

# UK COVID-19 PUBLIC INQUIRY

## MODULE 8

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### OPENING STATEMENT ON BEHALF OF LONG COVID KIDS AND LONG COVID KIDS SCOTLAND

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#### Introduction

*"I've been mostly housebound these last three and half years. And if I do need to go out and walk, you know, in more than five minutes to hospital appointments or just for fun, I need a wheelchair. So yeah, it's pretty unrecognisable from how I was in 2019." (Aged 17, Long Covid) <sup>1</sup>*

1. The Long Covid Groups (“**LCGs**”) in Module 8 are Long Covid Kids and Long Covid Kids Scotland, representing the parents, families and carers of children and young people (“**CYP**”) of paediatric Long Covid, a new, chronic childhood disease.
2. SARS-CoV-2 may cause serious physical harm and even death to CYP. Its longer-term sequelae results in paediatric Long Covid, a multi-organ, life-altering, disabling disease which the WHO describes as having “*an impact on everyday functioning such as changes in eating habits, physical activity, behaviour, academic performance, social functions and developmental milestones;*”<sup>2</sup> Long Covid affects all aspects of childhood – developmental, educational, social, physical and familial. There are over 200 symptoms reported across nine body systems with a significant functional impact,<sup>3</sup> leading to activity limitation and reduced quality of life.<sup>4</sup> Although the long-term effects cannot yet be fully known, the Council of

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<sup>1</sup> [INQ000587936/141]

<sup>2</sup> WHO Clinical Case Definition for Post-Acute Covid-19 condition in children and adolescents by expert consensus. Available online at: <https://www.who.int/publications/i/item/WHO-2019-nCoV-Post-COVID-19-condition-CA-Clinical-case-definition-2023-1>.

<sup>3</sup> [INQ000587960] §§ 5, 20

<sup>4</sup> Toepfner N, et al ‘Long COVID in pediatrics – epidemiology, diagnosis and management’ Eur J Pediatr. 2024. Available online at: <https://pubmed.ncbi.nlm.nih.gov/38279014/>

Europe calls on Member States to treat those with Long Covid as falling within the scope of the UN Convention on the Rights of Persons with Disabilities.<sup>5</sup>

3. The evidence before the Inquiry shows that decision makers (i) failed to take a precautionary approach to safeguarding the health of CYP, (ii) deliberately minimised the physical harm caused by SARS-CoV-2 to CYP contrary to the emerging clinical evidence and (iii) failed to prioritise the public health of CYP in policy decisions. Indeed, CYP with Long Covid were factored into policy decision only as conduits of viral transmission that could harm adults. As a result, CYP have attended educational settings without adequate Infection Prevention Control (“IPC”) measures, and in doing so have been exposed to avoidable long-term physical harm. In the absence of public recognition, CYP who developed Long Covid had difficulty obtaining recognition for their illness. The Long Covid experts describe paediatric Long Covid as an “invisible disability” for this reason, leaving CYP to have their symptoms minimised, disbelieved and psychologised.<sup>6</sup> Many did not receive adequate healthcare and/or suitable education as a result.
  
4. The UK’s response to SARS-CoV-2 has underscored the need for decision makers to place the best interests of CYP, and in particular their right to health and education, at the heart of any pandemic response. As Professor Taylor-Robinson states, “*the promotion of health equity in childhood is imperative not just for moral reasons, but for the long-term good of society and for economic growth.*”<sup>7</sup> Paediatric Long Covid should be recognised as a human rights issue: prolonged illness following infection has implications for children’s rights to education, health, family life and the right not to be discriminated against on the ground of disability and other protected characteristics (contained in Article 14 of the ECHR and in the Equality Act 2010).<sup>8</sup> Similarly, decision makers should prioritise the best interests of children in decision making concerning Long Covid. The matters detailed below show that Long Covid has not been treated as a human rights issue for children to date. Further, the approach of allowing SARS-CoV-2 to spread unchecked amongst CYP, with the consequential risk of them developing Long Covid, failed fundamentally to consider their best interests. The LCGs will invite the Inquiry to conclude that decision makers in the United Kingdom did not discharge their obligations under

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<sup>5</sup> Resolution 2591 (2025) of the Parliamentary Assembly of the Council of Europe ‘Long Covid and access to the right to health.’ Available online at: <https://pace.coe.int/en/files/34157/html>

<sup>6</sup> [INQ000587960/22 § 49]

<sup>7</sup> [INQ000280060/50 § 159]

<sup>8</sup> This is the view of the Children and Young People’s Commissioner for Scotland, and is a view echoed in academic literature: [INQ000649659/4 § 12]; Bhatt V, ‘Long COVID and children’s rights’, *Journal of Human Rights Practice*, Volume 15 Issue 1, February 2023, pp 336-345. Available online at: <https://academic.oup.com/jhrp/article/15/1/336/7074415>

the Human Rights Act 1998 or the Equality Act 2010 to CYP who developed Long Covid from SARS-CoV-2 infection.

5. This Opening Statement outlines the four core questions the LCGs seek answered to better support CYP who currently suffer from Long Covid, and to ensure the UK is better prepared to respond to a future, new paediatric disease:

***Question 1:** Why was the physical impact of the virus on CYP deprioritised given that some CYP were harmed?*

***Question 2:** Once it was known about, why was there a deliberate minimisation of the physical harm the viruses poses?*

***Question 3:** Why did government not promulgate policy aimed at protecting CYP against the impact of paediatric Long Covid?*

***Question 4:** Why were the public, parents, schools and carers not informed of the indiscriminate risk of Long Covid to CYP by public health messaging?*

**Question 1: Why was the physical impact of the virus on CYP deprioritised given that some CYP were harmed?**

6. Paediatric Long Covid was a foreseeable consequence of SARS-CoV-2.<sup>9</sup> Further the potential adverse effects of Covid-19 for CYP were apparent very early in the pandemic:

- 6.1. The long-term sequelae from previous coronaviruses such as SARS-CoV-1 and MERS had been studied and were well-known.<sup>10</sup>

- 6.2. The 2011 UK Influenza Pandemic Preparedness Plan on which the Coronavirus Action Plan was based, recognising that “*all ages are likely to be affected*”, as some younger adults and children experienced severe and even fatal illness in H1N1.<sup>11</sup>

- 6.3. Indeed by as early as April 2020, SAGE observed a “*possible Kawasaki-like syndrome*” in children, early evidence of long-term sequelae impacting CYP from SARS-CoV-2.<sup>12</sup>

7. Despite this, decision makers approached the pandemic applying the flawed, and unevicenced assumptions that (i) CYP would not be physically harmed by SARS-CoV-2, (ii) so did not require protective policy measures and (iii) needed only be considered as conduits of viral

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<sup>9</sup> [INQ000280198/31 § 7]; [INQ000251916]

<sup>10</sup> [INQ000280198/5]

<sup>11</sup> [INQ000514457/16]

<sup>12</sup> [INQ000089720/185]; [INQ000146629/186]; [INQ000587960/6 § 10]

transmission to the adult population. This led to a delay in recognising paediatric Long Covid and a consequential delay to the implementation of policy protecting CYP, for example IPC measures in educational institutions. Often such measures were not implemented at all, or were put in place only to be removed subsequently.

8. Further, the response by the UK Government was adult centric. Rates of infection, death and Long Covid in CYP were compared to rates in adults, rather than comparing viral impact with other childhood diseases, as is standard in paediatric medicine.<sup>13</sup> This had the twin effect of underestimating the impact of Covid 19 and Long Covid on CYP, and of de-prioritising protective policy measures for CYP. For example, whilst death rates for CYP from SARS-CoV-2 are clearly lower than compared to adults, Covid-19 paediatric deaths are more common than in any other vaccine-preventable paediatric illness and should command policy intervention.<sup>14</sup>
9. Nonetheless, both Scottish guidance from May 2020 and a SAGE Children’s Task and Finish Group (“TFC”) paper from August 2020 concerning decision making for the reopening of education in England in September 2020 relied on comparing adults’ higher susceptibility to infection against that of children’s.<sup>15</sup> The flawed comparison with adults continued well into 2021 when the Welsh Technical Advisory Group acknowledged case rates in CYP but used this only to consider consequential impact on transmission in the adult population.<sup>16</sup> Decision-makers were unwilling to view CYP as individuals requiring protection from the physical harms of the virus in their own right. Rather, CYP were considered only for their role in viral transmission to the adult population.

**Question 2: Once it was known about, why was there a deliberate minimisation of the physical harm the viruses poses?**

***Deliberate Minimisation of the Physical Harm caused by SARS-CoV-2***

10. The emerging evidence of possible Kawasaki-like syndrome and early clinical studies from China should have prompted decision makers in the UK to adopt a preventative approach to the public health of CYP. Instead, even in the face of emerging evidence to the contrary, there

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<sup>13</sup> Van Beusekom, M “Not ‘little adults’: Experts say Long Covid undercounted, misdiagnosed in kids.” October 2023. Available online at: <https://www.cidrap.umn.edu/covid-19/not-little-adults-experts-say-long-covid-undercounted-misdiagnosed-kids>; [INQ000649123/1]

<sup>14</sup> [INQ000272179]

<sup>15</sup> [INQ000182826/11]; [INQ000224417/2]

<sup>16</sup> [INQ000350570]

was a deliberate minimisation of the physical harm that SARS-CoV-2 causes to CYP in order to secure freedoms for both adults and CYP, over safeguarding the long-term health of CYP.

11. This caused decision makers to publicly minimise the physical impact of the virus. Thus, in August 2020 the Government launched a campaign, described by Boris Johnson as having the purpose of showing “*schools were safe*”. The campaign was accompanied by a consensus statement from the OCMO<sup>17</sup> saying “*there is clear evidence of a very low rate of severe disease in children of primary and secondary ages compared to adults...the great majority of children and teenagers who catch COVID-19 have mild symptoms, or no symptoms at all...very few, if any, children or teenagers will come to long term harm from COVID-19 due solely to attending school.*”
12. By the time of the August 2020 OCMO joint statement: (i) SAGE had expressed concern about Kawasaki-like syndrome persisting in some CYP, (ii) the WHO had published a scientific briefing confirming that some children required hospitalisation and intensive care, as well as referring to an inflammatory disorder in CYP, (iii) the Lancet had published an article on hyperinflammatory shock in CYP following infection, (iv) the BMJ had published an article on a severe disease phenotype in children, and (v) the Academy of Medical Science had confirmed that “*post-viral syndromes are well documented following other viral infections.*”<sup>18</sup> There was clear evidence of a risk of both acute and long-term physical harm to CYP following infection from SARS-CoV-2, yet this was not reflected in the OCMO statement.
13. The OCMO statement in fact had the effect of misleading parents into believing that CYP were unlikely to come to physical harm from SARS-CoV-2, instead of explaining the long-term damage to health from exposure to the virus in schools.<sup>19</sup> Further, and importantly, no subsequent, corrective statement has been issued by the OCMO to explain the full risks SARS-CoV-2 in fact poses to CYP.

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<sup>17</sup> [INQ000070464]

<sup>18</sup> [INQ000089720/185]; WHO “Multisystem inflammatory syndrome in children and adolescents temporally related to Covid-19” May 2020. Available online at: <https://www.who.int/news-room/commentaries/detail/multisystem-inflammatory-syndrome-in-children-and-adolescents-with-covid-19>; Riphagen, S “Hyperinflammatory shock in children during Covid-19 pandemic” May 2020. Available online at: <https://pubmed.ncbi.nlm.nih.gov/32386565/>; Swann, O et al “Clinical characteristics of children and young people admitted to hospital with Covid-19 in United Kingdom: prospective multicentre observational cohort study” BMJ, August 2020. Available online at: <https://www.bmj.com/content/370/bmj.m3249>; [INQ000588023 §§ 36-37]; [INQ000211967] (M2 disclosure).

<sup>19</sup> [INQ000588023/10 § 34]

14. Alongside the official OCMO statement, senior officials’ broad public platforms, political influence and media focus increased the reach of the inaccurate message that the virus was of minimal impact to CYP. In particular:

14.1 Professor Dame Jenny Harries was widely reported in the national newspapers as her having said that *“children are more at risk of being in a car crash on the way to school than from catching Covid-19.”*<sup>20</sup> As far as we are aware, Dame Jenny made no attempt to correct this statement either then or subsequently.

14.2 Professor Russell Viner also held an influential role in paediatric medicine as Chief Scientific Advisor to the Department of Health (“**DfE**”). Professor Viner, a former President of the RCPCH, also sat on SAGE. On 9 March 2020 he published a paper that claimed that CYP and schools would not play a significant role in the transmission of SARS-CoV-2 unlike other respiratory diseases.<sup>21</sup> Professor Viner’s paper wrongly pointed policy makers away from considering the introduction of IPC measures in schools.

14.3 In June 2021 a Consultant Paediatrician at Public Health England (“**PHE**”), Dr Shamez Ladhani attended a Permanent Secretary Stakeholder Group on education with senior officials from DfE, the Local Government Association, teachers’ unions and representatives from schools and educational institutions. Dr Ladhani advised the Stakeholder Group against ‘labelling’ children with Long Covid, as the ‘label’ of the medical condition *“has potential to cause longer-term psychological harm.”*<sup>22</sup> In the same meeting Dr Ladhani minimised the physiological harm of Long Covid commenting that *“any instances of fatigue or prolonged sense of feeling unwell...would likely be blamed on Covid-19.”* Dr Ladhani’s view diverged from that expressed at the same time by the CMO, who had a week earlier advised the Prime Minister that Long Covid is *“a large enough problem to be concerned about.”*<sup>23</sup> PHE/UKHSA do not address the remarks made by Dr Ladhani in their Rule 9 statement.

14.4 The Prime Minister, Boris Johnson, on 9 October 2020, expressed the view that the scientific data on Long Covid was *“BOLLOCKS”*, and akin to the *“gulf war syndrome.”*<sup>24</sup> In response to the draft Spring Road map in 2021 he repeated *“Do we*

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<sup>20</sup> E.g. The Telegraph reported: <https://www.telegraph.co.uk/news/2020/08/24/car-crash-greater-risk-children-covid-deputy-chief-medical-officer/>. Dame Jenny Harries had in fact said that the risk posed by Covid-19 to children is lower than that of seasonal flu or traffic accidents.

<sup>21</sup> [INQ000606841]

<sup>22</sup> [INQ000542824/3 § 2.2]

<sup>23</sup> [INQ000251916]

<sup>24</sup> [INQ000251910]; [INQ000255836/191-192]

*really believe in Long Covid? Why can't we hedge it more? I bet it is complete gulf war syndrome stuff.*"<sup>25</sup> On 1 June 2021 in response to advice from Professor Whitty on Long Covid that post-acute sequelae was well established from viruses and prevalence in children was around 7% according to the ONS he wrote, "*so not exactly gulf war syndrome?*"<sup>26</sup> It is inevitable that the disbelief in Long Covid expressed by the then Prime Minister permeated the policy approach taken by ministers and civil servants.

15. Further, the evidence to date provides examples of decision makers accepting a risk of CYP acquiring Covid and Long Covid and proceeding without mitigation or warnings to parents.

For example:

- 15.1 In advice given by Cabinet Office to decision makers in July 2021, officials expressly advised that younger unvaccinated individuals would form the "*bulk*" of Long Covid cases in the months of accepted high prevalence around 'Freedom Day'<sup>27</sup> but policymakers nonetheless failed to mitigate against this risk. The Cabinet Office's Covid-O accepted the risk of Long Covid as a "*strategic risk*" in a briefing to the Prime Minister.<sup>28</sup> A cross-Government evidence summary produced by DHSC, PHE and DfE in September 2021 to prepare to manage the virus over Autumn Winter 2021 similarly accepted the risk of Long Covid to CYP, despite its effect on school performance being a "*concern*."<sup>29</sup> However, decision makers considered as the incidence of paediatric Long Covid was less frequent than in adults, the "*strategic risk*" of exposing to CYP to paediatric Long Covid was one Government was willing to take. The LCGs urge the Inquiry to find that such an approach failed entirely to consider CYP's best interests.

- 15.2 A similar acceptance that a number of CYP would suffer from a long-term medical condition was apparent amongst decision makers in Scotland in July 2021. The Covid-19 Public Health Directorate team accepted that they were "*not really proposing much in the way of protection*" for under 12s who would be unvaccinated, would not be able to self-isolate on return to school, would not have physical distance requirements and would be exempt from gathering rules. They also accepted that a number of CYP in Scotland were developing Long Covid and were seeking healthcare for their symptoms. Nonetheless decision makers concluded that letting "*the virus run unchecked amongst*

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<sup>25</sup> [INQ000214216/52] (M2 Disclosure)

<sup>26</sup> [INQ000251918]

<sup>27</sup> [INQ000622771/3]

<sup>28</sup> [INQ000625626/3]

<sup>29</sup> [INQ000622769]; The educational impacts of Long Covid were also recognised by JCVI in August 2021 [INQ000235154]

*children*” and “*tolerating a high rate of prevalence within children*” was acceptable.<sup>30</sup> Against growing clinical evidence of paediatric Long Covid, the Scottish Government recommended no NPIs for under-12s. Policy makers knowingly accepted that under-12s would be exposed to the risk of developing Long Covid.

16. Overall then, even when decision makers understood the impact of Long Covid on CYP, the risk was accepted by decision makers who failed to take a protective or precautionary approach to the public health of CYP by, for example, mandating the use of NPIs.

### ***Failure to Centre Children’s Voices and Experiences***

17. The minimisation of harm caused by SARS-CoV-2 caused a further delay in CYP with Long Covid having their illness recognised and responded to.<sup>31</sup> Families were forced to become patient advocates, while watching their CYP struggle with the long term, often-disabling effects of the virus. Sammie McFarland and Helen Goss describe turning to social media to connect families and build a collective voice for CYP who had not recovered after infection from SARS-CoV-2, who were distressed by the pattern of debilitating symptoms and who had frequently had their symptoms dismissed, minimised or psychologised.<sup>32</sup>
18. The paediatric Long Covid experts cite the prevailing Government message that children were less affected by Covid-19 infection as a likely reason for the “*overall neglect of non-severe symptoms*” in CYP, and for the delay in recognition of paediatric Long Covid.<sup>33</sup> This approach caused the medical community to dismiss and psychologise CYP’s presenting symptoms, impeding their access to medical care.<sup>34</sup>
19. Further, the Government’s dismissal of the physical harm of the virus caused other bodies with duties to secure the health and welfare of CYP to fail to advocate for or assist CYP with Long Covid.

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<sup>30</sup> [INQ000530236]

<sup>31</sup> [INQ000587960/22 §§ 47-49]

<sup>32</sup> Their collective experience is reflected in the CYP voices in the Scottish Inquiry’s “*Let’s Be Heard*” Case Study (<https://www.covid19inquiry.scot/report/voices-of-children-young-people-case-study>) which has a section on Long Covid (pp 221-227) and in Verian’s “*Children and Young People’s Voices*” [INQ000587936/139-147].

<sup>33</sup> [INQ000587960/22 § 47]

<sup>34</sup> [INQ000587960/22 § 49]

20. First, some of the Children’s Commissioners focused their efforts in the relevant period on the resumption of in-person education, to the detriment of advocacy on the physical harm of the virus.
- 20.1 Baroness Longfield, the former Children’s Commissioner of England, fails entirely to refer to paediatric Long Covid in any of her Rule 9 statements to the Inquiry. Baroness Longfield acknowledges a reported increase in chronic conditions amongst CYP during the pandemic,<sup>35</sup> and gave oral evidence in Module 2 that she was made aware of paediatric Long Covid whilst in post and had met with families suffering from Long Covid.<sup>36</sup> Nonetheless, she failed to undertake any advocacy on paediatric Long Covid during her tenure.
- 20.2 The Children’s Commissioner for Wales similarly fails to refer in her Rule 9 statement to paediatric Long Covid, much less to any advocacy undertaken for CYP with Long Covid.<sup>37</sup>
- 20.3 The Children and Young People’s Commissioner of Scotland did engage with LCKS and was provided with “*early and invaluable information*” on Long Covid by WHO. It was therefore apparent that Long Covid in CYP was an issue of concern.<sup>38</sup> Nonetheless, the Commissioner does not refer to any advocacy on Long Covid during the relevant period.
21. In contrast, the then Northern Ireland Commissioner for Children and Young People, Koulla Yiasouma, raised concern about the impact of Long Covid in December 2021 by writing directly to the CMO to ask (i) for CYP to be fully protected from the virus and supported in their recovery, (ii) to outline the healthcare provisions in place for CYP with Long Covid, and (iii) asking for health guidance whilst children were in school.<sup>39</sup> The current Commissioner, Chris Quinn, recognises the studies available on paediatric Long Covid which show a “*significant, long-lasting impact of Long Covid in children and young people*” and the need for robust data from Northern Ireland to better support policy making.<sup>40</sup> There is no reason why the other Children’s Commissioners could not have engaged in a similar manner.

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<sup>35</sup> [INQ000588139 § 49]

<sup>36</sup> UK Covid 19 Inquiry, Module 2, Week 1 Day 4

<sup>37</sup> [INQ000587975]

<sup>38</sup> INQ000649659/52 § 202]; [INQ000649659/46 §§ 175-176]

<sup>39</sup> [INQ000588091/33 § 91]

<sup>40</sup> [INQ000588092/28 §§ 89, 91]

22. The Royal College of Paediatrics and Child Health (“**RCPCH**”) engaged throughout the pandemic by producing advice posters for parents and carers<sup>41</sup> and had ad-hoc engagement with SAGE focusing on SARS-CoV-2’s epidemiological risk to CYP. Their Director cites only *one* activity concerning paediatric Long Covid, namely that in August 2021 the RCPCH published a press release on the CLOCK 2021 study.<sup>42</sup> It appears that RCPCH failed to provide and education, training, public health information or set professional standards to inform research and policy on the indiscriminate risk of Long Covid, even as a growing body of evidence emerged. There is no evidence that the RCPCH took steps to provide paediatricians with clinical information concerning the identification of Long Covid.

*"I felt like I was kind of like, pushed around. Nobody wanted my case... My feeling is that the mental health people have no idea of what ME [Chronic Fatigue Syndrome] is, or what Long Covid is. So you just find yourself having to explain again and again... [And] when it got to crisis point, you know, my mum had to really sit me down and like beg me to try and talk to people because at that point I was so wary of any sort of like counsellor or therapist." (Aged 17, Long Covid)<sup>43</sup>*

**Question 3: Why did Government not promulgate policy aimed at protecting CYP against the impact of paediatric Long Covid?**

***Inconsistent Data Collection Painted an Inaccurate Picture of Long Covid’s Impact***

23. Protective public health and education policy requires (i) consistent national data collection on the prevalence of Long Covid amongst CYP, and (ii) ongoing monitoring of Long Covid (incidence, absences and impact) in educational institutions. However, there was an avoidable delay in collecting prevalence data on paediatric Long Covid. The ONS Covid-19 Infection Survey (“**CIS**”), the main vehicle to collect nationwide data on the prevalence of SARS-CoV-2, was commissioned to collect data on Long Covid in adults in September 2020. The published ONS CIS only included data on CYP, following advocacy from LCK. In October 2020 LCK published their YouTube film, “*Our Unhappily Ever After*”<sup>44</sup> and in December 2020 published a BMJ article “*Count Long Covid.*”<sup>45</sup> It was as a result of these efforts that ONS datasets published from April 2021 included data on both adults and CYP with Long Covid.

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<sup>41</sup> [INQ000651508/3 § 7]

<sup>42</sup> [INQ000620593]

<sup>43</sup> [INQ000587936/143]

<sup>44</sup> [INQ000272195]

<sup>45</sup> [INQ000268012/18 § 84]; [INQ000320273]; [INQ000588023/56 § 177]; [INQ000231948]

There was early recognition of the need for data on Long Covid to inform policy decisions<sup>46</sup> however, even when available, the ONS prevalence data was not included on the Covid-19 dashboards to inform decision-making.

24. Thereafter, however, prevalence data for CYP (or indeed for adults) has not been collected consistently or with sufficient coherence to enable useful comparison between data sets. Prevalence data was last published in April 2024, covering only England and Scotland, and 3-17 year olds, of which 65,988 were estimated to have symptoms lasting 12 weeks or more. The earlier dataset of 2023 however, covered the entire UK, and 2-16 year olds, of which 53,000 were estimated to have symptoms lasting 12 weeks or more. This approach to data collection leaves policy makers without reliable, comparable data to respond to Long Covid. This has resulted in public controversy<sup>47</sup> regarding the prevalence and severity of impact of paediatric Long Covid.
25. Notwithstanding the discrepancy between the metrics of the datasets, the figures show that a sizeable, and growing number of CYP are experiencing long-lasting symptoms following infection from SARS-CoV-2. In comparison to other long-term paediatric diseases, the RCPCH's website's latest figures note that 36,000 CYP under the age of 19, across all four nations, suffer from childhood diabetes and 112,000 CYP under the age of 19, across all four nations, suffer from epilepsy.<sup>48</sup> Long Covid is clearly a significant new paediatric disease.<sup>49</sup>
26. The data available to inform education policy was also inconsistent with national datasets. The primary source of data for education policy was derived from the Schools Infection Survey, which investigated the role of schools in the spread of SARS-CoV-2 from 2020 to 2022, concluding that infection rates within schools were lower compared to the wider community, echoing the findings of Professor Viner's earlier paper.<sup>50</sup> However this conclusion was inconsistent with ONS' data from the Covid-19 Infection Survey based on random community household surveillance, which found that infection rates were often highest when schools were open.<sup>51</sup> The SIS conclusion has been criticised for being conducted at a time when attendance,

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<sup>46</sup> E.g. [INQ000530232/3 § 11e]

<sup>47</sup> [INQ000622769/3]

<sup>48</sup> RCPCH, State of Child Health, Diabetes (<https://stateofchildhealth.rcpch.ac.uk/evidence/long-term-conditions/diabetes/>) and Epilepsy (<https://stateofchildhealth.rcpch.ac.uk/evidence/long-term-conditions/epilepsy/>)

<sup>49</sup> The RECOVER study found that Long Covid is common, affecting up to 10-20% of CYP with a history of Covid-19 infection, which is higher than the number of children with asthma [INQ000651361/1].

<sup>50</sup> [INQ000542938]

<sup>51</sup> [INQ000074951/2-3]

and therefore infection rates, were low, therefore artificially lowering the rate of viral outbreaks in educational settings.<sup>52</sup>

27. In relation to the monitoring of Long Covid for education policy, the evidence currently before the Inquiry suggests that government bodies did not seek data collection from schools on the incidence, impact and absences caused by Long Covid to inform education policy. For example, whilst UKHSA and the DfE used a specific code to record SARS-CoV-2 infection related absences from school, it appears that no specific code for Long Covid was created, even though this was raised by DfE in May 2021 as a data blind spot.<sup>53</sup> None of the Rule 9 statements from the spotlight schools address Long Covid, or suggest that data on the impact of Long Covid amongst pupils was collected in a formal or informal capacity. On occasion, institutions independently collected data on rates of Long Covid in adults (for example, in a CYP secure home) but failed to collect the equivalent data for CYP.<sup>54</sup> The evidence provides no explanation for this omission.
28. Similarly, the Government departments responsible for education in the four nations did not require schools to identify or monitor Long Covid amongst pupils, in order to better understand its impact in educational settings. Indeed, the evidence of Professor Sir Chris Whitty makes plain that for central Government, Long Covid was *not* a factor when considering NPIs around school closures,<sup>55</sup> even when its nature, prevalence and impact on CYP was accepted and understood.
29. In conclusion, there was inadequate data collection and monitoring of paediatric Long Covid, so that the true position could not and did not inform policy decisions. As Professor Jimmy Whitworth and Dr Charlotte Hammer, surveillance and infectious disease control experts in Module 1 concluded, “*surveillance also needs to include longer term sequelae, such as Long Covid.*”<sup>56</sup>

### ***Policy Decisions on the Provision of Safe Education***

30. The Prime Minister, the CMO and the Secretary of State for Education have made clear that their approach to NPIs in educational settings was led by the priority of “*keeping children in*

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<sup>52</sup> [INQ000272179]

<sup>53</sup> E.g. [INQ00075800] [INQ000553811] [INQ000542722 §§6-7] and [INQ000622769/5]

<sup>54</sup> [INQ000561310]; [INQ000561253/1]

<sup>55</sup> [INQ000588046/63 § 5.14]

<sup>56</sup> [INQ000196611/38 § 98]

*school.*<sup>57</sup> This meant, however, that there was inadequate consideration of keeping schools *safe* from viral transmission. The incorrect assumption that schools were not significant sites for transmission, that CYP played a minimal role in overall transmission, and would not be physically harmed by the virus themselves underpinned the policy response despite these assumptions being contrary to the repeated advice from SAGE.<sup>58</sup> The debate between opening and closing schools is a false dichotomy. Policy makers should have ensured the reopening of schools *safely* to avoid a parent having to choose between the education and the health of their children.<sup>59</sup>

31. LCK advocated for the implementation of IPC mitigation measures to improve the viral safety of educational settings. This included air filtration using HEPA air cleaners and improving ventilation supported by CO2 monitoring. Specifically:

31.1 In January 2021 as part of Parents United, LCK raised concern with the Government that schools were being reopened without Covid-safe mitigation measures such as ventilation and air filtration systems in place.<sup>60</sup>

31.2 In March 2021 LCK highlighted the need for testing systems to be more accessible for children and requested that funding be released to commission research into the impact of infection on children.<sup>61</sup>

31.3 In April 2021, in collaboration with Safe Ed for All, LCK raised concern about the risks of viral transmission in schools with the Secretary of State for Health and Social Care, Matt Hancock, calling for urgent mitigation measures.<sup>62</sup>

31.4 In May 2021 LCK wrote to the Secretary of State for Education, Gavin Williamson, again raising concern about the absence of mitigation measures in schools.<sup>63</sup>

31.5 In July 2021 LCK wrote to the Secretary of State for Health and Social Care, Sir Sajid Javid, to ask for mitigation measures to be taken to reduce exposure to infection such as the reinstatement of facemasks in schools and the funding of CO2 monitors and HEPA filters.<sup>64</sup>

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<sup>57</sup> [INQ000588024/13 § 16], [INQ000255836/107 § 397], [INQ000588046/63 § 5.14]

<sup>58</sup> E.g. [INQ000089720/101]; [INQ000089720/409]; [INQ000089720/416]; [INQ000089720/474]

<sup>59</sup> [INQ000588023/22 § 71]

<sup>60</sup> [INQ000272147]

<sup>61</sup> [[INQ000272148]

<sup>62</sup> [INQ000272150]

<sup>63</sup> [INQ000272151]

<sup>64</sup> [INQ000272152]

- 31.6 On 10 March 2022 LCK again emphasised the urgent need for improved ventilation in schools, and ongoing testing to better protect CYP in schools.<sup>65</sup>
- 31.7 On 1 April 2022 CYP with Long Covid wrote letters to Boris Johnson of the impact of Long Covid. The letters were prefaced by “*We are calling for Improved air quality in education settings for prevention, health and well being*”, “*Clean air for improved healthcare outcomes*” and “*Health and well being in the heart of education.*”<sup>66</sup>
32. By at least May 2021 the DfE were aware of and indeed discussed (i) the fact that CYP suffer from Long Covid, (ii) LCK’s advocacy for robust aerosol transmission mitigation and for greater public awareness of the risk of Long Covid, and (iii) ONS prevalence estimates on paediatric Long Covid.<sup>67</sup> The importance of IPC mitigation measures was also advised upon by the TFC from summer 2020, but the Government was nonetheless slow to respond.<sup>68</sup> For example, all schools were promised CO2 monitors by August 2021, one year after SAGE advised on the utility of improved ventilation and warned of poor ventilation in school settings<sup>69</sup>, however there was a delay in delivery and a failure to provide training on their use.<sup>70</sup> Further, LCK’s input was not sought in stakeholder groups focused on children’s rights, such as DfE’s Stakeholder group. Further, none of LCK’s advocacy for Covid-safe measures was acted upon, or responded to. Decision makers did not ensure the *safety* of schools for CYP.
33. By Spring 2021 the DfE opened schools fully, and the few mitigation measures that were in place, were removed.<sup>71</sup> LCK received reports that the lack of guidance from the Government had resulted in schools refusing to install quality HEPA filters donated by parents.<sup>72</sup> LCKS sent requests to local authorities under the Freedom of Information Act 2000 asking about ventilation, CO2 monitors and air cleaning in schools. The responses they received showed wide disparity between local authorities, ranging from no steps being implemented, to handheld CO2 monitors for staff, to some schools advising open windows and doors.
34. Subsequent studies have shown that the early advocacy by LCK was prescient. The CLASS-Act Study, co-led by experts to the Inquiry, Professor Catherine Noakes and Prof Clive Beggs, and published in June 2023, found a 48% reduction in airborne particulate matter with

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<sup>65</sup> [INQ000238600]

<sup>66</sup> [INQ000272162] (M2 Disclosure)

<sup>67</sup> [INQ000542722]

<sup>68</sup> [INQ000224417/2]

<sup>69</sup> [INQ000250969]

<sup>70</sup> [INQ000075591]; [INQ000075761]

<sup>71</sup> [INQ000649219]

<sup>72</sup> [INQ000648039]

HEPA/air cleaning technologies.<sup>73</sup> Professor Jim McManus states *“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.”*<sup>74</sup>

### ***Policy Decisions on the Provision of Equitable Education for CYP with Long Covid***

35. Long Covid significantly impacts CYP’s right to access education; it affects CYP’s ability to attend and engage in school, and its symptoms also impact CYP’s ability to learn, leading to significant learning losses. In relation to educational attainment, the expert report on the impact of Covid-19 on Educational Provision, Support and Progress concludes that *“unsurprisingly”* data from the COSMO Study shows that Long Covid *“substantially”* impacts scholastic performance and learning outcomes due to its severe limitations on daily activities.<sup>75</sup> The COSMO Study found that *“severe Long Covid is therefore a risk factor for young people’s educational attainment.”*<sup>76</sup> The report conclusively points to lower assessed GCSE grades for CYP with Long Covid and that CYP with Long Covid are more likely to have changed their plans for education and future career. The longer-term developmental and career impact as a result of educational disruption cannot yet be fully known, however the experts’ conclusions clearly point to Long Covid leading to career-altering changes for CYP.<sup>77</sup>
  
36. As above, there is no specific data on national school absences, however LCK’s Attendance and Education Experiences Survey, launched in February 2023, found that Long Covid significantly impacted school attendance. The survey reported that 10.4% of respondents were temporarily absent from school/college and 9.5% were too unwell to be in education at all.<sup>78</sup>
  
37. LCK’s survey also found that 81% of respondents did not require support with their learning before Covid-19 infection, but that 59% now needed support most or all of the time.<sup>79</sup> Long Covid symptoms place an inevitable physical limitation on CYP being able to access education, however the delay in publicly recognising Long Covid has further impeded the

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<sup>73</sup> [INQ000624554]; [INQ000651333]

<sup>74</sup> [INQ000588160/10 § 46]

<sup>75</sup> [INQ000587959/134 § 330]

<sup>76</sup> [INQ000267955]

<sup>77</sup> [INQ000587959/135 §§ 330-333]

<sup>78</sup> [INQ000588023/27 §§ 85-88]

<sup>79</sup> [INQ000588023/51 § 164]

ability of CYP disabled by Long Covid to access reasonable adjustments under the Equality Act 2010 in order to exercise their right to education. A paper from Disabled Students UK shows that the number of UK students with a declared disability has increased by 46%, with Long Covid adding to this figure.<sup>80</sup> Families have complained of further struggles to access support, of having to battle to obtain or defend the diagnosis of Long Covid, and of battles to access Education and Health Care Plans due to ambiguous eligibility criteria and an ongoing lack of awareness and acceptance of Long Covid. Long Covid has exacerbated existing inequalities in access to education.

38. There has been no evidence provided to the Inquiry that the known, long-term, disabling symptoms of paediatric Long Covid were considered and translated into national guidance for educational institutions on supporting CYP with Long Covid to access education during the relevant period.<sup>81</sup> The DHSC recognised, in a letter sent to LCK, 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,*”<sup>82</sup> but this has not been the reality for CYP with Long Covid. For the first time in 2025, five years after SARS-CoV-2’s onset, the DfE’s key research areas now include “*what works best in mitigating the adverse impacts of serious or prolonged ill-health (including long-covid) on educational achievement? What educational support is offered to children who have serious or long term ill health and how effective is that support.*”<sup>83</sup> A key question for the Inquiry is why it has taken 5 years to ask this and why, in the meantime, have CYP with Long Covid been left without adequate educational support.

### ***Inaccessible and Insufficient Paediatric Healthcare***

39. Decision makers’ failure to take a *preventative* approach to CYP health has resulted in ineffective, and often inaccessible, *provision* of healthcare to CYP. The approach to the provision of healthcare for Long Covid has differed widely across the four nations, with there being no dedicated CYP Long Covid clinics in Scotland, Wales or Northern Ireland during the Relevant Period<sup>84</sup>, and the number of services in England now being reduced.<sup>85</sup> This has resulted in inequitable access to healthcare for CYP with Long Covid across the four nations,

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<sup>80</sup> [INQ000591922]

<sup>81</sup> [INQ000280195/10 § 37]

<sup>82</sup> [INQ000272164]

<sup>83</sup> [INQ000610931/20]

<sup>84</sup> NHS Grampian opened a CYP service in March 2024 and NHS Lothian opened one in January 2025. However, as with CYP services in England, LCKS understands that they are risk of closure due to uncertain funding.

<sup>85</sup> [INQ000588023/46 §§ 150-156]

meaning that the only a small minority of paediatric Long Covid sufferers have accessed healthcare to date.<sup>86</sup>

40. The physical health impacts of paediatric Long Covid will place a long-term burden on public health services, as well as young people themselves. A large-scale U.S. study under the RECOVER initiative reviewed electronic health records from over one million CYP. It shows that CYP who had a SARS-CoV-2 infection had significant increased risk in developing post-acute cardiovascular outcomes including hypertension, ventricular arrhythmias, myocarditis, heart failure, cardiomyopathy, cardiogenic shock, thromboembolism, chest pain and palpitations.<sup>87</sup> It estimates approximately 5.8 million children in the US potentially affected, more than asthma the most common chronic health problem in children.<sup>88</sup>
41. Other known outcomes include growing evidence that CYP are at increased risk of developing Long Covid following reinfection.<sup>89</sup> Studies show that each reinfection may carry its own cumulative potential for harm. Lived experience from LCG members is that repeat infections trigger symptom flare-up, new symptoms and/or a further deterioration in health.<sup>90</sup> Instead of taking a long-term view to the provision of effective paediatric care for a new childhood disease, current services in the UK are being reduced, and funding is being cut. Insufficient resource has been mobilised into research and care pathways for CYP with Long Covid.

*Most respondents who spoke about having long COVID said they felt, and still feel, that the illness is not understood enough by medical professionals, and they did not receive the help they needed. One said they felt as though they were: “ignored and left to rot by the people who make policy decisions” and “ignored by medical professionals” (age 19). Another respondent with long COVID similarly felt they were “ignored” and felt that doctors “still don’t [understand long COVID] and I have to work it out for myself” (age 12).<sup>91</sup>*

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<sup>86</sup> [INQ000421758/18 § 47]

<sup>87</sup> [INQ000651361/1]

<sup>88</sup> [INQ000588023]

<sup>89</sup> [INQ000588160/10 § 46]

<sup>90</sup> [INQ000588023/33 §§ 108-111]

<sup>91</sup> Scottish Covid-19 Inquiry ‘Lets Be Heard: Voices of Children and Young People’ A Case Study. P.222. Available online at: <https://www.covid19inquiry.scot/report/voices-of-children-young-people-case-study>

**Question 4: Why were the public, parents, schools and carers not informed of the indiscriminate risk of Long Covid to CYP by public health messaging?**

***A Failure to Warn***

42. Public health officials have a responsibility to “*communicate to the public on health matters in times of emergency.*”<sup>92</sup> Any suggestion that there be public health messaging on the risks of Long Covid in CYP was, however, actively quashed.
43. There has been no central Government public health messaging campaign to inform parents and carers of the indiscriminate risk of paediatric Long Covid. Proactive opportunities to inform the public of the risk of Long Covid to CYP, were missed. For example, DfE guidance provided to parents and carers in January 2022 on the removal of mitigation measures, provided no warning or mention of the ongoing risk of Long Covid.<sup>93</sup> Official statements such as the August 2020 OCMO consensus statement instead emphasised the small risk of SARS-CoV-2 to CYP without balancing with reference to the real risk of long term damage to health. Even by September 2021, when the ONS was regularly publishing prevalence figures on paediatric Long Covid, and months after the CMO had advised the Prime Minister of its significant risk, Dr Michael McBride, CMO to Northern Ireland, continued to publicly minimise the risk of Long Covid in a public letter to parents and carers, “*COVID is a mild self-limiting illness for the vast majority of children. Risk of serious illness or death are extremely low for children. Concerns have been raised about long COVID in children. While work is ongoing to explore long COVID in children, emerging large scale studies indicate that this risk is very low in children and similar to that associated with other respiratory viruses in children.*”<sup>94</sup>
44. Discussions within the Scottish Government’s sub-advisory group on education and children’s issues reveal a similar conscious minimisation of the impact of Long Covid in public messaging “*messaging around Long Covid needs to be balanced, particularly given that other childhood infections (RSV, measles, parafllu) are potentially more problematic, and children are currently not being exposed to these and other illnesses at the same levels as before.*”<sup>95</sup>

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<sup>92</sup> [INQ000410237 §§ 3.3, 3.19]

<sup>93</sup> [INQ000520124]

<sup>94</sup> [INQ000070464]; [INQ000137386].

<sup>95</sup> [INQ000530234]

45. The DfE’s position on public messaging on Long Covid is more complex. In April 2021, DfE discussed the need for “*reactive communications*” on Long Covid with colleagues at PHE and DHSC, “*there may be a role for reactive communications. This is a sensitive area and DHSC will work with PHE and DfE to consider the issue of messaging more broadly.*”<sup>96</sup> In July 2021, two months after a DfE note dated 5 May 2021 noted options for providing key messages on Long Covid,<sup>97</sup> officials “*agreed to start drafting guidance with the aim of publishing to coincide with schools returning in September.*”<sup>98</sup> In August 2021 DfE then downgraded the original decision to issue operational guidance saying “*it is likely that DfE will issue some information to schools through informal routes rather than publishing operational guidance.*”<sup>99</sup> The LCGs are not aware of any formal or informal guidance on Long Covid being issued by DfE. There is no explanation by DfE for this change in position.
46. Further, the 5 May 2021 DfE note described a request by LCK for its “School Awareness Pack” to be distributed to schools and expressed a concern that this “misinformation” could be directly distributed to schools. Given the information vacuum for parents left by DfE and other Government departments and agencies, LCGs consider this criticism to be outrageous. Lay parents of sick children should not have been left in the position of having to offer guidance to schools on how to take a precautionary approach, reduce risk, or identify and support sick children. Further, the basis for the criticism is entirely unexplained in the evidence provided by DfE to date.
47. The DfE, alongside public health colleagues, failed to warn and help parents and carers, even after recognising that patient advocates were discharging Government’s responsibility by providing necessary guidance on a new paediatric disease to schools. The deliberate absence of public messaging has left parents, carers, educators and the general public unaware and unable to identify that CYP were suffering from the long-term physical symptoms of SARS-CoV-2.

## **Conclusion**

48. The longer-term sequelae of SARS-CoV-2 has created a significant new paediatric disease, that continues to alter the lives of a growing number of the UK’s CYP. Previously healthy CYP

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<sup>96</sup> [INQ000283437]

<sup>97</sup> [INQ000542722]

<sup>98</sup> [INQ000283463]

<sup>99</sup> [INQ000283464]

now suffer from developmental setbacks, a reduced ability to enjoy their private and family lives, and persistent physical symptoms that hinder daily functioning. Many CYP face substantial learning losses that impede their academic progress. Those educational losses are often compounded by existing inequalities. These impacts reflect the lasting consequences of a disease that has too often been minimised or dismissed by decision makers. The impact of paediatric Long Covid is profound – it affects all aspects of childhood and interferes with the rights of CYP with Long Covid to education, health, family life as well as the right not to be free from discrimination.

49. The LCGs members, who are the families, parents, teachers and carers of CYP with Long Covid, have been forced to act as patient advocates for vulnerable CYP when the Government watched, waited, ignored and consciously minimised the foreseeable physical harm of Long Covid. The evidence demonstrates that the UK failed to comply with its international legal obligations towards CYP.
  
50. The majority of the LCGs members contracted Covid-19, whether in the initial stages of the pandemic, or in the period thereafter, and a significant proportion continue to endure serious, long-term physical and other debilitating impacts of Long Covid. The Inquiry's investigations therefore have immediate relevance to CYP and their families. It is hoped that lessons can be learnt from the experience of paediatric Long Covid, so that the UK can better prepare for the impacts of a novel paediatric disease now, and in the future, in a manner that centres children's voices and ensures their access to fundamental rights. The LCGs ask the Inquiry to examine why, in the face of a foreseeable paediatric disease, the UK failed to discharge its legal obligations towards CYP in responding to Long Covid.

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**12 September 2025**