

UK COVID-19 PUBLIC INQUIRY

MODULE 8

CORE PARTICIPANT APPLICATION ON BEHALF OF LONG COVID KIDS AND LONG COVID KIDS SCOTLAND

I. Introduction

1. Long Covid Kids and Long Covid Kids Scotland (“**the Applicants**”) apply for Core Participant status in Module 8 of the Covid-19 Public Inquiry (“**the Inquiry**”) pursuant to Rule 5(2)(a) and (b) of the Inquiry Rules 2006 (“**the Rules**”).
2. The Applicants are support and advocacy charities, established by a group of families whose children contracted Covid-19 and suffered persistent debilitating symptoms resulting in the complex illness and disability, known as Long Covid.¹ Long Covid Kids (Charity number 1196170) was set up in September 2020 and supports some 11,000 children, young people and their families. Long Covid Kids Scotland (Charity number SC052424) is under the umbrella of Long Covid Kids and supports approximately 300 families in Scotland. Their members include children, young people and their parents and carers.
3. A significant number of Children and Young People (“**CYP**”) have been affected by Long Covid. The latest ONS statistics (released on 25 April 2024, relating to a period from November 2023 to March 2024) show that there are currently an estimated 55,801 children in England and Scotland (defined as 3 to 17 years old by ONS) who have Long Covid and have had symptoms persisting for at least 12 weeks.² CYP with Long Covid suffered the

¹ Pediatric Long Covid has a specific definition: The WHO clinical case definition for post-COVID 19 condition in children and adolescents by expert consensus: “[...] children and adolescents present with a wide range of symptoms such as anosmia, fatigue, loss of appetite, headache, anxiety (including school refusal and social anxiety), shortness of breath, chronic gastrointestinal symptoms, rash, food intolerances and allergies, cognitive dysfunction, sensory abnormalities dizziness, nausea”.¹ Additionally, “symptoms generally have an impact on everyday functioning such as changes in eating habits, physical activity, behaviour, academic performance, social functions (interactions with friends, peers, family) and developmental milestones.”

²<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/seifreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland>.

dual harms of both the indirect societal consequences of the pandemic, and the direct injury to their health from Covid-19. Their suffering was arguably compounded by the UK Government's approach to CYP which was described in other modules as *"incoherent"* and *"as a result children were often overlooked, and there were even occasions where it felt that (the Government) was indifferent to children's experience during Covid."*³

4. The Chair has indicated in previous modules of this Inquiry that she would *"investigate fully and properly every – all the impact upon children and young people"* in a dedicated module on the impact of the pandemic on children and young people.⁴ In anticipation of those investigations, the Applicants welcomed the announcement of Module 8 and have considered the Provisional Scope. They note that the Chair proposes to investigate the extent to which CYP were considered in preparedness and planning for a pandemic and in respect of decision-making by the UK Government and Devolved Administrations in relation to the application of non-pharmaceutical interventions as well as the impact of the pandemic on the education and physical and mental health and wellbeing of CYP. The Chair has confirmed that Long Covid would be considered in investigations on *"how decisions were made, communicated and implemented,"*⁵ and that this *"will include investigation of how Long Covid was considered"*⁶ in regards to decisions around NPIs. This necessarily applies to CYP.

5. The Applicants participated in earlier Modules, specifically Module 2 and 3, because of their significant interest, and direct and significant role in relation to decision making by central government on NPIs and the healthcare response to the pandemic. They seek Core Participant status in Module 8 given its specific focus on those decisions in relation to their core constituency, CYP with Long Covid. Through Core Participant status, the Applicants intend to ensure that the voices and distinct experiences of CYP with Long Covid are directly represented in the investigation into the impact of the pandemic on CYP.

³ Module 2, Day 4, 06.10.2023 pg33, ll.25- Day 4, 06.10.2023 4 pg34, ll.3]; [Day 4, 06.10.2023 pg43, ll.10-12.

⁴ Preliminary Hearing Module 2, 31 October 2022 p.93 [11-12].

⁵ Terms of Reference Consultation Summary Report, May 2022 p.18.

⁶ Terms of Reference Consultation Summary Report, May 2022 p.18.

II. Evidence in Support of Module 8 Application

6. The Applicants refer to and submit the following supporting material with their application:
 - 6.1. Witness statement of Sammie McFarland on behalf of Long Covid Kids for Module 2 dated 25 September 2023.⁷
 - 6.2. Witness statement of Helen Goss on behalf of Long Covid Kids Scotland for the Scottish Covid Inquiry dated 19 October 2023.⁸
 - 6.3. Our “Unhappily ever After” (October 2020) to raise awareness that children were also being affected by Long Covid and describing how profoundly life changing and disabling their suffering was.⁹
 - 6.4. Letters from Children with Long Covid to Boris Johnson dated April 2022.¹⁰
 - 6.5. Case studies from Long Covid Kids.¹¹
 - 6.6. Chronology of Advocacy by Long Covid Kids in England¹² and Scotland.¹³

III. Application of Rule 5(2) of the Inquiry Rules

7. The Chair is respectfully invited to grant Core Participant status to the Applicants in Module 8 of the Inquiry pursuant to Rules 5(2)(a) and (b) of the Rules. The Applicants have both (i) played a direct and significant role in the response to the pandemic as it impacted on CYP (engaging Rule 5(2)(a)) and (ii) have a significant interest in the Inquiry’s investigation into the impact of the pandemic on CYP (engaging Rule 5(2)(b)). The Applicants consent to the designation if the Chair is so minded.

i. Rule 5 (2)(a) – A Direct and Significant Role

8. The Applicants are children, young people and their families who became involuntary advocates for the recognition of Long Covid in CYP after finding themselves suffering from the long-term effects of Covid-19 in a lacuna of information and support. Their lived

⁷ INQ000280195 (Module 2).

⁸ <https://www.covid19inquiry.scot/evidence/witness-statement-provided-helen-goss-behalf-long-covid-kids-scotland-lcks-dated-19102023>.

⁹ <https://www.youtube.com/watch?v=RiIambG8vs0>.

¹⁰ INQ000272161.

¹¹ INQ000272174.

¹² INQ000272218.

¹³ Enclosed.

experience of the debilitating and disabling lasting effects of Covid-19 was vastly different to the publicly communicated risks of acute Covid-19 as only minimal to children. When they failed to recover as expected, the parents and carers of children suffering with Long Covid formed organisations to advocate for the recognition of Long Covid in CYP, calling for data collection and surveillance to better understand the nature of paediatric Long Covid and for support and treatment in healthcare, education and other services.

9. As set out in the enclosed Advocacy Chronologies, the Applicants lobbied at the highest level of Governments and have played a direct and significant role in shaping the UK government's recognition and response to CYP with Long Covid:
 - 9.1. They advocated for recognition that paediatric Long Covid is real and that for those suffering children Covid-19 was a serious disease with long term consequences.¹⁴
 - 9.2. From July 2020, the Applicants provided evidence to central government and public health services about the long-term ill-health and disability that Covid-19 was causing to CYP.
 - 9.3. From October 2020, the Applicants participated in monthly Ministerial Round Tables chaired by the Under Secretary of State for Health and Social Care (also attended by NHSE, NICE and on occasion by the Secretary of State for Health and Social Care), sharing their experiences of children with Long Covid.¹⁵ They also attended Ministerial Roundtables held by the UK and Scottish Governments.¹⁶
 - 9.4. From December 2020, the Applicants called for data collection on the impact of Covid-19 in CYP including the need to count Long Covid in children and record the hospitalisation rates for children with Covid-19.¹⁷
 - 9.5. The Applicants spoke directly to Boris Johnson, the then Prime Minister; Sajid Javid, the then Secretary of State for Health and Social Care,¹⁸ Humza Yousaf, the

¹⁴ Long Covid Kids Witness statement INQ000280195 para 26-37; Long Covid Kids Scotland Witness statement SCI-WT0568 para 0.6; see also Long Covid Kids Scotland submission to Scottish Government's Education, Children and Young People Committee on 24 Feb 2022 ([here](#)); In regard to Wales, on 22 June 2022 LCK Kids wrote to the First Minister asking for insight into the Long Covid Expert Group that they have established for a pathway to treat children leading to further correspondence.

¹⁵ Long Covid Kids all participated in the Long Covid Ministerial Roundtables held by the Department of Health and Social Care from 2020. The Ministerial Roundtables were chaired by Lord Bethell, the then Undersecretary of State at the Department of Health and Social Care and were attended on occasion by the Secretary of State for Health and Social Care. Long Covid Kids participated and presented at the Department of Health Roundtable.

¹⁶ UK 23.2.21; 30.3.21; 16.6.21; 21.7.21; 23.9.21; 7.12.21; Scotland 22.11.21; 21.2.22.

¹⁷ INQ000272219.

¹⁸ For example, Roundtable meeting with Sajid Javid 23.09.2021; Meeting with Humza Yousaf 28.6.2022.

then Cabinet Secretary for Health and Social Care, Gavin Williamson, the then Secretary of State for Education, other Cabinet members and the devolved administrations, on the urgent need for mitigation measures in schools, including adequate ventilation and monitoring of Covid-19 transmission, mask mandates, social distancing and remote learning to both protect and prevent Long Covid in CYP and support CYP with Long Covid in resuming education.¹⁹

9.6. The Applicants attended and participated in the NHSE Long Covid Taskforce, and the SIGN consultation to improve decision making in relation to the characterisation, identification, diagnosis and treatment of Long Covid in CYP.²⁰

9.7. The Applicants have been called upon and have given evidence to governmental committees on healthcare decision-making throughout the pandemic including providing evidence on the differing symptomology and prevalence of Long Covid in CYP.²¹

9.8. The Applicants have submitted evidence to the Department of Education's Inquiry into School Attendance, noting the disproportionate negative impact that Long Covid has on CYP's ability to access education.²²

10. The Applicants' advocacy of key decision makers on the need for recognition of CYP with Long Covid in healthcare and education services demonstrates that they played a direct and significant role in the matters under investigation in Module 8.

ii. Rule 5 (2)(b) – A Significant Interest

11. The Applicants are representative organisations of CYP and the parents and carers of CYP with Long Covid. They have a significant interest in the investigations into the impact of the pandemic on CYP given that CYP suffered twice over; first in relation to societal measures in place to limit the pandemic, and also by suffering long-term injury from the virus with the associated consequences for their health, social development and education.

¹⁹ See Annex (Chronology and correspondence with government, PM, MPs etc).

²⁰ Long Covid Kids were a member of the NHSE on Long Covid Taskforce.

²¹ Long Covid Kids gave evidence to the All Party Parliamentary Group - see [report](#) pdf p.16, 18, 19; Long Covid Kids Scotland participating in Cross Party Parliamentary Group for Long Covid 8.9.21; 8.12.21; 9.3.22; 8.6.22; 26.10.22 and briefing note for Scottish Parliamentary Debate on Long Covid 19.5.22.

²² <https://www.longcovidkids.org/post/how-does-long-covid-impact-attendance-and-educational-experiences>.

12. The dual suffering that CYP with Long Covid have experienced has an inevitable knock-on effect on their caregivers, families and households, who had no Government guidance or messaging to help them protect their children from the long-term risks of Covid-19. Given the unique and dual suffering that CYP with Long Covid experienced, the Applicants have a significant interest in Module 8's investigations. They hope that findings will be made that recognise their distinct experiences. Further, they hope that recommendations are made aimed at improving public understanding of CYP with Long Covid now, and to avoid similar suffering from the long-term health impacts of a virus in the Covid-19 pandemic and any future pandemics.
13. The Applicants' significant interest is demonstrated by their advocacy with decision makers on decisions made in response to the pandemic as it affected children with Long Covid. They have compelling and legitimate questions about the extent to which CYP with Long Covid were considered in respect of NPI decision making.
14. A particularly acute area of concern for CYP with Long Covid is the impact of the pandemic upon their education. Children and young people living with Long Covid have experienced enormous disruption to education.²³ The Chair is respectfully referred to the Case Studies (INQ00272174) which sets out that, without exception, all the CYP with Long Covid suffered significant disruption to their education causing loss of attainment, isolation and interference with their social development. Preliminary evidence from LCK's survey shows a child with Long Covid will lose an average of 20.6 learning hours per week, which amounts to 171,882 lost learning hours per year.²⁴ The learning and development of CYP with Long Covid varied widely and was dependent on the individual education providers' understanding of Long Covid and their subjective willingness to support the family. Their collective experience is that education providers fell short. As is detailed in the attached

²³ 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.

²⁴ See footnote 26 above and [INQ00272183/SM41].

chronology, an important aspect of the Applicants' work is centred on minimising the risk of Covid for CYP in schools. The Applicants have a significant interest in the investigation of the Department of Education's policies and guidance about NPIs, mitigations, reasonable adjustments, support and flexible learning, and are concerned to understand the extent to which the risk of Covid to CYP, and the circumstance of CYP with Long Covid, were factored into decisions around the safe provision of education.

15. The CYP with Long Covid have a significant interest in issues going to the impact of the pandemic on their physical and mental health, wellbeing, development, family lives and their access to healthcare. Their interest is significant in that distinct from the general population, they have suffered life changing loss of their health at a young age – the course of their lives are forever changed. They have also suffered the ignominy of being disbelieved and the associated trauma and distress arising from that lack of belief. As CYP they should have been listened to and responded so they could access healthcare – instead they suffered due to a pervasive narrative raising scepticism about Long Covid,²⁵ which was all the more so for paediatric Long Covid. By participating in this Module, the Applicants hope that their experiences will be recognised and recorded to avoid future suffering.

IV. The Effective Participation of the Applicants

16. Core Participants acquire a number of additional rights which can assist the Inquiry in its investigations namely: the right to make opening and closing statements, to make representations in relation to further Rule 9 requests to be put to relevant witnesses, and Rule 10 questions to witnesses called by the Inquiry. These are a significant body of rights which provide scope for the Core Participant to assist the Inquiry by shining a light on issues or topics that might not be immediately apparent on the face of the evidence before the Inquiry.
17. In an Inquiry of this magnitude and breadth, it can be difficult for the Inquiry to identify all relevant issues which can be drawn from the evidence. The assistance of the LCGs in

²⁵ See for example [A Critical Analysis of UK Media Characterisations of Long Covid in Children and Young People | medRxiv](https://www.medrxiv.org/content/10.1101/2024.04.13.24305152v1.full), 15 April 2024 available at: <https://www.medrxiv.org/content/10.1101/2024.04.13.24305152v1.full>.

Module 2 helped identify gaps in evidence in relation to Long Covid and decision-making, and the need for the long-term impacts of the virus to be factored into any balancing exercise taken in decisions in relation to the imposition of and lifting of non-pharmaceutical interventions.

18. The Applicants respectfully submit that they can similarly assist the Chair and her team in their investigations in Module 8 by ensuring that the Inquiry builds an understanding of how and why there was a delay and an unwillingness to recognise Long Covid in children, a delay in monitoring data and surveillance of Long Covid in children, and a failure to consider CYP with Long Covid when decisions were taken that impacted children. As Core Participants, the Applicants can ensure that the voices and experiences of CYP with Long Covid are properly represented in an investigation into this Module's investigation into CYP. Limiting their participation to the provision of witness statements or engagement in Every Story Matters, does not allow the Inquiry to build a picture of the way in which over 55,000 CYP with Long Covid in the UK, and counting, have been and continue to be impacted.

V. Legal Representation

19. If granted Core Participant status, the Applicant respectfully request that Jane Ryan of Bhatt Murphy Solicitors is designated as their recognised legal representative in respect of the Inquiry's proceedings, in accordance with Rule 6 of the 2006 Rules.

VI. Conclusion

20. The Applicants anticipate that if granted Core Participant Status, they could readily assist the Chair and her team in their investigations.

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17 June 2024