.

9. The Long Covid Groups are concerned about many of the decisions taken during the relevant period that allowed the virus to spread unchecked causing devastating harm to bereaved families and also people left suffering with Long Covid. The scope of this Opening Statement will not touch on all of these issues, but will necessarily focus on the key issues related to the prevalence of Long Covid. We will first address the delayed recognition of Long Covid before turning, secondly, to the failure to integrate Long Covid into pandemic decision-making.

II. THE DELAYED RECOGNITION OF LONG COVID

The Origins of the Term 'Long Covid'

10. Long Covid is a patient-made term. In the absence of public information and government advice about the possibility of the long-term effects of Covid-19, patients used social media and traditional media to communicate their lived experiences of suffering from protracted symptoms of Covid-19. The first posts on social media about the possibility of the long-term effects of Long Covid were in March 2020 and patient experiences began being documented in the traditional media by April 2020.[8] By 11 May 2020, a patient-led team published the first survey of prolonged symptoms reporting over 50 symptoms.[9]

[8] Callard and Perego, "*How and why patients made Long Covid,"* Soc Sci Med. 2021 Jan; 268: 113426 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7539940/ .
[9] [INQ000249034].

11. The Long Covid Groups all formed during this period to give voice to those suffering and to raise awareness of the long-term harm caused by Covid-19. Long Covid Support started a placard campaign on Twitter on 18 May 2020 listing symptoms and the number of days people had been ill.[10] On 8 July 2020, Long Covid SOS published a film online called 'Message in a Bottle' highlighting the stories of more than 100 people who had been unwell for around 3 months with their symptoms.[11] Long Covid Kids published a film on YouTube in October 2020 entitled 'Our Unhappily Ever After', raising awareness of the risk of Long Covid in children.[12] The Long Covid Groups did not ask to be patient advocates: it is a role that they have commendably stepped into, whilst seriously unwell themselves and/ or caring for chronically ill family members, driven by their motivation to prevent other people, including children, suffering as they have.

12. The Long Covid Groups advocated the highest echelons of Government decision- makers to call for recognition of Long Covid. Examples of their advocacy include:
    i. On 3 July 2020, Long Covid SOS sent a letter to the then Prime Minister, Boris Johnson, copying in all sitting members of Parliament, Chief Medical Officer (CMO) Professor Sir Chris Whitty, the Government Chief Scientific Advisor (GCSA) Sir Patrick Vallance, Professor Sir Stephen Powis, Medical Director of NHS England and the leaders of the devolved health administrations, asking for formal recognition of Long Covid and warning of an increase in numbers of people with Long Covid if there were to be a second wave.[13]
    ii. On 28 August 2020, Long Covid Support sent a letter to Jeremy Hunt MP, Chair of the Health and Social Care Committee, calling for the UK Government to assemble a multi-disciplinary Long Covid Taskforce.[14] This letter was forwarded by Mr Hunt to Matt Hancock MP, then Secretary of State for Health and Social Care, and raised at a Select Committee hearing on the long-term effects of Covid-19 on 9 September 2020.[15]
    iii. On 26 January 2021, Long Covid Kids members gave evidence to the APPG on Coronavirus on the incidence of Long Covid in children.[16]

Government Recognition of Long Covid

13. In the face of growing awareness of the long-term effects of Covid-19, the UK Government remained silent. On 16 July 2020, Mr Hancock was compelled to respond to a question about the long-term effects of Covid-19 from Andrew Gwynne MP in the House of Commons. Mr Hancock acknowledged that post-viral fatigue was a significant problem for "*a minority of people who have had coronavirus."*[17] He also promised an NHS service to help people suffering "*from symptoms of the*

[10] Natalie Rogers - Long Covid Support Impact Statement page 2 paragraph 4. [INQ0000_] (not yet disclosed).
[11] Ondine Sherwood - Long Covid SOS Impact Statement pages 7-8 paragraph 27-28. [INQ0000_] (not yet disclosed).
[12] Sammie McFarland - Long Covid Kids Impact statement page 5 paragraph 20.
[13] [INQ000238582].
[14] [INQ000248911].
[15] [INQ000249042].
[16] Sammie McFarland - Long Covid Kids Impact statement [INQ0000_] paragraph 36.
[17] [INQ000086680].

fatigue that comes to some."[18] There was no mention of the various other symptoms of Long Covid or that a significant number of people had reported being affected by this stage. This was not for lack of knowledge. Professor Kamlesh Khunti, Director of the UK National Institute for Health Research in Applied Research Collaborations noted that by August 2020, there was sufficient understanding for "*guidance on management of 'post-acute Covid' … to be published in the British Medical Journal."*[19]

14. It was only on 7 September 2020 that there was official Government guidance on the long-term effects of Covid-19 published by Public Health England (PHE) on their website.[20] This guidance coincided with Mr Hancock's appearance before the Health and Social Care Select Committee on 8 September 2020 for a hearing on Social Care: funding and workforce.[21] This was the first occasion that Mr Hancock made a clear statement of recognition of the impact of Long Covid and that it affected people of all ages including those who had community managed cases of Covid-19. The Select Committee asked Mr Hancock to reply to concerns set out by Long Covid Support in their 28 August 2020 letter to the Select Committee.[22]

15. On 21 October 2020, shortly after the Select Committee Hearing, Mr Hancock published a statement with a short film about the risks of long-term effects of Covid-19 on a Gov.uk website. He stated *"I am acutely aware of the lasting and debilitating impact long Covid can have on people of all ages, irrespective of the seriousness of initial symptoms….this should be a sharp reminder to the public- including young people- that COVID-19 is indiscriminate and can have long term and potentially devastating effects.*"[23] The statement was the first clear expression from the Government about the risks of long-term effects of Covid-19 on people who were suffering from community managed Covid-19. The Long Covid Groups welcomed these nascent steps at recognition of the condition, but remained concerned that Long Covid was not being considered seriously in the Government's response to the pandemic.[24]

16. The UK Government's reluctance to respond to the Long Covid Groups' advocacy for recognition stands in sharp contrast to the position of the World Health Organisation (WHO), who maintained open dialogue with patient advocates as they developed their understanding of the virus. On seeing their campaign, the WHO contacted Long Covid SOS in July 2020 and invited them to a meeting on 21 August 2020. The WHO Director General Tedros Adhanom Ghebreyesus told the audience he had "*heard loud and clear that Long Covid needs recognition, guidelines, research and ongoing patient*

[18] [INQ000086680].
[19] [INQ000223054].
[20] Prior to this, in July 2020, NHS England launched the Your Recovery website, an online portal for people suffering the long-term effects of Covid-19 [INQ000051231].
[21] [INQ000218365_0021].
[22] [INQ000218365_0021].
[23] Ondine Sherwood - Long Covid SOS Exhibit OS/11 [INQ0000_] Matt Hancock statement [INQ000094776] page.9; Briefing document to film: [INQ000071193].
[24] [INQ000231948]; [INQ000248937].

input and narratives to shape the WHO response from here on."[25] The WHO actively listened to the Long Covid Groups' call for recognition of Long Covid and translated this into public recognition, whilst the UK Government, remained silent[26].

17. Given the early recognition by the WHO, the Long Covid Groups look to this Inquiry to investigate why the UK Government delayed in publicly acknowledging the existence of long-term sequelae until Mr Hancock was obliged to give evidence to the Select Committee on Health and Social Care on 9 September 2020. Interlinked to this issue, is an examination of the crucial **role patient advocacy played in the recognition and response to Long Covid**, a question to be investigated in this Module.

Understanding and Knowledge of long-term sequelae

18. Key to assessing the adequacy of government decision-making in response to Long Covid, is an examination of **what decision-makers' understanding of long-term sequelae and Long Covid was**. The Inquiry will hear evidence that prior to the pandemic, the risk of long-term sequelae was well known:
    i. Professor Brightling and Dr Evans report that "*long-term sequelae following acute respiratory viral infections are well recognised. It was therefore predictable that there would be long-term sequelae following a pandemic of a respiratory infection*."[27]
    ii. A report prepared by the Academy of Medical Sciences "Preparing for a Challenging Winter 2020/21" approved by SAGE 46 on 9 July 2020 confirmed that "*post-viral syndromes are well documented following other viral infections."*[28]
    iii. Sir Patrick Vallance said: "*From my perspective, I was conscious that long-term sequelae were a possible outcome of Covid-19 from early in the pandemic, though it took time for the extent of those sequalae to become apparent."*[29]
    iv. We know that this risk was communicated directly to the then Prime Minister. In a note dated 31 May 2021, Professor Whitty advised the then Prime Minister "*Although there is often a common assumption that you either die of infections or get better, for many infections this is not true. The principle that even initially trival [sic] infections can cause long-term, and sometimes severe, effects is well established."*[30]

19. Contemporaneous documents disclosed to the Inquiry show that the risk posed by long-term sequelae was also acknowledged as an issue of concern by the NHS, NERVTAG and SAGE, at the very early stages of the pandemic. In March 2020, the NHS Demand Strategy Team Report on developing a

[25] [INQ000238649]; Ondine Sherwood - LC SOS Impact Statement [INQ0000_] page 9 paragraph 33.
[26] The engagement with the WHO was ongoing. For example in December 2020 Long Covid Support organized the Long Covid Forum in collaboration with ISARIC and GLOPIDR opened by the WHO Director General. Long Covid Support Impact Statement [INQ0000_] (not yet disclosed).
[27] Brightling and Evans Draft Report on Long Covid pages7-8 and page 38 paragraph 7.1 (not yet disclosed).
[28] [INQ000211967] page 24; [INQ000146629_0296] paragraph 28.
[29] [INQ000238826] page 203 paragraph 624.
[30] [INQ000073417].

Demand Recovery Package for the NHS post-Covid-19 noted with concern: *"if it is found that contracting C-19 has longer term health implications, this will increase demand for health and social care services."*[31] On 6 March 2020, in the context of identifying the date of onset of symptoms of Covid-19, NERVTAG advised that identifying the end of symptoms "*may be very prolonged or very difficult to define."*[32] On 28 April 2020, SAGE 29 emphasised the "*importance of cohort studies of Covid-19 survivors to understanding the longer-term effects.*"[33] It is not known if key decision-makers at No.10 were advised of this risk at the time.

20. While the extent and severity of Long Covid was initially unknown,[34] Professor Brightling and Dr Evans observed that "*if long-term sequelae followed a similar trajectory to SARS-CoV and MERS-CoV it was likely that post-infection sequelae would be common and could in some cases be severe."*[35] It is difficult to understand why there was no public communication that there was a risk of long-term effects of Covid-19 when that risk was well-known pre-pandemic, and was likely to be 'common' if it followed the same trajectory as the main comparator coronaviruses, SARS-CoV and MERS-CoV.

21. Even though "*initial planning for Covid-19 took no account of"* long-term impacts of Covid-19,[36] there were widespread reports of the severity of the long-term effects of Long Covid on individuals in social media and traditional media, as well as in medical journals from as early as March 2020 and onwards. Both SAGE and NERVTAG recognised the existence of long-term health sequelae at the same time that it was being reported by people with Long Covid on social media and in mainstream media. On 7 May 2020, SAGE 34 recorded "*the existence of longer-term health sequelae… and the importance of monitoring these impacts."*[37] On 15 May 2020, NERVTAG discussed "*ongoing clinical issues post-covid and the potential need for a clinical forum."*[38]

22. DHSC was clearly alive to concerns about the long-term impacts of Covid-19 although they failed to publicly acknowledge it. By June 2020, a DHSC presentation recorded one of the "*four major implications for the health and care system which we will have to cater for: (1) sequelae of the disease, which include post-ITU respite care and potential longer-term lung and organ damage."*[39] One month later, a DHSC Briefing note for a meeting on Community Health Services recognised that Covid-19 had a "*lasting impact"* on the health of survivors of Covid-19 which would place an increased demand for care in the community.[40]

[31] A hypothesis identified in March 2020 by the NHS Demand Strategy Team prepared a report Developing a Demand Recovery Package for the NHS post Covid-19 [INQ000049960].
[32] NERVTAG 8 on 6 March 2020 paragraph 3.14 (not yet disclosed).
[33] [INQ000146629] page 186.
[34] Patrick Vallance [INQ000238826] page 203 paragraph 624; Chris Whitty [INQ000251645_0206] paragraph 12.1.
[35] Brightling and Evans Draft Report on Long Covid page 38 paragraph 7.4 (not yet disclosed).
[36] Chris Whitty [INQ000251645_0206] paragraph 12.1.
[37] [INQ000146629] page 215.
[38] NERVTAG Birdtable 15 May 2020 §3.4. [INQ000070303_0003].
[39] DHSC Presentation dated 5 June 2020 titled Scenario planning for the health and care system in winter [INQ000051104].
[40] [INQ000051188].

23. On 17 July 2020, Mr Hancock chaired a Roundtable mandated to discuss the long-term impacts of Covid-19.[41] By summer 2020, the NHS were also alert to managing the risks of long-term impacts of Covid-19 and on 28 August 2020 prepared a detailed briefing note on managing the long-term effects of Covid-19.[42] This paper advised "*Around 10% of Covid-19 survivors experience post-acute disease beyond three weeks and a smaller proportion defined as chronic Covid-19 beyond 12 weeks."* The NHS estimated this translated to 60,000 people in the UK and reported they were expected to experience persistent or permanent physical health problems similar to those described for other coronaviruses (SARS and MERS). [43]

24. In relation to Long Covid in children, there was some early understanding that long-term sequelae could pose a risk to children which built on NERVTAG's view by the end of February 2020 that *"severe disease is possible in children, but is rare."*[44] At the SAGE 29 meeting on 28 April 2020, it was agreed to action priority studies on potential "*Kawasaki-like syndrome"* in children which would have explored how long-term sequelae in children presented.[45] This was the same month that the SPI-B Group on Education (SPI-Kids) subgroup was created to focus on the role of children in transmission of Covid-19 (which led to the development of the Children's Task and Finish Working Group (TFC)).[46]

25. Whilst the scientists considered whether children could be at risk of harm, the NIHR meanwhile, in their first review into Long Covid, looked directly into the experiences of children. Their report published in October 2020, Living With Long Covid, made plain that the risk of developing severe acute infections did not necessarily correlate with the risk of developing Long Covid and identified that they had heard *"powerful stories that ongoing Covid-19 symptoms are experienced by all age groups, from the youngest children...we cannot assume that groups who are at low risk of life-threatening disease and death during acute infections are also at low risk on living with Covid-19 long term"*[47] Further, a Briefing Note from the OCMO to Sajid Javid MP, the Secretary of State for Health and Social Care appointed after Mr Hancock, was only produced in August 2021 (on his request) confirming that children get an *"unusual condition which seems to be linked to COVID, called Paediatric Inflammatory Multisystem Syndrome (PIMS-TS or PIMS)*."[48] As the Inquiry will hear from the impact evidence of Sammie McFarland of Long Covid Kids, children with Long Covid and their families felt abandoned by the Government who failed to turn their minds to the long-term harm

[41] [INQ000094257].
[42] [INQ000205638].
[43] [INQ000205638].
[44] [INQ000047842] Email between DHSC and SAGE dated 24.02.2020 on NERVTAG meeting summary; NERVTAG 7 on 21 February 2020 at paragraph 5.1 (not yet disclosed).
[45] [INQ000146629].
[46] [INQ000221773].
[47] [INQ000058418].
[48] [INQ000073687]; [INQ000073686].

children with Long Covid were suffering from.[49] It is imperative that the experiences of those children are recognised and heard.

26. Patient advocacy continued to play a significant and necessary role in raising to the attention of key decision- makers, issues affecting people suffering with Long Covid. Following the Select Committee Hearing on 9 September 2020 where Mr Hancock was asked to respond to Long Covid Support's letter, the Long Covid Groups were invited to a regular Ministerial Roundtable on Long Covid organised by DHSC. The Ministerial Roundtables were chaired by Lord Bethell and Long Covid Support and Long Covid SOS were invited to join in October 2020.[50] Long Covid Kids joined the Ministerial Roundtable in February 2021.[51] The Ministerial Roundtable was an opportunity for Long Covid Groups to express their concerns relating to Long Covid to DHSC directly following months of correspondence and advocacy. The Long Covid Groups raised their concerns about the risk of long term harm to health from widespread prevalence of Covid-19, the need for improved public health messaging on symptoms and Long Covid, monitoring of data on Long Covid and also to emphasise that decision-making needed to consider the impact of Long Covid on schools, healthcare systems and in workplaces.[52] The Ministerial Roundtables were seen as a welcome development but over time the Long Covid Groups observed that issues raised, although met with sympathy, did not lead to meaningful action. **The Long Covid Groups are keen to understand how matters raised with DHSC fed into decision making at No.10 and if it did not, why not.**

27. **The issues arising to be explored are whether key decision-makers were advised of the known risk of long-term sequelae and if so, what, if anything, they did as a result. Further, knowing that there was a risk of long-term sequelae, should key decision-makers have recognised the severity and extent of Long Covid at an earlier stage in the pandemic?**

The Prime Minister's Dismissal of Long Covid

28. A critical issue for this Module will be whether the silence in public recognition of Long Covid was informed by then Prime Minister Boris Johnson's self-confessed and dismissive approach to recognising Long Covid as a *"serious condition."*[53] In October 2020, while DHSC was preparing to issue guidance on long-term sequelae and convening the Ministerial Roundtables on Long Covid, Mr Johnson scrawled *"BOLLOCKS"* over the document, expressing the view that Long Covid was akin to the "*gulf war syndrome."*[54] He has admitted that he did not believe Long Covid *"truly existed."*[55]

[49] Sammie McFarland - Long Covid Kids impact statement [INQ000_] paragraph 22, 23, 26. (not yet disclosed).
[50] [INQ000058536_0001].
[51] Sammie McFarland - Long Covid Kids impact statement [INQ000] paragraph 35 (not yet disclosed).
[52] Natalie Rogers - Long Covid Support Impact Statement paragraph 33. Ondine Sherwood - Long Covid SOS paragraphs 46-48.
[53] [INQ000255836_019] at paragraph 657.
[54] [INQ000255836_0191-0192].
[55] [INQ000255836_0191] at paragraph 657.

29. It is difficult to understand how the then Prime Minister still held this view in October 2020 as SAGE and NERVTAG had already recognised its existence five months earlier. Indeed, Mr Johnson had shared articles himself about the prolonged symptoms of Covid-19 on WhatsApp groups with his key advisors, Mr Cummings, the CMO and GCSA, Mr Hancock and Simon Case, as early as 17 May 2020.[56] There was a dissonance between the NHSE and DHSC's belated recognition of Long Covid and Mr Johnson's ongoing denial of Long Covid. We note that Mr Johnson's disbelief apparently persisted to at least June 2021, where he again maligned Long Covid, referring to it dismissively as 'Gulf War Syndrome' though he does not say in his statement when he accepted that Long Covid is a serious debilitating condition.[57]

30. **How could concerns raised at Ministerial Roundtables on Long Covid be addressed by No.10 if the Prime Minister did not believe Long Covid was real? A relevant question to be pursued in this Inquiry is how it came to be that Mr Johnson persisted in his flawed and dismissive belief that Long Covid was not a serious issue well into 2021, in direct contradiction to the stated approaches of the NHS and DHSC.**

31. On 15 January 2021, in the second year of the pandemic, the former Prime Minister was offered advice on Long Covid by his adviser Mr Shafi who counselled that he was "*right to be sceptical of any tendency to label all ailments as "Long COVID" but we will get you objective clinical advice from Chris on the extent to which this is a reasonable policy consideration."*[58] That advice was prepared for him by the CMO, Professor Whitty, on 11 February 2021[59] and included advice from the ONS on 4 February 2021 confirming that Long Covid affected a significant number of people.[60] There was also a detailed discussion on Long Covid at SAGE 79 on 4 February 2021.[61] Email correspondence from 19 February 2021 suggests that Professor Whitty preferred to brief Mr Johnson in person about Long Covid and committed to raise it over the next few weeks.[62] Yet Mr Johnson claims he only received advice on Long Covid dated from 1 June 2021 following a request in late May 2021.[63]

32. The advice from the CMO, Professor Whitty, dated 1 June 2021 was in a note drafted as a *"personal opinion.*" The delay and informal nature of the advice to the then Prime Minister is difficult to understand, not least because Ian Diamond's evidence is that No.10 first sought advice from the ONS on the prevalence of Long Covid on 25 September 2020[64] and in October 2020, No.10 sought reassurance from the CMO on whether Long Covid was sufficiently clinically established as a real

[56] [INQ000102087] and [INQ000102085].
[57] [INQ000251918].
[58] [INQ000146628].
[59] [INQ000072835], [INQ000072752].
[60] [INQ000072694].
[61] [INQ000063825].
[62] [INQ000072835].
[63] [INQ000255836_0192-0193] at paragraphs 661-663; [INQ000251917] and [INQ000251916].
[64] [INQ000268012] page 18.

condition that could impact young people.[65] The evidence clearly suggests that No.10 was aware of the risk of Long Covid well before October 2020 at the time of the second wave.

33. **Two further issues to be explored are first, why formal advice on Long Covid was not commissioned and presented to the Prime Minister before October 2020 as the country faced the implications of a significant second wave or soon after. Secondly, why there emerged such a divide in approach to Long Covid between the NHS and DHSC on one hand, and No.10 on the other, in the midst of the pandemic response?**

The Impact of Minimisation of Long Covid

34. It is indisputable that the former Prime Minister's view of the long-term effects of Covid-19 had a profound effect on the UK's response to Long Covid. Mr Johnson set the agenda and oversaw the UK response to the pandemic.[66] This Inquiry will be concerned to address the extent to which the Prime Minister's dismissive attitude to Long Covid influenced the Government's approach to adequately recognising and responding to the disease. It will no doubt be at the forefront of the Chair's mind that adults and children were, and still are, suffering from debilitating, painful and terrifying symptoms for weeks, months and now years after infection, whilst the then Prime Minister denied that their suffering *"truly existed*."

35. The delay in the UK Government (through the Secretary of State for Health and Social Care) in recognising Long Covid as a real condition affecting a substantial number of people has had a profound impact on people living with Long Covid. Professor Brightling and Dr Evans observed that research had recorded people describing "*the anguish of not knowing what their prolonged symptoms were, difficulties seeking healthcare advice due to lockdown conditions and many having unsatisfactory consults with healthcare professionals who were unaware of post-covid sequelae."*[67]

36. In their impact statements, Long Covid Support, Long Covid SOS and Long Covid Kids have documented the pain they and their members experienced in not being believed.[68] Recognition of Long Covid in community cases was particularly important for people with Long Covid as the lack of testing in the early stages of the pandemic meant that many struggled to prove they were suffering the long-term effects of Covid-19.[69] The lack of awareness of Long Covid resulted in many people not understanding what they were suffering from or being disbelieved. A simple and immediate measure that could have prevented and alleviated their pain was early public recognition by the then Prime

[65] [INQ000071115].
[66] [INQ000236243_0008] paragraph 14.
[67] Professor Brightling and Evans Draft Report page 11 paragraph 1.8. (not yet disclosed).
[68] Natalie Rogers - Long Covid Support Impact Statement, Sammie McFarland - Long Covid Kids Impact statement and Ondine Sherwood - Long Covid SOS impact statements (not yet disclosed).
[69] [INQ000248872_0010]; Natalie Rogers - Long Covid Support Impact Statement, Sammie McFarland - Long Covid Kids Impact statement and Ondine Sherwood - Long Covid SOS impact statements (not yet disclosed).

Minister and his key Government advisors that their experiences were caused by Covid-19. The delayed recognition of Long Covid only deepened their suffering.

III. THE FAILURE TO CONSIDER LONG COVID IN THE RESPONSE TO THE PANDEMIC

37. Decision- makers' reluctance to recognise Long Covid cascaded into an inevitable failure to protect people from the long-term health impacts of Covid-19. This failure was threefold – (i) a failure to incorporate Long Covid into surveillance systems, (ii) a failure to integrate the risk of harm from long-term sequelae into pandemic decision-making, and (iii) a failure to communicate to the public the risks of Long Covid.

Data and Monitoring

Surveillance of long-term sequelae

38. A critical factor to understanding the severity of the disease is awareness of the extent of long-term sequelae of the disease. The UK Government should have had a system in place to monitor and collect data on long-term sequelae at the outset, or in the very early stages of the pandemic. This gap in the understanding of the virus was identified at SAGE 29 on 28 April 2020 and should have been addressed at the latest from this point.[70]

39. The surveillance and collection of data on foreseeable risks is the preface to good decision-making. Yet monitoring of the foreseeable risk of long-term sequelae was completely overlooked.[71] From the outset of the pandemic, the Government placed a blinkered and narrow reliance on the twin metrics of deaths and hospitalisations to inform decision making.[72] For example, the International Severe Acute Respiratory and emerging Infection Consortium (ISARIC) was 'trial ready' at the start of the pandemic with a 'sleeping' observational study of people hospitalised for an acute infection of Covid-19. Conversely, the metric of long-term morbidity was not prioritised and received little or no attention. There were no planned studies to capture data on long-term sequelae at the start of the pandemic, which led to a '*significant delay'* in understanding the nature of post-covid sequelae.[73] Decision makers were not 'trial ready' with data monitoring for the risk of harm from long-term morbidity and Long Covid, as they should have been.

[70] [INQ000146629_0186] at paragraph 14.
[71] Brightling and Evans Draft Report at paragraph 7.2 (not yet disclosed on relativity).
[72] From January to May 2020, correspondence and briefings focused on hospitalisations and deaths as the impacts of Covid-19 with no mention of morbidity ([INQ000047557], [INQ000047585], [INQ000047644], [INQ000047684], [INQ000047792], [INQ000047796], [INQ000047842], INQ000087261, INQ000106453, INQ000049682, INQ000048213, INQ000049989, INQ000059172, INQ000106348, INQ000087412, INQ000056207, INQ000055927, INQ000106351).
[73] Brightling and Evans Draft Report at paragraph 9.1. (not yet disclosed).

40. **An issue to be explored is why the Government did not monitor long-term morbidity from the outset.**

41. Even if the significance of long-term sequalae was initially overlooked, its relevance was recalled relatively early on during the pandemic and should have prompted earlier course-correction on surveillance. SAGE recognised the importance of monitoring the impact of long-term health sequelae in May 2020 at SAGE 34.[74]

42. Some ad hoc studies did take place. In Summer 2020, data on Long Covid in the UK was published by the Covid Symptom Study. The study was set up to study the symptoms of Covid-19, and through the process of data gathering noticed a trend in patients reporting symptoms for longer than the expected three weeks.[75] PHOSP-COVID began recruiting patients on 14 August 2020 to monitor long-term sequelae of Covid-19 post-hospitalisation.[76] However, there was no equivalent public data from the UK Government on long-term sequelae in community managed cases and its leading study on Covid-19; the ONS Coronavirus Infection Survey (CIS) study, did not regularly publish data on the long-term impacts of Long Covid until 2021.[77]

43. The most significant absence of surveillance and reporting of data on long-term effects of Covid-19 is in the Government's Covid-19 Dashboard, described by Gavin Freeguard as *'the most prominent and successful example'* of dashboards to present data. This dashboard appears to be the central empirical tool for *'bringing the right people together around the right information to make decisions.*'[78] It "*provided information for the use of political and policy decision makers and the wider public.'*[79] A glaring omission from the Covid-19 Dashboard is the presence of any data on Long Covid. Of the 200 metrics used from 20 different data sources from government departments,[80] the prevalence of Long Covid was not, and still remains not, a measure that is published in this key decision-making tool.

44. As with the recognition of Long Covid, it was left to patient advocates alone to identify the gap in the Government's approach in failing to monitor the prevalence of Long Covid. As early as 5 August 2020, LC Support gave evidence to the APPG on Coronavirus of the need to collate data on Long Covid, explaining that *'The UK government is not counting the number of individuals who are left with long-lasting effects of Covid-19 as a measure of the severity and impact of the pandemic.'*[81]

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[74] SAGE 34 [INQ000120513].
[75] Covid Symptoms Study, 'How long does Covid-19 last?' 6 June 2020 https://health-study.zoe.com/post/covid-long-term; Covid Symptoms Study, "Long Covid: What do we know so far?" 27 July 2021 https://health-study.zoe.com/post/long-covid-what-do-we-know-so-far ; [INQ000223806].
[76] Brightling and Evans Draft Report page 13 paragraph 1.11.
[77] [INQ000268012_0018] paragraph 84.
[78] [INQ000260629_0019] at paragraph 38.
[79] Freeguard [INQ000260629_0018] at paragraph 52.
[80] Freeguard [INQ000260629_0018] at paragraph 52.
[81] APPG on Coronavirus, *Interim Report,* December 2020 https://www.appgcoronavirus.uk/home/interim-report-2020.

45. The Inquiry will hear evidence of the many bespoke datasets the Government commissioned from the ONS between January 2020 and February 2022 on wide-ranging areas.[82] However, it was only on 25 September 2020, four months after SAGE recognised the existence of longer-term sequelae, that the ONS received a request from No.10 for data on the prevalence of long-term symptoms following infection from Covid-19.[83] Further only on 1 April 2021- more than a further 6 months later-did the ONS start to publish statistics on the prevalence of Long Covid (following an experimental dataset published in December 2020).[84] In February 2021, DHSC began to produce a Long Covid Dashboard. This did not appear to feed into the Government's core Covid-19 Dashboard and it is unclear if the Long Covid Dashboard was shared with No.10 or any other Government department outside of DHSC.[85]

46. A key issue of concern is why the published monitoring of prevalence of Long Covid only began 13 months after SAGE recognised the existence of post-viral symptoms[86] and 11 months after WhatsApp messages about the media reports of prolonged Covid-19 symptoms were shared between Mr Hancock, Mr Johnson and Mr Cummings.[87] **The Inquiry will wish to investigate this delay - why did No.10 wait to commission this foreseeable data?**

47. Once prevalence data on Long Covid did become available, decision-makers had access to the stark picture of harm caused by the longer-term health impacts of infection from Covid-19. The ONS estimated that using CIS data to 1 August 2021, as many as 11.7% of adults and children infected with Covid-19 were experiencing Long Covid. This leapt to 14.6% amongst adults only using CIS data to 30 November 2021.[88] The extent of the harm was sizeable and growing, yet this still did not prompt decision-makers to use morbidity as a metric of pandemic harm in their assessments.

Data on Long Covid post-2022

48. The Inquiry's investigation into surveillance of Long Covid has immediate relevance. The ONS stopped collecting and publishing data on the prevalence of self-reported Long Covid in March 2023,[89] despite experts confirming that Long Covid endures as a major health problem.[90] As Covid-19 rates are reported to increase, there is still no monitoring of rates of Long Covid and how many people have been affected by Long Covid since the lifting of restrictions. Coupled with the absence of free tests, it is not possible now to know how many people are currently being affected by Long Covid including new cases.

[82] [INQ000268012_0023] paragraph 99.
[83] [INQ000268012_0018] paragraph 84.
[84] [INQ000268012_0018] paragraph 84.
[85] Edward Scully [INQ000273742_0004] paragraph 11.
[86] SAGE 34 on 7 May 2020 [INQ000146629_0215] at paragraph 20.
[87] [INQ000102087] – 17.5.2020 attachment/screenshot of article sent in CSA-CMO-Matt-PM-Dom group. Article open source: https://www.ft.com/content/91e4482e-d120-49ab-93e3-d314d99b5336.
[88] [INQ000271436] paragraph 239.
[89] I[NQ000271436_0078] paragraph 244.
[90] Brightling and Evans Draft report at page 45 paragraph 11.2 (not yet disclosed).

49. This begs the question - **why was there a delay in counting and reporting the number of people suffering from the disabling, long-term impacts of infection from Covid-19?**

Factoring in the risk of Long Covid in decision making on NPIs

50. It is uncontroversial that the extent of transmission of Covid-19 has a direct correlation with the prevalence of Long Covid. As Professor Whitty said: "*No Covid, no Long Covid.*"[91] It does not follow however from this proposition that there is no additional reason or benefit from considering the long-term health impacts when making decisions in response to the pandemic.[92] The Government needed to consider the long-term health impacts of the virus in order to minimise the number of people with Long Covid, to warn people of the debilitating damage to health they faced, to plan for absence from the workforce, financial support for people on sickness leave and the extra demands posed to health and social care. It is to the detriment of the Government's response to the pandemic that the wider economic and social harms from long-term sickness were not adequately considered and planned for.

51. The health burden from the direct impact of increased number of people suffering from long-term illnesses was a significant consideration to be factored into the decision-making process. The ONS has reported that the numbers of those economically inactive has risen and the number of people out of work due to long-term sickness has escalated since the pandemic. The ONS has said "w*hile symptoms of Long Covid may not be the only contributor to increased long term sickness in the working age population, the pandemics wider impact on health is still likely to be an important factor in increased long-term sickness*."[93] The increase in numbers of people with Long Covid resulted in further policy implications as people were disabled by Long Covid.

52. People from under-served groups and areas of deprivation suffer structural barriers to accessing healthcare; this impacts the recognition and support for people from those communities suffering with Long Covid.[94] There are also ongoing barriers that people with Long Covid now suffer from. Long Covid has been recognised by Disability Rights UK as causing "*mass disability…. The Government needs to recognise what it means that Long Covid is part of the UK's mix of disabilities*"[95]

53. Yet the UK Government has been slow to designate Covid-19 as an occupational disease and to formally recognise it as a disability, contrary for example to the USA, where Long Covid was

[91] [INQ000251916] page 3.
[92] Calum Semple explains that long term health impacts include an increased risk of complications in all age groups from Covid-19 infections which had a corresponding increased risk in death. [INQ000260637_0040].
[93] Half a million more people are out of the labour force because of long-term sickness - Office for National Statistics (ons.gov.uk). See also CIPD, Health and Wellbeing at work, Survey Report, September 2023, which found that 50% of respondents report employees who experience Long Covid and this may be an underestimate. https://www.cipd.org/globalassets/media/knowledge/knowledge-hub/reports/2023-pdfs/8436-health-and-wellbeing-report-2023.pdf
[94] Natalie Rogers - Long Covid Support Impact Statement [INQ0000_] para 86 (not yet disclosed).
[95] Kamran Malik [INQ000238535].

recognised as a disability in July 2021.[96] The failure to plan for long-term sequelae has led to the ongoing failure to plan for and minimise the economic and social harms that result from widespread long-term health impacts caused by infection with Covid-19.

Considering the Risk of Long-Term Illness

54. Prior to the first lockdown in March 2020, whilst many characteristics of Covid-19 were still unknown, the risk of long-term sequelae was known as a reasonably foreseeable risk. Any decisions made in relation to the transmission of the virus also carried implications for long-term health. Those risks were not reflected in advice to the Government, or in statistical tools such as Dashboards and CRIPs, which presented the risk from Covid-19 using the twin metrics of numbers of deaths and numbers of hospitalisations.[97] That led to a myopic reliance on deaths and hospitalisation rates which overlooked the impact of long-term health issues, skewing the picture painted to the public and to wider decision makers of the risks from the virus. This meant the very real danger of long-term and disabling health consequences were unacceptably overlooked in Government decision-making.

Long Covid and the First Lockdown

55. A crucial instance where long-term illness was overlooked was in the approach to lockdown. A clear thread emerging from the evidence is that there were significant delays in taking the decision to impose lockdowns. It was appreciated at the time that early interventions would be more effective and so the resulting delay is considered inexcusable.[98] Whilst consideration of the first lockdown should have come some time before,[99] even taking the No.10 officials' 13 March 2020 meeting as the first realisation that 'the one-wave strategy' would not work,[100] it is distressing that there was a nearly two-week delay before a full lockdown was imposed on 26 March 2020.

56. The Prime Minister's oscillation between lockdown and other policy options has been identified as a contributory factor.[101] A further issue was the reliance on 'herd immunity' or as Mr Shafi has explained it the 'one wave strategy,'[102] which was understood by No.10 advisors to be a policy objective of the Government before it was realised that this was unsustainable.[103] Mr Ben Warner's contemporaneous notes described the Government plan to "*follow a mitigate strategy. This means that we are aiming to build herd immunity by late Autumn.*"[104] The Inquiry will hear evidence which challenges the

[96] US Department of Health and Human Services, Guidance on Long Covid as a Disability under the ADA, section 504 and section 1557. Open Source (https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html)
[97] Freeguard [INQ000260629_0018] at paragraph 32;
[98] SAGE 11 on 27 February 2020 [INQ000146629_0063] at paragraph 13 and SAGE 13 on 5 March 2020 [INQ000146629_0073] at paragraph 11.
[99] Ben Warner [INQ000269182_0022-0023]; Professor Steven Riley [INQ000270553_020] paragraph 5.1.
[100] Imran Shafi [INQ000215035_0014] paragraph 61; [INQ000252711_0008].
[101] Lee Cain [INQ000252711_0010] paragraph 39-43.
[102] Imran Shafi [INQ000215035_0012] paragraph 48; see also Lee Cain [INQ000252711_0006].
[103] David Halpern [INQ000188738].
[104] Ben Warner [INQ000196052]; [INQ000196053].

reasonableness of this strategy.[105] Were the risks of long-term health sequelae considered and communicated at the time, even if still unquantified, the narrative in favour of 'herd immunity' or a 'one wave strategy' may not have rallied the same force and a change in approach could have been implemented with greater alacrity. Professor Whitty acknowledged the implications of not recognising the risk of Long Covid saying that when they did, it "*made us more cautious of the effects of Covid-19 in young and otherwise healthy adults as the pandemic progressed.*"[106]

Long Covid and the Second and Third Lockdown

57. While the flaws in the Government approach to the second wave are myriad, the Long Covid Groups highlight in particular the absence of consideration of the long-term impacts of Covid-19 on unrestricted transmission of the virus. The failure to consider Long Covid is inexplicable on the available evidence: by August 2020, Long Covid was a recognised risk from acute infections of Covid-19 and there was sufficient evidence for clinical guidance to be published.[107] Despite this, the risk of people suffering harm from Long Covid was not integrated into pandemic decision-making.

58. The failure to consider Long Covid in the build up to and response to the second wave is incoherent and inconsistent with evidence that key decision makers and advisers were aware of the risk of Long Covid. On 9 July 2020, SAGE endorsed the AMS report "*Preparing for a challenging winter 2020/21*." The report urged that "*July and August must be a period of intense preparation for our reasonable worst-case scenario for health in the winter"* and advised that there was likely to be a worse resurgence of Covid-19.[108] The AMS Report also warned that "*the UK will have to be prepared for an increase in patients with multimorbidity presenting with post-Covid-19 complications."*[109] DHSC had recognised the risk of Long Covid in internal strategies and by October 2020 the Secretary of State for Health and Social Care and DHSC had issued statements acknowledging that Long Covid was affecting a significant proportion of young people in community managed cases.[110]

59. Irrespective of the AMS Report warning, SAGE was too slow to add Long Covid to its agenda and did not create a sub-group for Long Covid or any formal grouping with secretariat support to gather regular advice on Long Covid. After recognising the existence of long-term sequelae in May 2020,[111] the first detailed discussion about Long Covid in adults was only held at SAGE 79 on 4 February 2021.[112] SAGE was aware of growing evidence on Long Covid briefly referencing the subject at SAGE 60 on 1 October 2020,[113] before the suggestion of more detailed evidence on the direct impacts of Long

[105] Professor Susan Michie [INQ000252610_0043]; Sir William Gowers [INQ000280045]; [INQ000253954]; Professor Steven Riley [INQ000270553].
[106] Chris Whitty [INQ000251645_207-208] paragraph 12.7.
[107] [INQ000205638]; BMJ August 2020 advice referred to by Professor Kamlesh Khunti; NHSE [INQ000205638].
[108] [INQ000211967].
[109] [INQ000211967].
[110] [INQ000238594].
[111] [INQ000146629_0215].
[112] [INQ000146629_0526].
[113] [INQ000146629].

Covid was raised at SAGE 69 on 19 November 2020.[114] This appears to have led to ONS reporting to SAGE on prevalence of Long Covid on 28 January 2021 at SAGE 78,[115] and a more detailed discussion about the ISARIC study on Long Covid on 4 February 2021 at SAGE 79.[116]

60. As for advice on Long Covid in children, this is inextricably linked with the prolonged and wholly erroneous view that children were not at risk of infection from Covid-19. Some children did suffer from complications from Covid-19, causing death in some instances, and more children continue to suffer from Long Covid.[117] The advice from SAGE in the leadup to the second lockdown was that the evidence on the necessity for closing schools to limit transmission was mixed and uncertain.[118] Children were considered to be less at risk from the virus but played a role in transmission. The decision to keep schools open in the second lockdown was informed by this mixed evidence. However, there was little, if any, consideration of how to manage the known risk of Long Covid in children.

61. SAGE only requested a paper on Long Covid in July 2021, this was a one-off commission and did not include recommendations.[119] By this time, the UK had been through three nationwide lockdowns and was considering the exit strategy. Throughout this period the then Prime Minister had maintained, on his own evidence, the unsafe and wrong belief that Long Covid was not a serious condition. A key issue to be explored is why SAGE was not commissioned by Government to gather advice and information on Long Covid at an earlier stage and how this affected Government decision- making.

62. The absence of consideration of Long Covid in pandemic decision-making meant that Long Covid was not factored into the balancing exercise to consider whether to impose NPIs. The second wave was deadlier and more harmful than the first.[120] The tragedy of the Government's response to the second wave is that unlike the first wave, the UK Government was armed with knowledge: they knew NPIs effectively limited transmission and there was information that a wider range of the population was at risk of Long Covid.[121]

63. It is suggested that Mr Johnson was overly concerned with the economic impacts of further lockdown measures and the harms caused by restrictions imposed in response to the virus (rather than the economic impacts caused by the virus itself).[122] He was also concerned by the arguments propounded by the signatories to the Great Barrington Declaration that measures should protect the vulnerable,

[114] [INQ000146629_0445].
[115] [INQ000146629_0514].
[116] [INQ000146629_0526].
[117] 88 deaths in children were registered as due to Covid-19 in England and Wales. ONS, "Deaths of Children from Covid-19 in England and Wales 2020 to 2022," 1 December 2022; https://www.ons.gov.uk/aboutus/transparencyandgovernance/freedomofinformationfoi/deathsofchildrenfromcovid19inenglandandwales2020to2022 Long Covid Kids Impact Statement [INQ0000_] (not yet disclosed).
[118] Patrick Vallance [INQ000238826_0132] paragraph 396.
[119] [INQ000238560].
[120] Patrick Vallance [INQ000238826_0136] paragraph 407.
[121] Patrick Vallance [INQ000238826_0124] paragraph 371.
[122] Patrick Vallance [INQ000238826/0132] paragraph 394.

whilst allowing the rest of the population to "resume life as normal."[123] Despite unequivocal warnings from SAGE of the need for immediate nationwide measures,[124] the former Prime Minister delayed decisions on a lockdown until a meeting was arranged for him to meet with proponents of the Great Barrington Declaration, Professors Sunetra Gupta and Carl Heneghan, on 20 September 2020.[125]

64. In an interview with The Times in September 2020, Nicola Sturgeon, former First Minister of Scotland, clearly articulated the significance of factoring in long-term harm to health from Covid-19 as a risk posed to the young when declining to follow a 'shielding' strategy which isolated the vulnerable.[126] Her evidence to the Inquiry further emphasises that Long Covid was a relevant consideration where she describes 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 supress it to the lowest possible level. The UK Government did not always seem to agree with this."*[127]

65. It is highly regrettable that discussions on responses to the pandemic have frequently been distilled into a binary assessment of the risk of harm from the virus to an elderly population counterbalanced against risk of harm from the measures taken to stop transmission to the younger population. Long Covid proved that equation to be flawed as young people were equally at risk from the virus; as Mr Hancock said "*Covid-19 is indiscriminate*"[128] Recognising Long Covid meant recognising that arguments advanced by the Great Barrington Declaration proponents were unsustainable and that there were economic costs from direct harm caused by Covid-19.[129]

66. The failure to consider Long Covid in the lead up to the second wave must also be properly contextualised in the lack of planning and organisation to mitigate the harm caused by the virus in this period. Before the restrictions had been lifted for the first lockdown, key government advisors were aware of the need to plan for further waves.[130] On 2 July 2020, Covid-S were advised about the need to plan for Winter 2020/21.[131] The CMO advised that the Government "*steer a steady path between a cautious approach and reopening the economy."*[132] The then Prime Minister encouraged less reactive and more forward planning but also directed that "*another national lockdown would be a disaster."*[133]

[123] [INQ000203988].
[124] SAGE 56 10 September 2020 [INQ000146629_0353-354]; SAGE 57 17 September 2020 [INQ000146629_0360]; SAGE 58 21 September 2020 [INQ000146629_0367]. SAGE 59 24 September 2020 [INQ000146629_0372].
[125] Patrick Vallance [INQ000238826_0125] paragraph 372.
[126] [INQ000103173].
[127] Nicola Sturgeon [INQ000273749_0003].
[128] [INQ000094776_0009]; [INQ000238594_0002].
[129] [INQ000064525] page 44 A 1562; Chris Whitty [INQ000251645_0209] paragraph 12.15.
[130] Tom Shinner prepared a paper for Simon Case and Simon Ridley cautioning that the Country was "*more vulnerable to a second wave of COVID than is apparent."* [INQ000174752].
[131] [INQ000088301]. Tom Shinner [INQ000228382_006] paragraph 24.
[132] [INQ000088245].
[133] [INQ000088245].

A glaring failure to learn from the first lockdown coupled with an intransient resistance to considering nationwide measures, contributed to a lack of preparation for the second wave which proved to be worse than the first. By the end of Summer, the Government had introduced a policy to encourage people to "Eat out to Help Out" which led to increasing transmission rates without agreeing a strategy or plan to identify triggers for a nationwide lockdown.[134] Government planning had focused on localised strategies through a tiering system without any backup planning for nationwide strategies should they fail.

67. Mr Shafi says that discussion about whether a second lockdown was required began in earnest in September 2020 as it became clear that infection rates were beginning to rise after the economy opened up in the summer.[135] It was clearly much too little, too late. There was effectively no plan in place when the Government decided to implement a second lockdown. A properly formulated plan as advised in the AMS Report of July 2020 (as above) should have considered all the harms caused by the pandemic including the long-term effects of Covid-19. This simply did not happen. The Long Covid Groups seek to understand why precious time between the first and second wave was squandered so that the UK was no better prepared.

68. The Government strategies informing their approach to the second and third lockdowns were rushed, ill-considered and as thin on detail as the 3 March 2020 '*Coronavirus: Action Plan'*[136] which was criticised for being a communications plan missing the detailed internal guidance needed to coordinate the response.[137] The strategies applied before the second and third lockdown also failed to make reference to Long Covid. Simon Ridley and James Bowler's Joint Corporate Statement for the Covid-Task Force suggest that the strategic plan in place when a second lockdown was agreed was the '*UK Government's Covid-19 Recovery Strategy*' published on 24 July 2020.[138] Further plans from November 2020 were little better. HMG's *'Analysis of the health, economic and social effects of Covid-19 and the approach to tiering'* published on 30 November 2020 neglected to make any mention of the long-term impacts of Covid-19.[139] The November 2020 Covid-19 Winter Plan was also silent on Long Covid.[140] Notably, passing references to Long Covid were erased from the drafts indicating a deliberate resistance to recognising Long Covid.[141] Professor Whitty said that Long Covid was relevant to the Government's move away from the Great Barrington Declaration proposals and yet it was not reflected in the key documents informing the strategy at the time.[142]

[134] Patrick Vallance [INQ000238826_0115-0116] paragraph 349.
[135] Imran Shafi [INQ000215035_0029]; see also James Bowler who said he advised the Prime Minister on the deteriorating situation and alternative options to Tier 3 interventions on 28 October 2020 [INQ000211689_0011].
[136] [INQ000056154].
[137] Ben Warner [INQ000269182_0018] paragraph 62.
[138] CTF Corporate Statement [INQ000248852_010] paragraph 4.2.
[139] [INQ000136696] paragraphs 2.4-27.
[140] [INQ000067100]; [INQ000106867].
[141] [INQ000128571].[INQ000062914].
[142] Chris Whitty [INQ000251645_0209] paragraph 12.15.

69. While DHSC and the NHS were cognisant of the need to respond to Long Covid, it is curious that this did not translate into the Government strategies on Covid-19 which made no mention of Long Covid. **The upcoming hearings provide an opportunity to understand whether the complete omission of reference to Long Covid was an ongoing reflection of the Prime Minister's belief that Long Covid was *'Bollocks*.'**

Long Covid and the "Exit Strategy"

70. By 2021, Government's key advisers were well aware of the need to consider Long Covid in pandemic decision-making. Mr Shafi advising the Prime Minister on '*Covid – the Choices Ahead*' on 15 January 2021 noted that a relevant issue was that younger people would be affected by long-term effects.[143] Sir Patrick Vallance agreed that there was a significant risk to young people including hospitalisations and absences from work before Long Covid was even factored in.[144] Mr Hancock explicitly warned of the need to manage the exit strategy and that a rapid release of NPIs would "*increase the incidence and long-term costs of treating Long Covid."*[145] Sir Patrick Vallance and Professor Angela Mclean were cognisant of the ethical considerations permitting widespread transmission noting people to "*worry about*" included "*those who suffer Long Covid*."[146]

71. The 2021 strategies began to incorporate references to Long Covid. However, they did not display a shift in approach but were simply acknowledgements of the existence of Long Covid without reflection on what the strategies meant for the increasing prevalence of Long Covid. For example, the Guidance '*Covid-19 Response – Spring 2021*' dated 22 February 2021 makes the first mention of Long Covid: It records that for some people regardless of age, Covid-19 has long-term effects. The same paper announced that the NHS was supporting people with Long Covid and funding for new studies.

72. The mention of Long Covid appears to be only lip service and fails to equip the public with reasonable knowledge of precautionary measures that can be taken in the community to reduce the risk of long-term harm. This could have included: resourcing improved ventilation in public buildings including schools, supporting policy recommendations on clean air, encouraging people not to go to work when symptomatic, providing adequate financial support for people with Covid-19 / Long Covid, setting mask mandates in appropriate spaces, supporting wider vaccine eligibility, supporting employers with

[143] [INQ000146628].
[144] [INQ000063215].
[145] [INQ000234297] page 7.
[146] Other groups identified as of concern included (i) the known vulnerable who choose not to be vaccinated; (ii) the vaccinated in whom the vaccine does not prevent disease, (iii) the known vulnerable still in the queue to be vaccinated, (iv) the unknown vulnerable, (v) those not vulnerable enough to need hospitalisation but will nevertheless be acutely very ill with Covid, (vi) children and (vii) people in hospitals who care for the sick and dying. [INQ000063422] page 6.

health and safety risk assessments, and ensuring that free lateral flow tests remained available. Simple measures to reduce transmission in schools have not been advised or implemented.

73. The Long Covid Groups fail to understand why the UK Government did not incorporate strategies to prevent and limit the transmission of Long Covid into their planning for Freedom Day. Further the references to Long Covid exclusively focused on access to treatment for Long Covid. The issue remains that there was no coherent strategy on how to mitigate the risk of Long Covid.

74. The UK Government's continuing dismissive attitude towards people with Long Covid is documented in the Covid-O meeting held on 5 July 2021. After noting that the Delta variant was "*highly contagious*" and that there were high rates of Covid-19, one of the points made was "*the term 'long covid' should not be used loosely as it described a number of syndromes, at a time when Personal Independent Payment claims had reached an all-time high."*[147] The pernicious suggestion was that Long Covid was not caused by Covid-19 and people were using it to make false claims for social assistance payments. Mr Johnson's dismissive attitude to Long Covid appeared to endure, despite advice to the contrary.

75. **A key question to be explored in the coming hearings is whether any consideration was given to Long Covid and managing it's risks in planning the Exit Strategy.**

Public Health Communications on Long Covid

76. The Inquiry will hear evidence that timely, adaptive and appropriate public messages were not issued in line with the changing understanding of the virus. Government messaging characterised Covid-19 as having *'cold-like symptoms'*[148]*, 'flu-like symptoms including a fever, a cough or difficulty breathing'*[149] and a *'self-limiting illness a bit like influenza (flu).'*[150] Understanding of the virus evolved over time. By May 2020, PHE understood that symptoms extended to gastrointestinal problems such as diarrhoea, nausea or vomiting or general loss of appetite or sense of smell,[151] which expanded further to include lung inflammation, pulmonary vascular disease, cardiovascular symptoms and disease, liver and kidney dysfunction, clotting disorders and thrombosis and lymphadenopathy,[152]

[147] Covid-O 5 July 2021 [INQ000092025].
[148] Statement in House of Commons with input from CMO and DCMO [INQ000047531].
[149] Oral statement from DHSC [INQ000051786].
[150] DHSC [INQ000047879]. Also see: [INQ000048101].
[151] [INQ000089689].
[152] PHE Guidance (https://webarchive.nationalarchives.gov.uk/ukgwa/20200908003226/https:/www.gov.uk/government/publications/covid-19-long-term-health-effects/covid-19-long-term-health-effects).

before culminating in the first NIHR review into Long Covid published in October 2020 laying out more extensive symptomology.[153]

77. At the first Ministerial Roundtable on Long Covid held on 13 October 2020, participants agreed that there was a need to identify the red flag symptoms of Long Covid and urgently communicate this to primary care providers so they could better understand the symptoms infection from Covid-19 can cause.[154] Discussions on the need to communicate the increasing number of symptoms associated with Long Covid continued at subsequent Ministerial roundtables on Long Covid.[155] Similar discussions were underway at the NHS Long Covid Taskforce Meetings.[156]

78. However, as the Government's understanding of the increased number of symptoms related to Covid-19 and their overlapping and fluctuating nature grew, this failed to translate into public health communications on Covid-19's manifold symptoms. [157] It was only in April 2022 that the NHS Covid Symptoms list was finally expanded to include nine more signs of illness.[158] The UK's delayed approach in raising awareness of the increasing symptoms contrasted sharply with the USA's CDC list of symptoms which was first updated in April 2020,[159] and with the WHO, who regularly updated their published list of identifying symptoms in line with scientific developments.[160] Long Covid Support made clear in their email to the ONS, DHSC and the NHS that the result is that *"a large proportion of people will remain unaware of ever having had Covid, let alone Long Covid, on account of the poor communication of the breadth of symptoms (even today, Googling "NHS Covid Symptoms" results in a page that lists only cough, fever and loss of taste or smell – with all the risks of unwitting spread that brings."*[161] **The Inquiry must explore why the Government delayed publishing updates on symptomology of Covid-19, which would have increased public awareness of the virus and in turn, helped minimise its spread in the community.**

79. More specifically for the Long Covid Groups, the Inquiry will need to examine whether decision-makers developed a communications strategy to highlight the known risk of harm of contracting Long Covid. The need to raise awareness was recognised. There were instances of public warnings of the risk of Long Covid which indicates a need to raise awareness of the risk of Long Covid.[162] The Royal

[153] [INQ000058418].
[154] [INQ000058536].
[155] Meetings held on: 16.11.2020 – [INQ000058981], 16.6.2021 – [INQ000061094], 23.9.2020 – [INQ000067049].
[156] Meetings held on 7.1.2021, 4.2.21, 3.2.22 (not yet disclosed).
[157] SAGE 79 discussion on Long Covid as a multi-system disease likely to present as a cluster of syndromes rather than a single one. [INQ000061587].
[158] Lacobucci, Covid-19: UK adds sore throat, headache, fatigue and six other symptoms to official list, BMJ 2022; 377 (Published 4 April 2022) https://www.bmj.com/content/377/bmj.o892.
[159] NPR, *CDC Adds 6 Symptoms To Its Covid-19 List* published on April 27 2020 https://www.npr.org/sections/coronavirus-live-updates/2020/04/27/845321155/cdc-adds-6-symptoms-to-its-covid-19-list.
[160] WHO *Common Symptoms of Covid-19* published on 27 October 2021 https://www.who.int/mongolia/multi-media/item/common-symptoms-of-covid-19.
[161] [INQ000099721].
[162] For example, [INQ000231948]; [INQ000248937], OS/11 [INQ0000_] (Not yet disclosed).

Society, in a report discussed at SAGE,[163] explicitly recognised the need to raise public awareness on Long Covid in order to improve reporting and minimise general transmission of Covid-19. The report recommended a Long Covid public messaging campaign, that *"this information campaign will require sensitive design and handling, to present the information in a neutral and objective way in order to avoid any impression of persuasion by spreading fear."*[164]

80. Government advisors appeared to recognise the need for increased public awareness on the risk of Long Covid, noting for example *"please can we spell out what the effects of Long Covid are in the section on this — not sure people really understand the impact this has on the young and healthy* "[165] of Mr Hancock's draft November 2020 speech. The urgent need for public messaging on the risk of Long Covid is re-iterated in direct communications to Mr Johnson by Long Covid SOS in January 2021, the second year of the pandemic.[166] Despite this collective recognition of the need for public awareness raising on Long Covid, there appears to have been no communications strategy in place for Long Covid.

81. Moreover, when key developments in the understanding of Long Covid and its risks emerged, these were not translated into public communication. At SAGE 79 for example, SAGE participants discussed that Long Covid is likely to be a cluster of syndromes rather than a single one and that each syndrome may have a different outcome as Covid-19 is a multi-system disease, yet there is no action point relating to advising the government of the need for public communication of this growing knowledge.[167] Even when there is a discussion on what to say about Long Covid, as there was by email exchange between the CMO's office and DHSC as they considered how Long Covid should feature in the Spring 2021 Road Map,[168] Long Covid is reduced to a passing comment in the Spring 2021 Road Map[169] and bears no mention in the Prime Minister's February 2022 statement marking the end of the pandemic.[170] The public continued not to be warned of the indiscriminate risk of Long Covid at the very time when the Government asked them to "*learn to live with this virus*" and take responsibility for their own risk.

82. Throughout the pandemic, communication of the risk of Long Covid was routinely minimised, and regularly overlooked. Indeed, there appears to have been only one public health video on Long Covid released by DHSC[171] with an accompanying public statement by Mr Hancock.[172]

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[163] [INQ000056507].
[164] The Royal Society, "Urgent Need for more research to understand Long Covid" 28 October 2020, https://royalsociety.org/news/2020/10/urgent-need-to-understand-long-covid/
[165] [INQ000234189] page 26.
[166] [INQ000238583].
[167] [INQ000061587].
[168] [INQ000072826].
[169] [INQ000086876].
[170] [INQ000086653].
[171] [INQ000071194].
[172] [INQ000094776].

83. The Inquiry must consider **how and to what extent decision makers warned the public about the risk of developing Long Covid and took the disease into account in public health communications.**

IV. CONCLUSIONS

84. There were undoubtably individual failings during the pandemic, but those of most note are the system ones that allowed those individuals to fail. Through disclosure, we can already see the signs of key decision makers attempting to re-write history and shift the blame - to the scientists, to the advisors, to the people – to anyone other than themselves.

85. The Long Covid Groups look to this Inquiry to hold the decision makers to account, to challenge any attempt to rewrite the narrative, to ensure that we can truly understand why this Government were allowed to get decisions so wrong and to make sure the same mistakes are never repeated. They turn to the Inquiry to answer their central question – **whether the suffering of nearly two million adults and children from Long Covid was avoidable?**

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