UK COVID 19 INQUIRY

MODULE 8

CLOSING STATEMENT ON BEHALF OF
LONG COVID KIDS AND LONG COVID KIDS SCOTLAND

I. INTRODUCTION

1. Long Covid Kids **("LCK")** and Long Covid Kids Scotland **("LCKS")** represent the growing number of children and young people who have been left debilitated, and in some cases disabled, by the long-term sequelae of SARS-CoV-2 infection. Children and Young People **("CYP")** with Long Covid have been rendered invisible by Government decision-making. They have suffered twice: first from the physical, developmental, educational and social impact of the virus, and second from the harmful and stigmatising consequences of the Government's pandemic response failures. Their concerns remain unheard and ignored by the Government. A parent member of Long Covid Kids describes her child's experience of suffering with Long Covid, *"people have used the term ghost children…it was as if he did not exist."* [1]

2. LCK and LCKS embarked on Module 8 wanting answers to why their children are unwell, why so little was done to help them and why, even now, the most basic steps have not been taken in response to a new paediatric disease. The answer to those questions, to the extent that answers have been provided to the Inquiry, is shameful. Even after the evidence of paediatric Long Covid was brought to the attention of the UK Government and the devolved administrations, decision makers did not take the necessary steps to protect children from developing Long Covid. To the contrary, the existence of paediatric Long Covid was ignored or minimised. Even now, five years after the onset of the virus, wholly inadequate steps have been taken to assist children who developed Long Covid to access healthcare and education. These failures constitute an ongoing breach of the Government's duty to place the best interests of children at the heart of their decision making, and to respect the human rights of those children and their families.

3. This Closing Statement first outlines the impact of Long Covid on CYP. It goes on to cover the foreseeability and early understanding of paediatric Long Covid. It considers next why there was a failure to respond to paediatric Long Covid by examining (i) how paediatric Long Covid

[1] [INQ000651344_0024]

confronts the Government's pandemic narrative (ii) how an adult-centric approach overlooked the physical harm of the virus to CYP and (iii) the failures of political, clinical and public health leadership on the new disease. The Closing Statement then considers six failures of Government in responding to paediatric Long Covid, namely the failures to: (i) prevent chronic illness; (ii) ensure access to education; (iii) monitor disease and collect data; (iv) to warn the public; (v) to inform and guide schools; and (vi) to ensure access to healthcare. The twelve corresponding findings of fact the LCGs invite the Inquiry to make are set out at the beginning of each section. The Closing Statement concludes with the ongoing failures in response to paediatric Long Covid and sets out 10 recommendations to ensure the UK can better support CYP who currently suffer from Long Covid, and to ensure that the UK is better prepared to respond to a future, as yet unknown pandemic.

II. THE IMPACT OF LONG COVID ON CHILDREN AND YOUNG PEOPLE

> *I. FINDING: Paediatric Long Covid is a debilitating and disabling new childhood disease caused by infection by SARS-CoV-2. It impacts all aspects of CYP's lives, childhoods and development.*

4. Long Covid is a significant new childhood disease which has a devastating impact on all aspects of CYP's lives and development. There is no current prevalence data of Long Covid in the UK however the RECOVER study estimates that there are almost 6 million CYP with Long Covid in the USA, which makes paediatric Long Covid's prevalence more than that of paediatric asthma.[2] Long Covid develops after infection with SARS-CoV-2. It comprises over 200 symptoms across nine body systems.[3] The long-term physiological complications of paediatric Long Covid are not yet fully known, but a study found that CYP infected with SARS-CoV-2 are at significantly increased risk of serious and diverse post-acute cardiovascular outcomes.[4] Long Covid has caused otherwise healthy CYP to become 'newly-disabled', be reliant on a wheelchair, and to even become bed-bound.[5]

5. These physical symptoms have an inevitable and profound impact on daily functioning. The COSMO study found that 70% of CYP who self-reported with Long Covid said that it had limited their daily activities and that they suffered from a 'severe' outcome.[6] The Long Covid experts describe a severe outcome as being unable to conduct activities of daily living like showering and self-care, having reduced mobility and being unable to speak for more than a few minutes.[7]

---

[2] [INQ000651361_0001]; [INQ000588023_0009 § 28]
[3] [INQ000587960_0004 § 5]
[4] [INQ000651264]
[5] [INQ000587960_0004 § 5]
[6] [3/174/12-25]
[7] [INQ000587960_0004 §§ 5, 20]

These physiological impacts significantly disrupt CYP's ability to attend school, which has a consequential impact on educational attainment. They require support such as reasonable adjustments to properly access education, and in the absence of this support they can suffer academic exclusion as well as social isolation and stigmatisation.[8] The Long Covid experts state that Long Covid in CYP has a particular impact on developmental milestones as it occurs at a crucial time of biopsychosocial changes.[9]

6. Many CYP with Long Covid have struggled to obtain a diagnosis or to have their symptoms believed because of the significant and ongoing challenges in accessing healthcare.[10] There was an additional delay in the recognition of Long Covid in CYP, beyond even the delay in recognising it in adults.[11]

7. Studies highlight a correlation between Long Covid and deprivation.[12] Long Covid therefore creates new inequalities amongst CYP, as well as exacerbating existing inequalities. Finally, its risk is indiscriminate: *"anyone can develop Long Covid."*[13] It follows that many more CYP are likely to develop Long Covid in the future as SARS-CoV-2 remains in circulation.

III. THE FORESEEABILITY / UNDERSTANDING OF PAEDIATRIC LONG COVID

II.	*FINDING Paediatric Long Covid was a foreseeable consequence of SARS-CoV-2 and there was clear understanding of its impact in scientific, clinical and political circles very early in the relevant period.*

8. Expert reports in Modules 2 and 8 confirmed the foreseeability of long-term sequelae from SARS-CoV-2,[14] and the Inquiry has found that long term illness was predictable.[15] The paediatric Long Covid expert report notes the known impact of other post-viral (or post-bacterial) infections, like Kawasaki disease, on CYP, whilst also noting its similarity to paediatric Long Covid.[16] The presentation of Long Covid in CYP was not therefore, an unpredictable or unusual consequence of the virus. Indeed, Duncan Burton stated that the foreseeability of post-viral impact in CYP was generally acknowledged by clinicians, including the National Clinical Director for Children, who considered that whenever there is viral impact,

---

[8] [INQ000588023_0025 § 81]
[9] [INQ000587960_0008 § 16]
[10] [INQ000588023_0042 § §133]
[11] [INQ000587960_0022 § 49]
[12] [3/175/7-9]
[13] [Module 2 Report § 8.24]
[14] [INQ000587960_0023 § 52]; [INQ000280198_0031 § 7]; [Module 2 Report §§ 1.52, 8.23]
[15] [Module 2 Report §§ 1.52, 8.23]
[16] [INQ000587960_0007 § 11]

there is likely to be some post-viral process on a CYP's body.[17] Despite this, no steps were taken to plan for, prepare or monitor post-acute sequelae in adults, or CYP.

9. An understanding that the long-term sequelae of SARS-CoV-2 impacts CYP took shape within the scientific community from May 2020, very early in the relevant period. Dr Arora confirmed that PHE, as well as the *"rest of the scientific community",* including DHSC and the CMOs, were aware of the susceptibility of CYP to Long Covid from May 2020 onwards.[18] This understanding followed clinical observations of Kawasaki-like syndrome in children from April 2020 onwards.[19]

10. That CYP may develop Long Covid was also well understood by Government decision-makers early in the relevant period.
    a. **Wales**: the First Minister Mark Drakeford confirmed[20] that the Welsh Government were aware of Long Covid as a distinct condition from Autumn 2020 when a written statement on Long Covid was issued to Ministers.[21] He confirmed that its impact on children was understood *"certainly by the end of 2020"* and that "*by the beginning of February, we [were] more aware of the potential impact of Long Covid on children".*[22]
    b. **Scotland**: Caroline Lamb confirmed that by October 2020 the Health and Social Care Department of the Scottish Government recognised that CYP were at risk of developing Long Covid.[23] That Scottish Government departments more generally shared this understanding is apparent from Neil Rennick's confirmation in October 2020 that the Education and Justice business area of the Scottish Government appreciated that *"children might also suffer from Long Covid."*[24]
    c. **Northern Ireland**: by at least March 2021 there was a clear understanding that Long Covid impacts *"younger people"* in a CMO/CSA Review of Cross Departmental Proposals,[25] though uncertainty about its prevalence was noted.
    d. **England**: understanding of paediatric Long Covid was advanced enough in 2020 for NHSE to convene the first meeting with clinical stakeholders to discuss the creation of a national Long Covid paediatric service on 24 November 2020.[26]

---

[17] [7/47/3-7]
[18] [12/44/10-21]
[19] [INQ000608179]; [INQ00053212]; [INQ000588046_0060 §§ 5.4-5.6]
[20] [15/203/9-25 – 15/204/1-9]
[21] [INQ000412528]
[22] [INQ000620750_0156 § 425]; [15/204/7-9]
[23] [INQ000548307_0052 § 151]
[24] [INQ000649083_0200 § 706]
[25] [INQ000262668]
[26] [INQ000587960_0020 § 40]

11. From 15 October 2000, all four nations had the benefit of the NIHR's first research paper on Long Covid, which included patient testimony from CYP with Long Covid.[27] NICE published guidelines for Long Covid in adults and children on 18 December 2020.[28] A Note prepared for the CMO by DHSC's Long Covid policy team referred to the (i) impact of Long Covid on CYP and (ii) the rise in referrals for children with Long Covid symptoms by paediatric services. The Note confirmed that by January 2021 there was cross-UK engagement on Long Covid such that it had been discussed by the four UK CMOs and with senior clinicians across the Devolved Administrations.[29] The same document notes that at this point NHSE, NICE and RCPCH had discussed the development of a CYP-specific clinical case definition. Further, on 9 March 2021, Cabinet Office produced it's *"In-depth: Long COVID"* report highlighting that Long Covid is *"disproportionately affecting certain groups of people such as groups that were previously considered as 'low risk' from COVID-19…including children"* as a 'key insight.'[30] In conclusion, therefore, there was understanding of the existence of paediatric Long Covid in the scientific, clinical and decision-making circles of all four nations, by early 2021 at the latest.

IV. WHY WAS THERE A FAILURE TO RESPOND TO PAEDIATRIC LONG COVID?

12. We set out the key failures in the approach taken to paediatric Long Covid in Section V below. No satisfactory explanation has been provided to the Inquiry as to why the response to paediatric was, and remains, so inadequate. Understanding the "*why*" matters, both to improving the immediate changes required to the response to paediatric Long Covid, but also to improving the response to long-term sequalae in CYP in a future pandemic.

13. Three key themes are apparent from the evidence which inform the "*why*" question, namely: (i) the existence of paediatric Long Covid contradicts the Government's enduring pandemic narrative; (ii) the Government approached the pandemic with an adult centric approach which overlooked viral harm to CYP; and (iii) there were failings of political, clinical and public health leadership on paediatric Long Covid. These are each addressed in more detail below.

(i) Paediatric Long Covid undermines the Government's pandemic narrative

14. The existence of paediatric Long Covid contradicts the three pillars of the Government's pandemic narrative that (i) SARS-CoV-2 is mild and harmless for CYP; (ii) that CYP will recover after infection from SARS-CoV-2; and (iii) that the Covid-19 pandemic is over and has been successfully defeated.

---

[27] [INQ000475507]
[28] [INQ000587960_0020 § 41]
[29] [INQ000283397_0006]
[30] [INQ000548262_0001] [M9 Disclosure]

15. The three Long Covid expert reports confirm that SARS-CoV-2 can cause serious physical harm to children and that paediatric Long Covid is a multi-organ, disabling disease caused by infection with SARS-CoV-2. As outlined above, infection from the virus is not mild for all CYP; some can die and many more will never recover from its long-term sequelae. The virus remains in circulation today, increasing the number of CYP developing Long Covid. The fact of paediatric Long Covid's lasting impact, and the lived experience of the children and families who form the membership of LCK and LCKS, undermine the Government's pandemic narrative of successfully defeating Covid-19. As a result, decision makers were unwilling to act on scientific knowledge, prevalence data, the lived experience of patient advocates or on policy advice on paediatric Long Covid, all of which damaged their pandemic narrative.

*(ii) **An adult-centric approach overlooked viral impact on CYP***

> *III. FINDING The Government took an adult-centric approach to pandemic policy which overlooked the physical harm the virus causes to CYP.*

16. The Government approached the pandemic by applying the assumptions that Covid-19 would be mild for all CYP and that they will all recover from an infection, or "bounce back." These assumptions were both false and contrary to the available scientific evidence.

17. The evidence base the Government had as it approached the pandemic indicated that CYP *were* likely to be physically impacted by SARS-CoV-2, by both acute infection and post-viral conditions:
    a. The Coronavirus Action Plan was based on the 2011 UK Influenza Pandemic Preparedness Plan. The Influenza Plan recognised that *"all ages are likely to be affected"* based on the evidence that adults and children experienced severe and even fatal illness in H1N1.[31]
    b. The Influenza Pandemic of 2018/19 saw a very large proportion of deaths and serious illness in children, higher than that in adults, as Professor Sir Chris Whitty confirmed.[32]
    c. The impact of long-term sequelae on CYP was foreseeable given experience of previous coronaviruses.[33]

18. Contrary to the evidence available, the UK Government nonetheless assumed that CYP would not be physically impacted by the virus. Insofar as children were considered, it was as conduits

[31] [INQ000514457_0016]
[32] [13/147/§19-23]
[33] [INQ000587960_0023 § 52]

of viral transmission to the adult population, such that the virus' physical impact on CYP was almost entirely overlooked.

19. Following consideration of the impact of the virus in other parts of the world, Professor Whitty explained that the Government relied on *"reasonable evidence, not convincing evidence overwhelmingly, but convincing evidence, that children were relatively unaffected in terms of severity."*[34] He noted that it was still not known if this was due to a reduced risk of infection or due to children having milder, or clinically undetectable infections.[35] Despite the foreseeable impact of the virus on CYP and early acknowledgement that the virus *could* infect CYP, the Inquiry has heard evidence that CYP were only considered for their role in viral transmission to the adult population, without consideration of the epidemiological risk to CYP as individuals requiring protection.[36] For example, Professor Whitty confirmed that school closures were not designed to protect CYP from the physical harm of the virus.[37] Their sole aim was to reduce overall community transmission, rather than to reduce CYP's exposure to harm,[38] *"these kind of interventions were not designed to try and protect individual children. They were designed to try to pull down the overall rate of infection for the whole of society."*[39]

20. This adult-centric approach to pandemic policy making continued throughout the relevant period. Government departments such as DfE maintained that CYP were at low risk of serious illness, by incorrectly comparing the viral risk in children to that in adults, and not to the risk presented by other childhood infectious diseases.[40] Education unions raised concern that the DfE's data analysis was flawed and risked minimising the virus' impact on CYP. These concerns were ignored.[41]

21. The repeated comparison of paediatric Long Covid to that in adults, as for example in Professor Whitty's Rule 9 statement, resulted in minimisation of the impact of paediatric Long Covid, *"although rarer than in adults, there are acute and chronic post COVID-19 syndromes in children…the already relatively smaller risk of post-COVID-19 syndromes relative to adults has become smaller still…the (welcome) fact that the proportion of cases which led to significant and prolonged symptoms afterwards was smaller"* than in adults.[42]

---

[34] [13/2/15-18]
[35] [INQ000588046_0007 § 3.1]
[36] [INQ000087326]; [INQ000610966_0003]
[37] [13/16/14-16]
[38] [13/33/5-22]
[39] [13/74/5-8]
[40] [INQ000272179]
[41] [INQ000649124]; [INQ000649125]; [INQ000649126]
[42] [INQ000588046_0059 § 5.1]; [INQ000588046_0063 § 5.15]

(iii) ***Failures of Political, Clinical and Public Health Leadership***

IV.	*FINDING There was a failure of political, clinical and public health leadership in relation to paediatric Long Covid, which minimised the disease's impact and delayed its recognition.*
V.	*FINDING These failures left patient advocates, the parents and carers of newly-unwell CYP, to advocate for recognition of the disease.*

22. Notwithstanding clear awareness that some CYP in the UK would develop long-term injury from infection with SARS-CoV-2, there was and remains, a failure of leadership in relation to paediatric Long Covid. This has delayed the *"collective realisation"*, and formal recognition that Long Covid affects CYP.[43]

23. As to the politicians, first, none of the witness statements provided by politicians who gave oral evidence in Module 8, refer to paediatric Long Covid. This omission reflects a wider failure in political leadership on the long-term impact of the virus.

24. The Inquiry has previously heard evidence of the former Prime Minister's disparaging remarks about Long Covid.[44] Mr Johnson gave evidence in this module that he cannot ever remember being advised about paediatric Long Covid.[45] This is not supported by the evidence. As he confirmed orally, Mr Johnson asked for a paper on Long Covid,[46] which was produced on 31 May 2021 by Professor Sir Chris Whitty. The 'Short Note on Long Covid' advised the Prime Minister that CYP could develop Long Covid and that the prevalence was between 7-8% for 2-16 year olds at the time.[47] Following the CMO's advice, discussion took place about rising rates of Long Covid within Government. A Covid-O Cabinet Meeting of 6 July 2021 referred to Long Covid in children stating it was a "*strategic risk and potentially an area of concern.*"[48] and on the next day the Duchy of Lancaster prepared a paper to inform Ministers of the risks and planning priorities for Autumn/Winter. Under the heading "Long Covid in Children" (underline in original) this stated: *"we can expect cases to rise rapidly in this group.'* [49] Further, on 1 April 2022 a group of children with Long Covid visited No. 10 with personal letters addressed to Mr Johnson. The letters detailed the life-changing harm caused by Long Covid.[50] Mr Johnson did not meet the children, DHSC instead provided a standardised reply.[51] The former Prime

---

[43] [INQ000587960_0022 § 47]
[44] [INQ000399540_0014 §§ 38-47]; [Module 2 Report § 8.28]
[45] [14/86/17-23]
[46] [14/86/17-20]
[47] [INQ000251916]
[48] [INQ000625626_0002]
[49] [INQ000607384_0003]
[50] [INQ000272162]
[51] [INQ000272163]

Minster did not at any time make any public statements to acknowledge paediatric Long Covid, much less take any steps to minimise its impact. He continues, five years after the onset of the virus, to minimise the existence of paediatric Long Covid.

25. Secondly, there has been a lack of clinical leadership on paediatric Long Covid. Professor Viner, the Chief Scientific Advisor to the DfE, confirmed in March 2022 at a Ministerial Roundtable on Long Covid that paediatric Long Covid was foreseeable, its existence recognised by clinicians, and that it was impacting *"a large number of children."*[52] Notwithstanding this, the expert report observes a psychologization, *"minimisation and disbelief"* by some clinicians, who *"labelled parents (affected by the pandemic) as 'anxious' and 'hypervigilant' and assumed exaggeration of their children's symptoms, again refuting Long Covid diagnosis and therefore support."* The damaging consequence of *"this non-belief"* is that *"it made the process of trying to get help even more difficult, and in some cases impossible."*[53] The expert's conclusions on the lack of clinical knowledge on paediatric Long Covid are mirrored in the experiences of the LCK and LCKS who describe the minimisation and disbelief that their members' children experienced, and continue to experience.[54] Professor Viner confirmed in oral evidence when questioned by both the Chair and CTI that he had not provided any advice to the DfE on paediatric Long COVID.[55] There is no reasonable explanation for this failure.

26. The RCPCH represents 24,000 paediatrician members across the UK. The college is responsible for *"transforming child health through knowledge, research and expertise, to improve the health and wellbeing of infants, children and young people across the world,"*[56] yet the only evidence provided to the Inquiry of its activity on paediatric Long Covid is a single press release in August 2021 on the CLoCK 2021 study[57] (the findings of which have subsequently been superseded by the CLoCK 2024 study results). There is no evidence that RCPCH produced any clinical guidance, conducted any training, provided any public health information or set professional standards to inform its members on the risk of Long Covid, even as a body of evidence emerged.

27. Indeed, Professor Turner, President of the RCPCH, to the contrary, offered unnuanced oral evidence which failed to recognise that the virus had *any* impact on CYP *"we very quickly had*

---

[52] [INQ000193796-003]
[53] [INQ000587960_0022 § 49]
[54] [INQ000651344]
[55] [15/32/13-17]
[56] [INQ000651508_0001 § 3]
[57] [INQ000620593]

knowledge, data, experience, that children [sic were] not being directly affected by the virus"[58], *"the individual child was at no increased risk – of no meaningful increased risk for coming to any harm from Covid"* and that *"the virus bounced off them."*[59] Clinical knowledge of Long Covid amongst paediatricians appears unlikely to improve when even the President of the RCPCH is dismissive of the physical impact of SARS-CoV-2 on CYP.

28. Professor Whitty appeared to accept the lack of clinical knowledge of paediatric Long Covid when he told the Inquiry that *"the medical profession and other healthcare workers… need to understand where the current science is so that they can respond appropriately when children who have symptoms compatible with Long Covid present."* He went on to state that he is not the right person to lead on improving clinical knowledge of Long Covid.[60]

29. Overall, therefore, there is a lack of interest and failure of leadership amongst senior clinicians in addressing paediatric Long Covid, which has been profoundly damaging to CYP suffering from Long Covid.

30. Thirdly, there was a lack of leadership amongst public health officials in respect of Long Covid. PHE, and later UKHSA, are responsible for providing clinical and public health advice to inform Government decision-making,[61] yet PHE has not provided evidence of any advice given on paediatric Long Covid to inform decision making. To the contrary, despite confirming clear knowledge of paediatric Long Covid from May 2020, the corporate statements provided by PHE and UKHSA for this module make no reference at all to Long Covid.

31. The sole reference to PHE 'advice' on paediatric Long Covid to Government departments has been gleaned from DfE meeting minutes. Susan Acland-Hood has told the Inquiry that the weekly Permanent Secretary Stakeholder Group meetings on Education had a stable membership of attendees who had the responsibility to take action across the system, *"to make things happen."*[62] She confirmed that DfE followed the scientific and public health advice of PHE and DHSC[63] and that Consultant Paediatrician Dr Shamez Ladhani was the *'PHE recommended'* person to advise on Long Covid.[64] Dr Ladhani's minuted advice on 9 June 2021 was *"Dr Ladhani was clear that children should not be labelled with Long Covid (i.e. a medical condition), as this has potential to cause longer-term, psychological harm."* The minutes also note Dr Ladhani's minimisation and psychologization of the physiological harm

---

[58] [7/100/10-12]
[59] [7/108/5-7]; [7/98/16-17]
[60] [13/152/5-11]
[61] [INQ000588110_0010 § 1.22]
[62] [11/112/13-23]
[63] [11/115/20-25]; [11/120/1-9]
[64] [11/119/19-22]

of paediatric Long Covid, "*any instances of fatigue or prolonged sense of feeling unwell…would likely be blamed on Covid-19.*"[65]

32. Ms McFarland has explained the real-life consequences of this advice, *"he says 'label', I say 'diagnosis' and without diagnosis our children were unable to access care or to be believed, and that put additional pressure on families and children and young people themselves. It brought additional stigma. It makes me wonder if they wanted a barrier to stop our children being diagnosed because they didn't want people to understand the amount of children that were getting sick."*[66]

33. The failures in leadership caused a consequential delay in recognition and response to Long Covid in CYP, further to the delay in formally responding to Long Covid in adults.[67] Patient advocates (lay parents and carers of chronically unwell children) had to fill the vacuum of leadership by building the evidence base demonstrating CYP's post-infection experience, campaigning for recognition and having to advocate for measures to minimise the prevalence and impact of Long Covid on CYP.

V. FAILURES IN RESPONDING TO PAEDIATRIC LONG COVID

34. The evidence reveals systemic failures in responding to paediatric Long Covid. These can be categorised as: (i) implementing policies that failed to prevent chronic illness amongst CYP; (ii) a failure to ensure educational settings were adequately safe from viral transmission; (iii) a failure to ensure education was accessible for CYP with Long Covid; (iv) a failure to adequately collect data and monitor paediatric Long Covid; (v) a failure to warn the public about the new disease; (vi) a failure to inform schools and teachers on how to support pupils with Long Covid; and (vii) a failure to ensure adequate healthcare for CYP with Long Covid. These failures are detailed below.

(i) *A Failure to Prevent Chronic Illness*

> *VI. FINDING Pandemic policies did not protect CYP and did not prevent the development of chronic illness.*

35. The Inquiry has found that there was sufficient information available by October 2020 for decision makers to understand that Long Covid was a significant policy and health issue,[68] and as detailed in section III above, there was clear knowledge of Long Covid's impact on CYP by

[65] [INQ000542824_0003 § 2.2]
[66] [3/63/23-25 – 3/64/1-8]
[67] [INQ000587960_0022 §§ 47-51]; [13/105/15-20]
[68] [Module 2 Report § 8.28]

early 2021, at the very latest. However, this knowledge and awareness did not translate into policies that protected CYP from the long-term physical harm of the virus.

36. Even when decision makers were expressly advised that CYP were at risk of acquiring Covid and developing Long Covid, that risk was unnecessarily accepted because decision makers used the flawed comparator of relative risk to adults. The Government did not heed the call by education unions for a precautionary approach to protecting CYP.[69] Government documents from summer 2021 show that decision makers were advised that the prevalence of Long Covid amongst CYP would increase:

    a. **9 March 2021**: the Cabinet Office advised that *"groups that were previously considered as 'low risk' from COVID-19 are being affected by long COVID, including children, younger age groups among adults, those with no pre-existing health conditions, ethnic minorities and those who experienced mild disease and were not hospitalised with COVID-19."*[70]

    b. **6 July 2021**: a Covid-O meeting was held to build a *"collective understanding"* among Ministers about the trajectory of the virus, and to respond to the risks posed. The meeting note referred to *"Long Covid in children"* and concluded that *"there remains an unquantified risk that higher levels of COVID-19 infection will lead to increased levels of Long COVID."* It continued *"given the uncertainty of vaccination and children, Long COVID represents a strategic risk and potentially an area of concern."*[71] The evidence of Long Covid in children was presented in comparison to the *"post-Covid symptoms experienced by adults"* and prevalence data was provided as relatively lower than in comparison to prevalence of Long Covid in adults. In this meeting, Ministers were advised that summer/autumn high prevalence period posed an unquantifiable risk that CYP would develop Long Covid. Measures to mitigate this risk were not discussed. Rather Ministers were urged to accept an unquantifiable number of CYP developing Long Covid as a *"strategic risk."*

    c. **7 July 2021**: the Duchy of Lancaster published a paper for a ministerial meeting to understand risk and to agree planning priorities for Autumn/Winter. The paper noted at the outset that the pandemic would not be over by then and that there was a need to manage the risk of serious illness. Page 3 of the paper detailed the specific 'operational risk' of *"Long Covid in children",* noting clearly that *"we can expect cases to rise rapidly in the group."*[72] Again, Ministers were advised that an unknown number

---

[69] [INQ000649219_0003]
[70] [INQ000548262_0001] [M9 Disclosure]
[71] [INQ000625626_0002]
[72] [INQ000607384_0003]

of CYP would develop long-term illness, but with *"low prevalence"* in comparison to adults. The paper offered no mitigation for this '*operational risk*'.

d. **9 July 2021**: the Covid-19 Taskforce issued a 'for information' paper entitled *"Long Covid: Risks to the Population and the Health Service"*[73] which again advised that *"the bulk of Long COVID cases in the coming months may come from younger, unvaccinated individuals."*[74] The Taskforce provided no advice on mitigation measures to minimise the impact of Long Covid on CYP. The impact of Long Covid was again compared to that in adults and minimised as *"rarer, and less severe."*[75]

e. 19 July 2021: the Cabinet Office advised that *"we can expect cases to rise rapidly amongst children and young people given most will remain unvaccinated over the coming months…high prevalence will likely increase the health burden arising from long COVID."*[76]

37. The Covid-19 Public Health Directorate team of the Scottish Government took a similar approach of failing to prevent CYP developing Long Covid in July 2021.[77] The then First Minister was concerned that decisions were being taken *"based on a view that Covid is not a serious risk to children, when there still seems to be a lot of scientific disagreement on risks of e.g. long Covid, and possibly especially from Delta,"*[78] and explained this to officials within Government departments responsible for CYP and public health. Notwithstanding this concern being raised, the evidence shows that the Scottish Government incorrectly took decisions on the assumption that Covid-19 was not a serious risk to CYP.

38. By way of further example, an email thread from within the Scottish Government shows that on 26 July 2021 officials within the Covid-19 Public Health Directorate team gave advice that Long Covid was occurring in children.[79] The advice expressed concern that there should be some protective measures in place against health risks while *"we let the virus run unchecked amongst children,"* and suggested that a cautious approach should be taken to paediatric Long Covid. Despite these concerns and suggestions that *"something"* is retained for children under-12.

39. By 2 August 2021 the Government nonetheless decided to proceed with *"no NPIs for under-12s."* This left under-12s unprotected from acquiring Covid-19 and developing Long Covid.

---

[73] [INQ000622771]
[74] [INQ000622771_0003 § 7]
[75] [INQ000622771_0002 § 4]
[76] [INQ000624073_0001, 3] [M9 Disclosure]
[77] [Module 2 Report § 8.51]
[78] [INQ000470032_0003]
[79] [INQ000530236_0003]

When asked about this decision, Mr Swinney pointed to *"a whole host of steps"* to protect CYP's health through *"wider interactions of the health and care system."*[80] The LCGs note that Mr Swinney's answer did not deal with the Government's failure to *prevent* CYP from developing illness. Long-term illness could and should have been prevented amongst CYP; it is no answer to point to the provision of post-facto healthcare as a solution.

40. These failures in decision making resulted in more CYP needlessly developing Long Covid. Whist the data on prevalence of Long Covid amongst CYP is incomplete and difficult to compare (data collection is covered in greater detail in sub-section (iv) below), it is clear that the number of CYP with Long Covid, as known and predicted by the Government, is rising:
    a. ONS data estimates that in March 2023 (UK wide) 62,000 CYP aged 2-16 had Long Covid of any duration and 59,000 2-16 year olds had Long Covid for 12 weeks or more.
    b. ONS data estimates that in March 2024 (for England and Scotland only) 111,816 CYP aged 3-17 had Long Covid of any duration and 65,988 3-17 year olds had Long Covid for 12 weeks or more.[81]

(ii) ***A Failure to Make Schools Safe***

VII.	*FINDING Government failed to consider Long Covid in relation to NPIs for schools. In consequence, schools are not adequately safe from viruses, pathogens and other pollutants.*

41. Government witnesses have presented pandemic policy in schools as being binary: schools either remaining open or being closed. There was, however, another option – namely to ensure that educational settings were *safe* for CYP. NPIs in relation to school closures and openings should have been guided by epidemiological advice on the impact of the virus, and measures to minimise this impact, but the Inquiry has heard that Long Covid was *"not a factor when considering school closures."* Professor Whitty even now refers only to the binary approach: *"the harm from closing schools would have outweighed the benefits, especially as children could still be infected with COVID in the community,"*[82] when focus should have been placed on mitigation measures to ensure schools were more Covid-safe.

42. The LCGs advocated for mitigation measures in educational settings to ensure a *"sensible, safe and sustainable approach to education during the pandemic."*[83] This included air filtration using HEPA air filters, as well as improved ventilation.[84] For example in January 2021, ahead

[80] [8/205/7-15]
[81] [INQ000651354]
[82] [INQ000588046_0063 § 5.14]
[83] [INQ000272147]; [INQ000588023_0019 §§ 61-80]
[84] [INQ000588023_0022 § 71]

of the parliamentary debate on Long Covid, LCK sent a briefing to MPs recommending that the Government (i) ensure lower overall rates of infection within the community; (ii) develop of mitigation measures to facilitate social distancing and reduce the risk of airborne transmission; and (iii) provide schools with sufficient resources to implement the mitigation measures required. These recommendations were not implemented. In April 2021 the same concern was raised when LCK wrote to the then Secretary of State for Health and Social Care again asking for urgent mitigation measures in educational settings. LCK received no response, and the suggested measures were not implemented. In May 2021 LCK wrote to the then Secretary of State for Education, copying in the education ministers of the Devolved Administrations asking for urgent mitigation measures to avoid further prolonged lockdowns and disruptions to education.[85] This letter was not responded to. LCKS sent requests to local authorities under the Freedom of Information Act 2000 asking about ventilation, CO2 monitors and air cleaning in schools in Scotland. The responses received showed wide disparity in the 'safety' of schools for staff and pupils across Scotland.[86]

43. These concerns were also taken up by the education unions who were advocating for effective safety and mitigation measures throughout the relevant period, to ensure schools were safe for both staff and pupils. For example, in July 2021 UNISON called for urgent mitigation measures such as improved ventilation for schools,[87] and provided a briefing to MPs recommending ring-fenced finance to improve ventilation in the school estate. It took repeated calls from the unions before HEPA filters and CO2 monitors were introduced in early 2022. As Kevin Courteney of the TUC states, however, this was *"too little and too late."*[88] The evidence discloses no explanation for the Government's failure to take timely and effective action on the repeated calls for mitigation measures in educational settings.

44. Professor Noakes has explained the importance of clean air and ventilation in educational settings, whilst acknowledging the limited research in this area. She noted that *"ventilation has been a measure for decades to reduce the concentrations of not just microorganisms, viruses and bacteria in there, but also other pollutants in the air"*[89] and so is the *"gold standard"* of IPC measures. Her longer-term recommendation is to improve ventilation with a retrofit programme across the UK school estate.[90] Professor Noakes noted that as a supplement to ventilation, air cleaning or air filtration systems like HEPA can be put in more quickly. Applying this to

---

[85] [INQ000272151]
[86] [INQ000588097_0017 §§ 60-64]
[87] [INQ000649219_0003]
[88] [INQ000588135_0043 § 117].
[89] [15/67/16-20]
[90] [15/79/4-8]

classrooms, her Class-Act study looked specifically at air-cleaning devices in classrooms and found that HEPA devices lowered the rate of illness absence across all of the schools.[91]

45. The Inquiry is invited to consider this expert evidence in the context of the conclusion of Professor Jim McManus that *"being in school or education and being protected free from harmful exposure to pathogens are equally important… this is especially so given the emerging evidence on the long-term harms of repeated Covid-19 infection and the fact that infection and disease in children who are vulnerable for whatever reason can significantly harm their health, education and their future."*[92] In line with the LCGs' advocacy during the relevant period, improved ventilation and clean air in educational settings is the *"low-hanging fruit"* of an IPC response and would limit harmful exposure to SARS-CoV-2, and reduce exposure to other pathogens and pollutants, improving school attendance and maintaining overall health.

(iii) ***A Failure to Ensure Access to Education***

VIII.	*FINDING Long Covid can adversely impact CYP's educational attendance and attainment. CYP with Long Covid should have access to flexible learning options, reasonable adjustments and EHCPs to ensure access to education.*

46. The Inquiry has heard evidence from CYP, patient advocates, schools and the Inquiry's experts on Long Covid's impact on both educational attendance and attainment. O, aged 11 when first infected in 2022, for example, describes the severity of the impact of Long Covid on her education. *"O's school attendance has been severely disrupted by Long Covid, plummeting to 42% in Year 7 and a complete absence in Year 8. The relentless fatigue, pain, and debilitating brain fog made engaging with classroom learning an insurmountable challenge. This led to her feeling increasingly frustrated, forgotten by her peers, and significantly behind in her education. The school's lack of recognition of Long Covid and the absence of appropriate policies meant her condition worsened; for example, she was pressured to attend even when severely unwell. This ultimately forced her parents to fight for alternative provision. She now receives one-on-one home tuition via an Education, Health and Care Plan (EHCP), a process that was arduous and time-consuming due to the Local Authority's reluctance to acknowledge Long Covid as a valid reason for her inability to attend school."*[93] LCK's Attendance and Education Experiences Survey of February 2023 charts how common this experience is. It found that 75% of respondents had their attendance greatly impacted by Long Covid, with 9.4% are too unwell to be in education at all, and 54% of respondents suffering from learning losses. The study

[91] [15/65/17-25 – 15/66/1-24]
[92] [INQ000588160_0010 § 46]
[93] [INQ000588023_0024 § 80]

also calculated that a pupil with Long Covid will lose an average of 20.6 learning hours per week, which amounts to over 171,000 lost learning hours per year.[94]

47. It is regrettable that the spotlight schools identified were not asked to provide evidence on the impact of Long Covid. However, the evidence shows that some were (i) aware of Long Covid; and (ii) aware of its consequential impact on lost learning from as early as Autumn 2020. An email thread from November 2020 between Sir Hamid Patel of Star Academies, Ofsted and DfE for example, discusses proposals for regional mitigation of national exams. Sir Hamid proposes that individual students suffering from long-term COVID illness be given the opportunity to provide medical evidence and have a special appeals process to compensate for sickness-related absence, showing early recognition of its impact on educational attendance and attainment.[95] Further, the impact is ongoing. John Barneby confirmed in oral evidence that Long Covid *"clearly"* has an impact on educational needs and attendance.[96]

48. Experts to the Inquiry confirm the impact of Long Covid on education. Dr Segal and Professor Whittaker noted that of the Long Covid patients coming to NHSE services, 75% of CYP were attending less than 50% of school, and 20% were out of all education.[97] They noted the impact this has on both educational attainment and on development, as well as its contribution to anxiety concerning a return to education. Professor McCluskey's report on educational impacts detailed the negative effects Long Covid has on school attendance, school performance and participation in extra-curricular activities and cited the COSMO study to conclude that *"unsurprisingly"* Long Covid impacted school performance, with sufferers more likely to have changed their plans for education and future career.[98]

49. Government departments were aware of and discussed the impact of Long Covid on educational performance during the relevant period. On 20 July 2021 DfE officials considered whether pupils with Long Covid should be offered remote education noting *"There are also questions being raised about whether remote education should be offered to students with LC and other conditions [...] Colleagues are also exploring whether anything can be done to support children who are attending school but have LC symptoms."*[99] Professor Viner, Chief Scientific Advisor to DfE attended a Long Covid in Children Expert Group meeting on 2 August 2021 which similarly noted the negative impact Long Covid had on learning experiences,[100] yet in oral evidence he confirmed that he has not provided DfE with any advice on Long Covid

---

[94] [3/44/20-25 – 3/45/1-8]
[95] [INQ000622487_0004]
[96] [7/195/1-4]
[97] [INQ000587960_0004 § 5, 16]
[98] [INQ000587959_0134 §§ 330-331]
[99] [INQ00066583]
[100] [INQ000238600_0091]

to date.[101] The educational impact of Long Covid was also recognised in a cross-Government document prepared by the Cabinet Office in September 2021 entitled *"short-term and long-term effects of COVID-19 on school performance and learning have been a matter of concern."*[102] The DHSC, in a letter to LCK dated 7 December 2021, stated that *"absence from education owing to Long Covid symptoms should be treated in the same way as any other absence owing to medium – or long-term health conditions,"*[103] yet this fails to reflect the lived reality of pupils with Long Covid.

50. As with O's experience above, pupils with Long Covid need reasonable adjustments and support to access education, but despite early recognition amongst Government, there is still no standardised approach for the management of pupils with Long Covid. Indeed, Ofsted have confirmed that despite the educational impact of Long Covid, they did not carry out any analysis on children who contracted Long Covid during the relevant period and do not hold any relevant data on Long Covid.[104] The Long Covid experts describe this as leaving some CYP to *"battle with school to support the young person, requiring them to provide evidence of diagnosis and failing to instigate activity management and support them to remain connected with education,"* whilst others reported *"that educational settings did not believe in Long Covid and were dismissive of the need for a supportive return to education."*[105] The Government has provided no reason for failing to provide guidance to schools in order to ensure pupils with Long Covid can access education, a point that was discussed from at least mid-2021 onwards.

51. In oral evidence, Professor McCluskey agreed that Long Covid's impact required the adaptive recommendations laid out in MacLean's study.[106] These can be summarised as supportive measures that (i) recognise paediatric Long Covid and its educational impact; (ii) acknowledge the difficulties families face in navigating healthcare; (iii) raise awareness of paediatric Long Covid; and (iv) offer reasonable adjustments such as reduced timetables and remote learning. The Inquiry is invited to find that these recommendations are, as Professor McCluskey states, *"a fair request"* to support pupils with Long Covid in accessing education.[107]

(iv) ***A Failure to Monitor Disease and Collect Data***

IX.	*FINDING There was and remains inadequate monitoring and data collection concerning paediatric Long Covid.*

[101] [15/32/17]
[102] [INQ000622769_0004]
[103] [INQ000272164]
[104] [INQ000588111_00177 § 476]
[105] [INQ000587960_0018 § 35]
[106] [6/180/16-24]
[107] [6/180/24-25]

52. The evidence shows an absence of data on Long Covid in CYP in relation to (i) educational impacts; (ii) national prevalence; and (iii) healthcare needs. The Inquiry has found that good quality data are critical to help inform both good advice and good decision making.[108]

53. In relation to the monitoring of Long Covid to inform educational policy, there is no evidence that data was sought from schools on the incidence, impact or absences caused by Long Covid. To the contrary, the evidence before the Inquiry is that there was no Government communication to schools on Long Covid.[109] While UKHSA and DfE collaborated to use a specific code to identify Covid-infection related school absences, no code was created for Long Covid. The evidence shows that DfE recognised that Long Covid-related absences were a data blind spot in May 2021 and again in July 2021,[110] but still no codes have been created. Neither DfE nor UKHSA have provided evidence to explain their approach to data collection and Long Covid, but the Inquiry has Dr Arora's recommendation that Long Covid absences should be recorded and collected.[111]

54. As to national prevalence data, the LCGs' Opening Statement described the delay in beginning to collect prevalence data on Long Covid in CYP, the controversy this caused around the disease's impact,[112] and the inconsistency of prevalence datasets which deprived decision makers of reliable, comparable data to analyse the impact of paediatric Long Covid.[113] National prevalence data from the ONS on Long Covid stopped in March 2024. This means that the full impact of paediatric Long Covid remains unknown.[114] It is only through anecdotal evidence that the significant impact of the disease is known, *"while some will see it as reassuring that a very small percentage of children get COVID-19 or long COVID, this still constitutes a large number of children who are experiencing an undeniable impact on their health and their lives and it is important to recognise this."*[115]

55. Professor Hammer has given evidence on the importance of surveillance of long-term sequelae, and its importance has been underscored in Module 2's report,[116] yet all four nations lack healthcare data on paediatric Long Covid.

---

[108] [Module 2 Report §15.32]
[109] [5/120/7-14]
[110] [INQ000542722]; [INQ00066583]
[111] [12/63/10-15]
[112] [INQ000530232_0003 § 11e]
[113] [LCGs Module 8 O/S_0010 §§ 23-29]
[114] [INQ000652462] [M9 Disclosure]
[115] [INQ000193796]; [3/176/21 – 3/177/3]
[116] [INQ000196611_0038 § 98]; [Module 2 Report § 15.32]

a. **England:** Duncan Burton of NHSE referred to data on CYP collected by the Long Covid hubs, noting that the data was not published due to poor completion rates and poor data quality.[117] Mr Burton was not able to provide an answer when asked whether NHSE had made any subsequent efforts to improve data collection on Long Covid in CYP.[118]

b. **Scotland:** Caroline Lamb, Director General of Health and Social Care on behalf of the Scottish Government, also noted a paucity of data: "*HSCA do not hold data about long-term sequelae amongst children and reliable data is not available for Scotland. Whilst the Scottish Government collects data on the prevalence of long covid amongst children as part of the annual Scottish Health Survey, this survey does not allow us to understand the long-term health effects and complications that may persist or emerge after the acute phase of a Covid-19 infection…it is reasonable to assume under recording [of paediatric Long Covid by GPs]*".[119]

c. **Northern Ireland:** the Children's Commissioner made a call for better data collection that covers CYP with Long Covid and cited the demographic differences between the devolved nations as a reason for disaggregated monitoring of the disease.[120]

d. **Wales:** the lack of data on CYP with Long Covid was identified as a problem as early as April 2021 in Wales by the Welsh Government's International Intelligence sub-group.[121]

56. Whilst all four nations identify gaps in data collection on the impact, severity and prevalence of Long Covid as a concern, nothing was, or has been done ever since, to remedy flaws in data completion and quality or to resume or start data collection in areas where there was none. To the contrary, the evidence shows missed opportunities to monitor and evaluate the impact of paediatric Long Covid in all four nations.

(v) ***A Failure to Warn – Public Health Messaging***

X.	*FINDING The public and parents have not been provided with public health information on Long Covid in CYP.*

57. Despite the former Prime Minister, Boris Johnson, PHE/UKHSA, the CMO and DFE all agreeing in principle that timely and accurate public health messaging on paediatric Long Covid would have been an effective public health response, no public health information about paediatric Long Covid has been provided in any of the four nations. Some 5 years after the

---

[117] [INQ000588020_0230 §§ 707-708]
[118] [7/49/5-14]
[119] [INQ000548307_0053 §§155-156]
[120] [INQ000588092_0028 § 89]
[121] [INQ000313828]

virus' onset, parents of CYP who are now developing Long Covid are in the same position of lack of awareness, understanding and empathy, as the first members of LCK and LCKS in the summer of 2020. We invite the Inquiry to conclude that silence about a new paediatric disease amounts to a public health failure. As the Module 2 report stated, *"information should not be withheld from the public unless there are clear and lawful reasons for doing so."*[122]

58. The former Prime Minister, Mr Johnson, accepted that *"if we had advice about the particular risks of Long Covid in children, then – then we should have"* communicated the risk to parents in the summer of 2021.[123] Despite being shown Government advice dated 7 July 2021 which expressly referred to *"Long Covid in children"*,[124] Mr Johnson appeared to say that he had never been advised of the disease and made the bizarre suggestion that the four references to Long Covid in children in the advice were typographical errors meant to refer to adults.

59. Dr Arora of PHE agreed in principle that the public should have timely, accurate information, "*even if it's to say, 'This is what we don't know'…I do, as a principle, think that it is always good to share as much as you possibly can with professionals and the public."*[125] She further confirmed that there was general understanding across DHSC and CMOs of the phenomenon of Long Covid in CYP from May 2020.[126] However public press statements from UKHSA, such as "*A safe return to schools*" dated 3 June 2021, over one year after paediatric Long Covid was understood, failed to refer to the potential long term harm caused by the virus. The statement instead minimises the physical harm that the virus causes, *"in children and young people symptoms are often absent or very mild…reassuringly, children and young people rarely become seriously ill following COVID-19 infection."*[127] This statement, and others like it, misled parents into thinking that CYP did not come to physical harm from the virus, and perpetuated disbelief of the illness. So far as LCK and LCKS are aware, UKHSA has not published any public health information concerning paediatric Long Covid.

60. Similarly, to date, none of the CMOs have issued a public statement informing parents and carers of the potential long-term effects of SARS-CoV-2 for CYP. The OCMO consensus statement of August 2020 instead minimised the risk SARS-CoV-2 poses to CYP, without any reference to its possible long-term harm. Professor Whitty defended the failure to issue a public statement on Long Covid in two inconsistent ways. First, the CMO said that in August 2020 the risk of Long Covid to CYP had not yet been identified.[128] This is inconsistent with the

[122] [Module 2 Report § 15.30]
[123] [14/87/15-17]
[124] [INQ000607384_0003]
[125] [12/60/10-18]
[126] [12/44/10-22]
[127] [INQ000624309_0003-4]
[128] [13/105/15-25]

evidence of Dr Arora that there was general understanding across DHSC and CMOs of the phenomenon of Long Covid in CYP from May 2020.[129] Professor Whitty did accept in response to questions from CTI, if they had in 2020 the knowledge of paediatric Long Covid that was available nine months later in 2021, *"we probably would have added one sentence into it, which is to say that some children do have long-term effects from this, because that would have been an important and accurate point to add."*[130]

61. Professor Whitty offered a second, different explanation when asked why no public statement was issued nine months after the consensus statement, or at any time since, to provide such *"important and accurate"* information. He said *"I didn't think that there was a situation where nobody knew about it and only I knew about it and needed to tell people. That would be completely incorrect… if you asked most parents does this exist, I think most parents would at least have been aware of the debate around it. So I think the idea that this is not a known thing, I'm not sure I would fully agree to…I don't think this is something which nobody knows about."*[131]

62. The evidence does not support the proposition that the risk of Long Covid was well known about by the general public or by clinicians. Guidance on managing Long Covid from NICE from 2022 concludes that even since the end of the relevant period *"there was a lack of recognition among healthcare professionals and the public that children can be affected by ongoing symptomatic COVID-19 or post-COVID-19 syndrome."*[132] That Long Covid was "*in quite a lot of publications and … covered in various bits of the media at various points"* is not to the point, even if correct. Parents and clinicians should not have to piece together information about a serious and novel paediatric disease from media sources: they deserve accurate public health advice from a reliable Government source.

63. Even once knowledge of paediatric Long Covid was well-established, in September 2021, public statements issued by a CMO minimised the actual harm caused by paediatric Long Covid. Dr Michael McBride, CMO to Northern Ireland, issued a public letter to parents and carers in September 2021, at the same time that schools were returning to face-to-face teaching without mitigation measures in place. The letter refers to Long Covid, but does so by minimising its risk and consequences, *"Concerns have been raised about long COVID in children. While work is ongoing to explore long COVID in children, emerging large scale*

[129] [11/44/10-22]
[130] [13/106/1-8]
[131] [13/150/3-7 – 13/151/17-25]
[132] [INQ000238545]

studies indicate that this risk is very low in children and similar to that associated with other respiratory viruses in children."[133]

64. The CMO's role is to act as principal medical adviser to the Government, which includes taking preventative measures towards infectious diseases which cause harm to children.[134] Public messaging of public health risks is a core preventative measure.[135] In the case of paediatric Long Covid the CMOs were, and remain, reticent to provide public health information. Both the August 2020 consensus statement and Dr McBride's September 2021 letter were issued with the aim of reassuring parents that schools were safe, but in doing so they failed to provide information about the real risk of Long Covid. The failure to warn about the potential physical harm to children had real world consequences. It is simply wrong to say, as Professor Whitty did, that a warning would have "*made no difference*" to the way people behaved. Quite apart from being entitled to accurate public health information, parents would have been able to make an informed risk assessment on decisions such as vaccination, masking or presence in populated closed spaces. The silence contributed to the ongoing lack of knowledge amongst healthcare providers, to the consequential failures to diagnose Long Covid and provide suitable support, and to the pervasive disbelief in Long Covid.

65. No witness has provided an adequate explanation as to why extra 'caution' and reticence was taken when considering public messaging for paediatric Long Covid as compared to explaining the impacts of acute Covid to the adult population. While some witnesses have suggested that Long Covid poses a unique obstacle in determining *"what information should be provided and could be provided,"*[136] LCK and LCKS invite the Inquiry to scrutinise the rationale of this analysis. All of the witnesses and entities detailed above have agreed in principle that the public should be provided with accurate and timely public health information of the virus' risk, and none dispute that it would have been helpful to share the very existence of paediatric Long Covid with the public.

66. Other witnesses have suggested that the provision of public health information on paediatric Long Covid would not have necessarily changed outcomes.[137] Again, the Inquiry is invited to scrutinise the rationale of this approach. Module 2 found *"public messaging about the incidence and existence of Long Covid would likely have had a considerable positive impact on those experiencing it, and perhaps, on those dismissive of its symptoms."*[138] Contrary to

---

[133] [INQ000137386_0003]
[134] [INQ000588046_0002 §§ 1.3, 1.5]
[135] [Module 2 Report § 8.25]
[136] [12/60/8-10]
[137] [13/151/1-3]
[138] [Module 2 Report § 8.25]

Professor Whitty's claims that *"most parents"* know about Long Covid, the evidence clearly shows a lack of public awareness that CYP can develop Long Covid, that otherwise-healthy CYP are at risk of becoming disabled, and as such, parents and CYP themselves, should be informed so that they can undertake their own risk assessment for exposure to long-term harm.

(vi) ***A Failure to Inform – Guidance to Schools***

> *XI. FINDING Schools and teachers have not been provided with guidance to support pupils with Long Covid in accessing education.*

67. The Inquiry has been provided with limited disclosure on the response to Long Covid by the education departments of each of the four nations. But it is apparent that none provided guidance to schools on Long Covid.

68. In England, piecing together the documentary evidence from DfE, two matters arise. Firstly, the DfE had clear knowledge of Long Covid's impact by at least April 2021, yet failed to issue guidance to schools. In April 2021 DfE officials discussed Long Covid with PHE and DHSC colleagues, noting that "*this is a sensitive area and DHSC will work with PHE and DfE to consider the issue of messaging more broadly*."[139] No explanation has been provided for why Long Covid was considered a 'sensitive area'.

69. On 11 May 2021 Sir Gavin Williamson was provided with a Note on Long Covid produced by DfE officials[140] which confirmed that CYP were suffering from long-term ill health following infection from SARS-CoV-2. Despite educational attainment and school safety being a matter for DfE, no information was provided to schools. Instead, a further meeting on 18 May 2021 records that DHSC, PHE, NHSEI and DfE agreed instead on messaging to *"focus on reassuring people that occurrence of long COVID in children is rare, but to also provide signposting for any child that may be experiencing long-term symptoms following COVID-19 infection."*[141] The meeting minutes show that even by July 2021, the Government's messaging was aimed at *reassuring* parents and maintaining school attendance, to the exclusion of sharing knowledge and information about the impact of Long Covid.[142]

70. In July 2021, DfE decided to issue operational guidance on Long Covid *"with the aim of publishing to coincide with schools returning in September"*[143], and was concerned to develop

---

[139] [INQ000283437]
[140] [INQ000651498 § 6.27]; [INQ000542722]
[141] [INQ000283448]
[142] [INQ000066583]; [INQ000625626_0002]
[143] [INQ000283463]

"a stronger public narrative on Long COVID".[144] By August 2021, however, DfE instead decided to issue formal guidance containing *"some information to schools through formal routes rather than publishing operational guidance."*[145] But no such guidance or information to schools about Long Covid has been issued. DfE's evidence does not account for the change of position.

71. Sir Gavin Williamson first suggested that the DfE's change of position would have been on DHSC advice although no such advice has been disclosed.[146] When pressed on why DfE did not nevertheless issue guidance to schools given the impact of Long Covid on educational attendance and attainment, he suggested that any such information had to be 'correct', 'accurate' and 'right.'[147] Sir Gavin could not explain why sharing information with schools such as that produced by DfE officials would not have been correct, accurate, and right. Even now, schools remain without information or guidance to help them to support pupils with Long Covid.[148]

72. Secondly, in May 2021 and at the same time as deciding not to issue guidance to schools, DfE referred to LCK's 'School Awareness Pack' as 'misinformation', noting *"the potential spread of misinformation on long COVID in children"* as an issue of concern for PHE and DHSC.[149] This allegation is unexplained, as well as being unfair and untrue. But in any event, it should never have been left to parent and carer members of LCK to fill the information gap. And when LCK did so, desperate at the lack of information available, they now know they were being maligned by the very organisation which had failed in its duty to provide guidance to schools. As Ms McFarland stated, *"We tried so hard to raise awareness and to get people to listen, and when I read that, it made me realise that we never stood a chance of getting the truth out because they didn't want it to be out. Our information wasn't misinformation; the misinformation was hiding the facts from families."*[150] Overall, this reveals a failure by Government to (i) provide clear guidance to schools, and (ii) work collaboratively with patient advocates to provide accurate, balanced information.

73. In Scotland, the Government's sub-advisory group on education and children's issues took a similar approach to DfE in the summer of 2021, noting *"messaging around Long Covid needs to be balanced, particularly given that other childhood infections (RSV, measles, paraflu) are potentially more problematic, and children are currently not being exposed to these and other*

---

144 [INQ000622771_0005]
145 [INQ000283464]
146 [10/124/1-4]
147 [10/125/14-10/126/21]
148 [5/120/7-14]
149 [INQ000542722_0003]
150 [3/59/5-10]

illnesses at the same levels as before."[151] There is no documentary evidence from Wales or Northern Ireland to explain why the two nations failed to issue guidance to schools on Long Covid.

74. The experts explain that the lack of public acknowledgment or official guidance concerning Long Covid *"made the process of trying to get help even more difficult, and in some cases impossible."*[152]

(vii) ***A Failure to Ensure Access to Healthcare***

> *XII. FINDING: CYP with Long Covid do not have access to adequate and effective specialised healthcare.*

75. Failures of political, clinical and public health leadership resulted in paediatric Long Covid being overlooked by healthcare service provision in all four nations. The recognition that Long Covid impacted CYP from May 2020 did not translate into timely, equitable and adequate healthcare. Indeed, the provision of healthcare for CYP with Long Covid has been delayed, piecemeal and inadequate.

a. **Wales:** decision makers decided against establishing Long Covid specific paediatric services, speculating that the likely demand could be met through local paediatric services.[153] There were no ring-fenced services for CYP and no dedicated paediatric services in the Adferiad programme.

b. **Northern Ireland:** there is no evidence of any dedicated service available for CYP with Long Covid. As with Wales, referrals were managed through general paediatric services and so there was no uniformity of care pathway available to all CYP.

c. **Scotland:** Mr Swinney referred to a *"whole host of steps being taken to try to support young people and to protect their health and wellbeing through some wider interactions of the health and care system"*. There were, however, no services for CYP with Long Covid during the relevant period. Scotland developed a national clinical care pathway for paediatric Long Covid in 2024, after the relevant period,[154] and the experts refer to only 3 of the 9 health boards having services in place now.[155] The evidence shows that *"the Scottish Government's measures and key decision-making did not (and still does not) go far enough to safeguard the health and development of CYP."*[156]

---

[151] [INQ000530234]
[152] [INQ000587960_0022 § 49]; [[INQ000587960_0004 §§ 5, 15]
[153] [INQ000620750_0160 § 439]
[154] [INQ000651266]; [INQ000651287]
[155] [INQ000587960_0022 § 47]
[156] [INQ000588097_0007 § 25]

d. **England:** NHSE observed CYP with Long Covid symptoms from June/July 2020, yet the first plan for Post COVID services in October 2020 did not explicitly refer to the needs of CYP with Long Covid.[157] No explanation has been provided for the failure to explicitly include CYP. It was only in July 2021 that 15 CYP Long Covid hubs were committed to, of which only 14 services were finally funded and established, and all took different models.[158] The resulting services had geographic gaps, particularly in areas of lower population density where paediatric services are more spread out. The gaps in service provision have grown as several of the original services are now closing, or are at risk of closure, with only 8 of the 14 confirming that they will continue. NHSE has confirmed funding for Long Covid services only up to 2026, there is no certainty that services will be provided after that.[159] The Post Covid Society has warned that the reduction in specialist paediatric services *"can result in chronic ill health, poor school attendance, and stunted biophysical development."*

76. The experts have concluded that the lack of specialised services across the four nations had meant that there are large geographical gaps where tens of thousands of CYP are being deprived of specialised care, and large numbers remain unwell, housebound and out of education as a result.[160] CYP's ability to access the sparse care services available has been adversely affected by poor clinical awareness of Long Covid. The experts describe *"a minimisation and 'disbelief' by some HCPs"*,[161] resulting in missed diagnoses, difficulties in accessing clinical pathways and educational support.[162] These gaps have forced some families to pay for private healthcare.[163]

VI. CONCLUSION - PERSISTING FAILURES

77. The evidence has shown a series of failures in recognising paediatric Long Covid, in mitigating its impact through NPIs, in monitoring its impact, in ensuring CYP were protected from developing its debilitating symptoms, and in providing supportive measures and improving clinical understanding to ensure CYP can access healthcare and education. These failures are not just historic. The following persist today:

---

[157] [INQ000588020_0229 § 699]
[158] [INQ000587960_0021 §§ 43-44]
[159] [INQ000588023_0046 §§ 150-152]
[160] [INQ000587960_0027 § 64]
[161] [INQ000587960_0022 § 49]
[162] [INQ000588023_0044 § §142-143]
[163] [INQ000588023_0045 § 147]

a. SARS-CoV-2 continues to be in circulation, and an unknown number of CYP continue to develop Long Covid. Yet there are no mitigation measures in place to minimise the development of chronic illness amongst CYP.
b. There is still no public health information to warn parents or the public about the risk of Long Covid from any government agency of any of the four nations.
c. Clinical knowledge and awareness of the disease remains poor, with the President of the RCPCH continuing to dismiss the risk of physical harm to CYP from Covid 19.
d. Schools have not been provided with any information on how to support pupils with Long Covid in accessing education.
e. There is no ongoing data collection on the prevalence, severity or educational impact of Long Covid on CYP. Long Covid's impact on educational attendance and attainment is neither understood, nor being responded to.
f. Healthcare for CYP with Long Covid remains hopelessly inadequate. There were no dedicated Long Covid services for CYP in Scotland, Wales or Northern Ireland during the relevant period. Many specialist services in England have been closed, and several more are closing. The vast majority of CYP have no access to adequate healthcare and their families are still forced to seek expensive private healthcare.

78. It has taken the scrutiny of a Public Inquiry for Government witnesses to publicly acknowledge the impact of paediatric Long Covid for the first time. Paediatric Long Covid has undermined the pandemic narrative that Government witnesses are still relying on. The disease demonstrates that (i) SARS-CoV-2 is not mild for all CYP, (ii) that not all CYP recover after infection and (iii) that the pandemic is not over and was not successfully defeated. Key witnesses have disclosed only sparse evidence on the Government's response to Long Covid in CYP, but the available evidence nonetheless demonstrates that decision makers: (i) repeatedly ignored evidence of the virus' long-term physical harm, (ii) deliberately exposed CYP to developing chronic illness, and (iii) have failed to implement mitigation measures and NPIs to minimise the harm of Long Covid to CYP.

VII. RECOMMENDATIONS

79. The LCGs invite the Inquiry to adopt the following 10 core recommendations, alongside the detailed recommendations that LCK and LCKS set out in their witness statements:

1. Apology and Accountability

1.1 The UK Government should apologise formally to CYP with Long Covid for its minimisation of the disease, and its inadequate response to date.

1.2 The DfE should apologise formally to LCK for its disparaging comments about the Schools Information Pack.

2. **Children's voices:**

2.1 The UK Government and the Devolved Administrations should create formal mechanisms to ensure that the lived experience of CYP and patient advocates are incorporated into any planning for future pandemics.[164]

2.2 Module 2's recommendation that the UK Government legislate to place children's rights impact assessments on a statutory footing in England, is welcomed.[165] Further, the UK Government should incorporate the UNCRC into domestic law across the UK.

3. **Clean Air and Covid Mitigations:** The UK Government should legislate to recognise the right of children to breathe clean air in school, and the Human Rights Act 1998 should be read as though this were a Convention right (see, by analogy, section 1 of the Clean Air (Human Rights) Bill). All four nations should take immediate steps to improve and monitor the air quality and ventilation in all early years and educational settings in order to limit the exposure of pupils and staff to SARS-CoV-2, as well as to other pollutants and pathogens. Such steps should include the development and implementation of clean indoor air policies, the provision of guidance and long-term funding for upgrading ventilation, provision of air quality monitors, HEPA and air filtration.

4. **Public health messaging about paediatric Long Covid**: the UK Government and the Devolved Administrations should provide public health information to the general public on the indiscriminate risk of paediatric Long Covid.[166]

5. **Schools Guidance:** in consultation with LCK, LCKS, the Health Conditions in Schools Alliance and other relevant stakeholders, the Department for Education (and the equivalents in the Devolved Administrations) should issue guidance to schools promptly. Such guidance should require schools to ensure that pupils with Long Covid are provided with appropriate adjustments to access education and to be fully included in school life.

6. **Healthcare**

6.1 NHSE and the health authorities in the devolved administrations should undertake to provide all CYP with Long Covid with access to dedicated, child-centred, specialist, multi-disciplinary Long Covid paediatric services.

---

[164] [Module 2 Report § 12.104]
[165] [Module 2 Report Recommendation 7]
[166] [Module 2 Report § 8.25]

6.2 In Scotland, the 2024 National Paediatric Long Covid Pathway should be implemented into every health board with ring-fenced funding.

6.3 Clinicians should be informed about Long Covid in CYP via specific clinical educational material with a view to improving the clinical understanding of paediatric Long Covid to ensure equitable access to diagnosis and healthcare.

7. **Research:** the UK Government should commit to funding and commissioning targeted research into Long Covid in CYP to establish its underlying pathophysiology and causes, and to determine its clinical, educational, psychological, and social impacts. This should be supported by adequately resourced paediatric healthcare services capable of hosting and delivering research trials.[167]

8. **Data and Surveillance**: the UK Government should gather data on the national prevalence and severity of paediatric Long Covid as well as measure the impact of Long Covid on school absences and educational attainment. This should be conducted on an ongoing basis.[168]

9. **Pandemic Planning**

9.1 Future pandemic plans should include preparation for a novel virus which has an adverse impact on the physical health of CYP.

9.2 Future pandemic plans should adopt a precautionary approach to CYP's health and prepare for monitoring of, and response to, paediatric morbidity through robust data gathering systems, sitreps and dashboards.[169]

10. **Support for Children and Young People with Long Covid**: the commencement of sustained financial support for the increasing number of CYP who are developing Long Covid and suffering from its consequential losses to health, education and career opportunities.

SARAH HANNETT KC
SANGEETHA IENGAR

JANE RYAN
BHATT MURPHY
28 NOVEMBER 2025

[167] [INQ000280198_0036 § 11.3]
[168] [Module 2 Report § 15.32]
[169] [Module 2 Report §§ 8.31, 15.5]