

UK COVID-19 PUBLIC INQUIRY

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

Hearing Date – 11 June 2025

I. INTRODUCTION

1. These submissions are made on behalf of Long Covid Kids and Long Covid Kids Scotland (the “**LCGs**”). The LCGs represent a sizeable cohort of children and young people (“**CYP**”)¹ who have been disproportionately impacted by *both* the virus, and by the measures put in place in response to the virus. The LCGs were formed to fill a lacuna of information, support and care for children and families rendered newly-vulnerable by this new paediatric disease.
2. The experience of the LCGs’ growing membership demonstrates the scale and extent of the physical, social and developmental harm the virus can, and still, causes:²

¹ The last ONS statistics from March 2024 show that over 1% of children and young people aged 3-17 years were estimated to have Long Covid. It last reported in April 2024 found that 111,816 3-17 years olds in England and Scotland suffered Long Covid of any duration. It reported 65,988 suffered symptoms lasting 12 weeks or more. As a comparator solely on numbers for other childhood diseases, the Royal College of Paediatric health states in regard to “Long Term Conditions” that Epilepsy is estimated to affect 112,000 children and young people in the UK; 36,000 children and young people (defined as under 19) have diabetes.

² In addition to CYP becoming newly-infected with SARS-CoV-2 and developing Long Covid, CYP with Long Covid who become *re-infected* with the virus face an additional risk of Long Covid recurring. A joint survey conducted by Long Covid Kids and Long Covid Support and published in August 2022 surveyed 484 adults and 112 children and young people who had had at least two Covid infections. The survey concluded that of those who were in recovery or remission, reinfection causes a recurrence of Long Covid in 60%. Available online at: <https://www.longcovidkids.org/post/a-world-first-effect-of-covid-reinfection-on-people-living-with-long-covid>

J, age 10, living with Long Covid since November 2021: “No one at school or in health believed me until I ended up in crisis in hospital with a feeding tube. All the doctors asked about was how I see myself in the mirror”. J “was very active and loved to roller skate with her family. Now she needs a wheelchair and can’t walk or attend school. Our whole family are suffering along with her. It’s not fun for anyone.” J “just wants to be back to normal, she is on a lot of medication to help with constant pain, nausea, brain fog and fatigue.”

T, 19 years old, initial infection August 2021, diagnosed with Long Covid September 2021 - “I missed one year of school after completing year 12. I returned to school a year later but couldn’t manage 3 A levels so dropped 2 subjects. I now have one A level and would like to go to University but I am unable to at the moment because my Long Covid illness is hampering my ability to obtain the necessary qualifications to be accepted on a university course.” On what public messaging they saw about Long Covid: “None before I was ill and I don’t remember seeing anything since.”

3. Whilst previous Modules explored aspects of the impact of Long Covid on adults, they specifically did not delve into Long Covid’s impact on CYP, deferring that issue to this, the Children’s Module.³ The LCGs look forward to participating in Module 8, the only module of the Inquiry in which the distinct impact of Covid-19 and Long Covid on CYP will be investigated.
4. The LCGs wish to emphasise four points at the outset.
5. **First**, contrary to the narrative adopted by Government decision makers and others, CYP do suffer significant physical harm from SARS-CoV-2, both from acute infection and from Long Covid.
6. **Second**, the evidence to date demonstrates that there has been a deliberate minimisation of the harm caused by Long Covid generally but in particular, in relation to the harm caused to children. This can be seen by the approach taken by the former Prime Minister,

³ Transcript Module 2, First Preliminary Hearing, 31 October 2022 [p.93 l.5-22]; Transcript Module 2, First Preliminary Hearing, 31 October 2022 [p.168 l.19 – p.169 l.16]

Boris Johnson,⁴ and also by the uncorrected comments of others such as the OCMOs in relation to the opening of schools and other places of childcare.⁵ Our clients have experienced how disbelief and minimisation adversely impacted the health of children with Long Covid.

7. **Third**, it is therefore vital that this Inquiry does not repeat the mistake made by the Governments of the four nations, all of whom took a divergent approach to Long Covid⁶ by stating the incorrect assumption that Covid is benign for CYP⁷ and that any future virus will be the same. The CYPs afflicted with Long Covid (and their parents and carers) are looking to this Inquiry for answers and for meaningful and robust recommendations for future pandemics.
8. **Fourth**, you will hear evidence that the UK Government and other decision makers did not take into consideration the needs, experiences and best interests of children. It is our clients' submission that the best interests assessment necessarily includes the right of the child to the highest attainable standard of health.⁸ In scrutinising decision making the Inquiry must ask questions about the apparent failure to prepare for a new childhood disease, respond to emerging evidence of sick children, school attendance for sick children, the guidance to schools and others, IPC in schools,⁹ the communications and warnings to parents, and centre the voices of the children harmed.
9. It is simply not good enough to say that a minority of children are adversely affected or that compared to adults the risk was less – there is no other paediatric disease in the world where prevalence is compared to adults and the Inquiry must be very careful not to fall into the error of comparing children to adults.¹⁰

⁴ [INQ000399540 § 4.1], [INQ000255836/191], [INQ000165938], [INQ000251910/9] (Module 2 disclosure)

⁵ [INQ000070464] (Module 3 disclosure)

⁶ [INQ000532401/28 §§ 73-75]

⁷ [INQ000532401/26 § 68]

⁸ UN Convention on Rights of a Child, Article 24

⁹ Long Covid Kids and Long Covid Scotland endorsed Clinically Vulnerable Families' request for an IPC expert in educational institutions see joint letter dated 27 March 2025

¹⁰ Van Beusekom, 'Not Little adults: Experts say Long Covid undercounted, misdiagnosed in kids' (2023). Available online at: <https://www.cidrap.umn.edu/covid-19/not-little-adults-experts-say-long-covid-undercounted-misdiagnosed-kids>

10. With those matters in mind, these submissions address the following topics on the Agenda:
- a. List of Issues
 - b. Rule 9 Requests and Evidence on Long Covid
 - c. Expert Witnesses

II. LIST OF ISSUES

11. The LCGs have two broad concerns about the current draft of the List of Issues.
12. **First**, the LCGs welcome the investigation of Long Covid as a principal impact of the pandemic upon the physical health of CYP (LoI § 4D). The impacts continue to emerge. For example, a recent study confirmed that Long Covid in children can lead to new onset diseases such as diabetes and alterations in the immune system.¹¹ Importantly, however, SARS-CoV-2 has a more general impact on the physical health of CYP which should not be minimised (CTI Note § 25D and § 26A). The evidence of this is also continuing to emerge. For example, a recent US study analysing data from the electronic healthcare records of over 1 million children from 19 children's hospitals between March 2020 and September 2023 found that children and adolescents with prior SARS-CoV-2 infection are at a statistically significant increased risk of cardiovascular outcomes.¹² The LCGs are concerned to ensure that their experience of ongoing suffering from a disabling, complex, multi-organ new disease is not minimised by the same Inquiry tasked to investigate their suffering.
13. **Second**, Long Covid must not become siloed in the Inquiry's analysis. Long Covid impacts *all* aspects of children's lives and development (CTI Note § 25 D) and so any scrutiny of the impact of Long Covid must take a holistic approach. Acknowledging the extent of the physical and developmental harm of Long Covid is a key starting point for Module 8's investigations, but Long Covid cannot only be investigated as a discrete issue under the header of 'physical health.'

¹¹ Ewing et al 'Long COVID clinical evaluation, research and impact on society: a global expert consensus', April 2024. Available online at: <https://ann-clinmicrob.biomedcentral.com/articles/10.1186/s12941-025-00793-9>

¹² Zhang et al 'Cardiovascular post-acute sequelae of SARS-CoV-2 in children and adolescents: cohort study using electronic health records', April 2025, Nature Communications

14. To ensure the Inquiry’s investigation respects these two points, the LCGs propose the following amendments to the List of Issues:
- i. Paragraph 1 - *Addition* – Whether the physical harm that a potential virus poses to CYP was factored into pandemic planning.
 - ii. Paragraph 1A – *Addition* - Whether the risk of long-term sequelae from a virus was factored into pandemic plans.¹³
 - iii. Paragraph 1B(i) – *Amendment* - What consideration was made for keeping schools *safely* open.
 - iv. Paragraph 2 – *Amendment* - The assessment of NPIs should expressly include consideration of the assessment of decisions in respect of schools.
 - v. Paragraph 3A(xv) – *Addition* – This should include specific measures for (i) clinically-vulnerable CYP and (ii) CYP with Long Covid.
15. The LCGs welcome CTI’s indication that this Module will focus its investigations on grounds of potential importance to future pandemic planning (§ 15). To that end, the LCGs propose the following core lines of inquiry to guide Module 8’s lesson learning from the emergence of Long Covid in children, a new paediatric disease:
- i. Whether in the face of the long-term sequelae of SARS-CoV-2, the Government discharged its legal duties to safeguard children’s right to health and education?
 - ii. How should the Government respond in the future to the potential harm a novel virus poses to CYP?

III. RULE 9 REQUESTS AND EVIDENCE ON LONG COVID

16. Of the evidence disclosed to date in Module 8, there is only a limited reference to Long Covid. The LCGs understand from CTI’s Note that a large number of Rule 9 statements will be disclosed to CPs soon. It is hoped that key questions on Long Covid have been

¹³ The LCGs note that the Inquiry’s Module 1 report ‘*The resilience and preparedness of the United Kingdom*’ did not specifically reference the UK’s preparedness for the long-term sequelae of SARS-CoV-2 and there are no recommendations relating to the need to prepare for the consequence of long-term illness from a novel disease. This is despite the LCGs corresponding directly with Module 1’s ILT on 26 April 2023 with reference material on the foreseeability of the long-term sequelae of SARS-CoV-2. Module 8 therefore offers the only opportunity for the Inquiry to investigate the UK’s preparedness for Long Covid, in order to provide meaningful recommendations on preparation for a future, novel virus.

put to relevant decision makers so that their witness statements in response squarely address issues of Long Covid.

IV. EXPERT EVIDENCE

17. The Inquiry has now disclosed the first of three expert reports and the LCGs note with concern that the draft child development expert report did not make any reference to the developmental impact of Long Covid, despite assurances by ILT in a meeting on 14 March 2025 that this would be covered.
18. As matters stand, Module 8 lacks an evidential baseline on paediatric Long Covid from which to conduct its investigation. Whilst Modules 2 and 3 did benefit from an expert report on Long Covid in adults from Professor Brightling and Dr Evans,¹⁴ the reports caveated that the authors lacked specific paediatric expertise.
19. Only a paediatric expert report on Long Covid can provide expert analysis on why there was an additional delay in recognising paediatric Long Covid, further to the delay in recognising Long Covid in adults.¹⁵ It would also resolve the question of prevalence of paediatric Long Covid, recognising that prevalence of a disease is an important metric used to inform public health decision-making. The LCGs are concerned that the prevalence of Long Covid in CYP has often incorrectly been compared to the prevalence of Long Covid in adults, instead of by comparison to other significant paediatric diseases. The LCGs look to a paediatric expert to resolve such questions on how and when the impact of the long-term sequelae of a novel disease on CYP should be recognised, and on how the impact and scale of paediatric Long Covid should be quantified and considered by decision makers.
20. As detailed above, Module 8 is the sole platform where the Inquiry can determine the actual scale of impact of paediatric Long Covid and can make recommendations to

¹⁴ [INQ000380198] and [INQ000421758]

¹⁵ [INQ000280198/14-15 § 2.4] and The WHO developed a clinical case definition of Long Covid in adults in October 2021 (https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1), yet it was only in February 2023 that WHO developed a clinical case definition for Long Covid in children and adolescents.

prevent widespread disabling ill-health from a novel paediatric disease in a future, different pandemic, as well as ensure an adequate response to the new paediatric disease of Long Covid. A paediatric expert report would be an efficient use of the Inquiry's time and resources as it would reduce the amount of hearing time needed to put questions to otherwise resolve disputes of factual evidence.

V. CONCLUSION

21. The Long Covid Groups remain available to assist the Inquiry with its investigation in Module 8.

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30 MAY 2025