

## UK COVID-19 PUBLIC INQUIRY

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### **MODULE 8: JOINT WRITTEN SUBMISSIONS ON BEHALF OF LONG COVID KIDS AND LONG COVID KIDS SCOTLAND**

*Hearing Date – 6 September 2024*

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#### **I. INTRODUCTION**

1. These submissions are made on behalf of Long Covid Kids and Long Covid Kids Scotland (**‘The Long Covid Groups’** or **‘LCGs’**) in advance of Module 8’s first preliminary hearing. The LCGs are support and advocacy charities established by families whose children suffer from the complex and disabling illness known as Long Covid.
2. The LCGs welcome the commencement of Module 8 and its dedication to investigating the distinct impact of Covid-19, and the impact of decisions made in response to Covid-19, on children and young people (**‘CYP’**) across the four nations.
3. These submissions address the following topics on the Agenda:
  - a. Background
  - b. The Provisional Scope of Module 8
  - c. Expert Evidence
  - d. Rule 9 requests
  - d. Disclosure and
  - f. Children and Young People’s Voices

## II. BACKGROUND

4. Long Covid Kids was established in September 2020 by the families of children who did not recover from Covid-19. They have grown to support over 11,000 children, young people, their families and carers. Long Covid Kids Scotland acts under the umbrella of Long Covid Kids and supports approximately 300 families and carers in Scotland. The LCGs' members are children, young people, their parents and carers, whose lives have been transformed by Long Covid.
5. The UK public were told that CYP would suffer only minimal harm from Covid-19<sup>1</sup>, but for some CYP, this was not correct. CYP have lost their health to Covid-19, and some have lost their lives to Covid-19. The LCGs formed to fill a crucial lacuna in information and understanding that Covid-19 can impact CYP. The LCGs raised awareness about the direct impact of Covid-19 on the health of CYP who did not recover and called for a paediatric clinical case definition, public health messaging about the risk of Covid-19 to CYP, and for child-centred healthcare and support.<sup>2</sup> The LCGs also served as a “*life raft*” for affected families who were unable to access adequate support and care and understanding.<sup>3</sup>
6. The scale and span of Long Covid's ongoing impact on CYP is sizeable.<sup>4</sup> Long Covid is indiscriminate in nature, and as a result a considerable proportion of CYP in the UK suffer from its debilitating symptoms. The latest available statistics indicated that as of March 2024 there were over 55,000 CYP in England and Scotland alone suffering from symptoms that persisted for at least 12 weeks.<sup>5</sup> Long Covid has been defined by the WHO as presenting “*with a wide range of symptoms*” in CYP and having “*an impact on everyday functioning such as changes in eating habits, physical activity, behaviour,*

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<sup>1</sup> [INQ000070434]

<sup>2</sup> [INQ000280195] at §18.

<sup>3</sup> [INQ000280195] at §21.

<sup>4</sup> In addition to Long Covid, some CYP suffer from PIMS as well. The LCGs work closely with the PIMS Society to collectively advocate for CYP who suffer from all of the physical impacts of Covid-19.

<sup>5</sup> ONS 25 March 2024 Winter CIS. Available online at:

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/sel freportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland>

*academic performance, social functions (interactions with friends, peers, family) and developmental milestones.”<sup>6</sup>*

7. The debilitating nature of Long Covid has devastated children’s childhoods and impeded their development. CYP with Long Covid have suffered twice over; first from the direct physical harm of Covid-19 on their health and secondly from the indirect consequences of the pandemic. These dual harms continue to adversely affect the health, education and day to day lives of a significant number of CYP and have a knock-on effect on their caregivers, and families.
8. The inaccuracy of messaging, and the pervasive misunderstanding of Covid-19’s impact on CYP, has left sufferers carrying the additional burden and stigma of being disbelieved and disparaged,<sup>7</sup> whilst also reckoning with the impacts of their illness.
9. The LCGs welcome Module 8 as the forum where the impact of Long Covid on CYP will be properly scrutinised to inform recommendations for the safeguarding of all CYP, not only for a future pandemic, but also for the present and ongoing response to Covid-19.

### **III. THE PROVISIONAL SCOPE OF MODULE 8**

10. The LCGs are grateful for CTI’s clarification (§13, CTI Note) that Module 8 will investigate the past, current and ongoing impact of Covid-19 and its associated measures, on CYP. CYP continue to develop Long Covid following infection from Covid-19, and continue to suffer from its ongoing physical, social, educational and developmental impacts.
11. In view of the devastating and direct harm caused to CYP from Covid-19, Long Covid should be investigated as an important thread through all aspects of this Module. Whilst

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<sup>6</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>7</sup> Connor, C et al ‘*A critical analysis of UK media characterisations of Long Covid in children and young people*’, April 2024. Available online at: <https://www.medrxiv.org/content/10.1101/2024.04.13.24305152v1>

it is understood that the scope is necessarily provisional and to be seen as a *'flexible framework'* at this stage (§25, CTI Note), the LCGs anticipate that the impact of Long Covid will be explored under all topics in scope. For example, a thorough investigation of the impact of Long Covid on CYP requires an investigation into:

- a. the extent to which the impact of both the acute and long-term sequelae of a novel disease on CYP were considered as part of any preparedness and planning for a pandemic,
- b. the extent to which the indiscriminate risk of Long Covid in CYP was considered by the UK Government and the Devolved Administrations in respect of the application of NPIs,
- c. the impact of Covid-19 and its associated measures on the education and early years provision of CYP with Long Covid,
- d. the impact of Long Covid on CYP's physical, mental health, wellbeing, development, family lives and on their access to healthcare services,
- e. the impact of Long Covid on CYP's ability to engage with and access social care services and support from other agencies,
- f. the impact of Long Covid on CYP in contact with the criminal justice system,
- g. the impact of Long Covid on CYP in contact with the immigration system,
- h. the impact of Long Covid on CYP's ability to access, and reliance on, the internet, social media and online resources.

12. Long Covid cannot be artificially siloed as a discrete issue to be investigated given its pervasive impact on all CYP, and on all aspects of CYPs' lives.

13. The LCGs welcome the confirmation that Module 8's investigations will be child-centred, by avoiding comparison to adult experiences, and by focusing on the specific and distinct experience of CYP. CYP experience illness and disability differently to adults. Their healthcare needs differ to that of adults.<sup>8</sup> One crucial example is

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<sup>8</sup> Carter et al *'The Concept of Child-Centred Care in Healthcare: A Scoping Review'*, March 2024. Available online at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10885088/#:~:text=Child%2Dcentred%20approaches%20recognition%20that,underpins%20the%20approach%20%5B2%5D> and Scott, H et al *'Implementation of child-centred outcome measures in routine paediatric healthcare practice: a systematic review'*, July 2023. Available online at: <https://hqlo.biomedcentral.com/articles/10.1186/s12955-023-02143-9>

considering the prevalence of paediatric Long Covid. Paediatric medicine requires this to be compared against the prevalence of other childhood diseases amongst CYP, and not assessed against the prevalence of Long Covid in adults (a distinct disease).

### III EXPERT EVIDENCE

14. The LCGs agree that the instruction of qualified experts with the appropriate expertise and experience will assist and support the Inquiry's work. The ILT has identified provisionally that expert evidence should be sought on the impact of the pandemic on the mental and physical health of children (CTI § 44(c)). The LCGs note with concern, however, that none of the areas outlined at § 44 expressly includes Long Covid in CYP.
15. At present, the Inquiry does not have the benefit of an expert report on paediatric Long Covid. Module 2 and 3's Long Covid expert report is authored by two experts in adult respiratory medicine.<sup>9</sup> Section 2 of the Long Covid Experts' Module 2 is a brief section on children and adolescents and contains the caveat that the comments on Long Covid in children and adolescents derive from a literature review and discussions with paediatricians only.<sup>10</sup>
16. Crucially, the Long Covid expert reports' conclusions on CYP are not grounded in clinical experience or expertise in paediatric medicine. The Inquiry does not have an expert paediatric analysis of Long Covid. Children are '*not little adults*': the symptomology and presentation of Long Covid in children is different to that in adults, as are the diagnostic processes and care pathways.<sup>11</sup>
17. The Long Covid experts in their Module 2 report explain at § 2.4 that the recognition of long-term sequelae in the paediatric population developed at a much slower pace in

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<sup>9</sup> [INQ000280198/2-3]

<sup>10</sup> [INQ000280198/13 § 2 [INQ000421758/2] It is noted that the experts in finalising their report for M2 consulted with Terrence Stephenson and Roz Shafron and discussed paediatric Long Covid with Dr Terry Segal in preparation for their M3 report. This demonstrates the limitations of adult medicine experts opinion on matters of paediatric medicine.

<sup>11</sup> Van Beusekom, Mary, University of Minnesota '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-undercountedmisdiagnosed-kids>

the UK than the understanding and recognition of the long-term sequelae in adults.<sup>12</sup> The delay in recognising and responding to Long Covid in CYP is well documented. Ensuring that the UK better prepares for and prevents the impact of the long-term sequelae of any future novel disease requires the Inquiry to investigate and make recommendations on paediatric Long Covid.<sup>13</sup>

18. A paediatric expert on Long Covid could assist the Inquiry in understanding:

- a. Why there was a delay in recognising the impact of Covid-19, and specifically of the long-term sequelae of Covid-19, in CYP;
- b. When the longer term health impacts of Covid-19 in CYP were first recognised by clinicians in the UK;
- c. The clinical presentation of Long Covid in CYP and how this differs from Long Covid in adults;
- d. The impact of applying an adult framework to paediatric illness in a pandemic;
- e. How the UK could better approach identifying, monitoring, measuring and responding to the long-term impact of a novel disease on CYP for future pandemics; and
- f. How the current processes for diagnosing, responding to and caring for CYP with Long Covid could be improved.

19. The LCGs have identified four appropriate experts who could fill this evidential gap.

They are:

- a. Dr Terry Segal, consultant in general paediatrics and adolescent medicine at University College Hospital London. She has treated over 400 children and young people with Long Covid.<sup>14</sup>

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<sup>12</sup> [INQ000280198]

<sup>13</sup> Buonsenso, D et al, Preliminary Evidence on Long Covid in Children, January 2021. Available online at: <https://www.medrxiv.org/content/10.1101/2021.01.23.21250375v1.full-text> 3 Brackel, C et al Pediatric long-COVID: An overlooked phenomenon?, June 2021. Available online at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8242715/> 4 Newlands et al, Children and Young People with Long Covid- Comparing those Seen in Post Covid Services with a Non-Hospital Cohort, 7 September 2023 found that by studying children actually seen in Long Covid clinics that “Post-COVID service children have more symptoms and are more severely affected by their symptoms following infection with COVID-19 than children in the CLoCk study” Children | Free Full-Text | Children and Young People with Long COVID—Comparing Those Seen in PostCOVID Services with a Non-Hospitalised National Cohort: A Descriptive Study (mdpi.com)

<sup>14</sup> Dr Terry Segal: University College London Hospitals NHS Foundation Trust ([uclh.nhs.uk](http://uclh.nhs.uk)); publications include Managing post-COVID-19 syndrome (long COVID) in children and young people. Wacks M, Wortley

- b. Dr. Danilo Buonsenso, paediatrician at the Department of Women, Child and Public Health, Catholic University of Rome; Masters in Paediatric Infectious Disease at University of Oxford. He treats children with Long Covid in paediatric clinics.<sup>15</sup>
- c. Dr Carlos Oliveira, Assistant Professor of Paediatrics (infectious Diseases & Global Health) of Biostatics (Health Informatics) and of Biomedical Informatics and Data Science, Yale School of Medicine. He has experience diagnosing and treating Long Covid in children at the Yale paediatric post covid programme.<sup>16</sup>
- d. Professor Peter Rowe, Professor of Paediatrics, John Hopkins Children Centre. He has experience diagnosing and treating Long Covid in children.<sup>17</sup>

20. The LCGs request that the Inquiry instructs a paediatric expert with clinical experience of Long Covid in CYP to bridge the significant gap in evidence on Long Covid in CYP.

#### **IV      RULE 9 REQUESTS**

21. It is noted that CTI has met with some organisations in preparation for sending Rule 9 requests, and that some Rule 9 requests which are ‘foundational’ to the Module’s investigations have already been sent (§§ 27-28, CTI Note). The LCGs suggest that, in line with § 34 of CTI’s Note, Core Participants be provided with a list of Rule 9 requests that have been sent and those intended to be sent, as soon as practicably possible. This would allow all Core Participants to assist the Inquiry in identifying key gaps in evidence at an early stage.

22. The LCGs wish to confirm their willingness to provide a Rule 9 statement to assist the Inquiry in its investigation of the ongoing impact of Long Covid on CYP.

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E, Gregorowski A, Segal TY, Whittaker E. Arch Dis Child Educ Pract Ed. 2023 Apr 20;edpract-2022-324950. doi: 10.1136/archdischild-2022-324950.

<sup>15</sup> Dr Danilo Buonsenso: <https://www.policlinicogemelli.it/en/doctors/dott-danilo-buonsenso>; publications include: Preliminary Evidence on Long COVID in children Danilo Buonsenso, 2021 <https://www.medrxiv.org/content/10.1101/2021.01.23.21250375v1> ; Viral Persistence in children infected with SARS-CoV-2 current evidence and future research strategies, The Lancet , September

<sup>16</sup> Dr Carlos Oliveira: <https://medicine.yale.edu/pediatrics/profile/carlos-oliveira/>

<sup>17</sup> Professor Peter Rowe: <https://profiles.hopkinsmedicine.org/provider/peter-rowe/2704456>

## **V DISCLOSURE**

23. It is noted that disclosure is hoped to begin in Spring 2025 (§37, CTI Note) ahead of public hearings in Autumn 2025 (§14, CTI Note). At this stage, the LCGs raise concern that this is unlikely to be sufficient time for Core Participants to properly review disclosed materials in order to be of effective assistance to the Inquiry. It is also noted that this affords significantly less time for Core Participants to review disclosure than previous modules have.
24. The LCGs experience from previous modules (Modules 2 and 3) is that early disclosure has enabled the active participation of lay clients from Core Participant groups and enabled Core Participant teams to feed into and assist the Inquiry from an early stage in their investigations. This is all the more so in this module where client groups consist of parents, carers and unwell children, and so require further measures to be taken to facilitate their understanding and involvement.
25. The LCGs understand that the Inquiry will be receiving and processing a significant volume of disclosure and simply ask that disclosure is provided to Core Participants as early as is practicable.

## **V CHILDREN AND YOUNG PEOPLE'S VOICES**

26. The LCGs commend the Inquiry's efforts to engage directly with young adults who were under 18 at the time of the start of the Covid-19 pandemic (§45, CTI Note) through ESM, and with 600 CYP through the targeted research project conducted by Verian. CYPs voices must be heard as central to this Module's work.
27. The recognition of the need to investigate the impact of the pandemic on CYP with Long Covid under (2)(f) of the Key Lines of Enquiry ('KLOE') for the ESM is welcomed. The LCGs hope that both the ESM and the Verian research project will ensure that a sufficient cross-section of the experiences of CYP with Long Covid are sought under each head of the KLOEs, so that their difficult and diverse experiences can be recorded as part of the Inquiry's record of evidence. Several of the CYP



represented by the LCGs now suffer from new disabilities, borne from Long Covid, and it is hoped that both the ESM and research project will make reasonable adjustments to ensure their participation in these important evidence-gathering projects.

28. As set out at § 7 above, the impact of the pandemic on CYP with Long Covid extended beyond the physical harm of the virus on their health, it affected their social wellbeing and education. Decisions made in response to Covid-19 frequently aggravated rather than alleviated their suffering. The experience of CYP with Long Covid relates to all areas of investigation in this module and must be considered across all of the KLOEs. Specifically, the LCGs suggest the following additional KLOEs to ensure that the experiences of CYP with Long Covid are captured:

- **Section 1 – Impact of education closures and disruption as a result of the pandemic on CYP**
  - Long Covid: recognition, absences and support including reasonable adjustments for attendance, attainment and development. There is extensive evidence on the significant impact that Long Covid has on education. All surveyed members of the LCGs reported disruption to their education. The Long Covid in Children and Young People Education Experiences and Attendance Survey was submitted as evidence to the Department of Education’s Inquiry into School Attendance, 2023.<sup>18</sup> This found that 69.2% of Respondents reported that their education status had been affected in some way by infection from Covid-19. Changes in education status include a significant reduction in hours as well as having to leave education altogether. The survey found that a child with Long Covid would lose an average of

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<sup>18</sup> Long Covid in Children and Young People (CYP) Education Experiences and Attendance Survey’ and this evidence was submitted evidence to Department of Education’s Inquiry into School Attendance (2023). This found that 69.2% of respondents reported that their education status has been affected in some way by infection from Covid-19. Changes in education status include a significant reduction in hours, leaving education entirely and the implementation of a new provision of hybrid or home learning by the Local Authority. The survey found that a child with Long Covid will lose an average of 20.6 learning hours per week and when scaled up to the total respondents of this survey it is 171,882 lost learning hours per year. **40.2%** of respondents thought that the school lacked an understanding of the impact that Long Covid has had on their child or young person’s education and a further **25.9%** have experienced pressure from schools to send their child or young person to school when they have been unwell. **81%** of CYP did not require support with their learning before COVID-19, since covid **59%** need support most or all of the time.

20.6 learning hours per week, which amounted to a total of 171, 822 hours of lost learning per year when scaled up to the total number of survey Respondents. The learning and development of CYP with Long Covid varied widely and depended on the individual education providers' understanding of Long Covid, as well as their willingness to support the family. This is a crucial KLOE.

- (f) Covid-measures in education: The LCGs suggest that this be amended to read '*Current Covid Measures in education*'. Covid-19 continues to be transmitted, and CYP continue to develop Long Covid. One KLOE should be the impact of voluntary Covid-measures such as mask-wearing on CYP, as well as the impact of general protective measures such as improved ventilation in schools and public buildings. Members of the LCGs report that CYP who choose to wear a mask to minimise risk experience bullying and other negative responses. CYP with Long Covid can also speak to the impact that improved ventilation and other protective measures have on their ability to safely attend school.
- (g) SEN: The LCGs suggest that this be amended to '*SEND*' for Special Educational Needs and Disability. This falls in line with point 3 of the provisional scope for Module 8.

## **VI CONCLUSION**

29. The Long Covid Groups look forward to assisting the Inquiry at all stages of their investigations in Module 8.

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