

## **COVID-19 PUBLIC INQUIRY**

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### **JOINT WRITTEN SUBMISSIONS ON BEHALF OF LONG COVID KIDS, LONG COVID SOS, LONG COVID PHYSIO AND LONG COVID SUPPORT**

#### **MODULE 3 SECOND PRELIMINARY HEARING**

*Hearing Date – 27 September 2023*

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#### **I. INTRODUCTION**

1. These submissions are made on behalf of the Long Covid Groups - Long Covid Kids, Long Covid SOS, Long Covid Physio and Long Covid Support – in advance of the second preliminary hearing for Module 3.
2. This note addresses the following topics on the Agenda:
  - i. List of Issues;
  - ii. Listening Exercise – Every Story Matters;
  - iii. Expert Witnesses.
3. We are grateful for the comprehensive information shared by the Inquiry Legal Team in advance of this Module 3 preliminary hearing and appreciate that preparations for Module 3 are well advanced. At the outset, we also welcome CTI's clarification at § 26 of the intended meaning of § 10 of the Module 3 provisional outline of Scope.

## II. SUBMISSIONS

### List of Issues

4. The Long Covid Groups welcome the early disclosure of a clear List of Issues which will help focus minds in preparation for Module 3. We recognise that the scope of Module 3 potentially captures a wide range of topics related to healthcare over an extensive two -year period and consequently, the List of Issues are necessarily broadly drafted.
5. Nevertheless, we observe with concern that Long Covid was included at the end of the list in three short paragraphs. Whilst we of course welcome the express references to Long Covid in the List of Issues, we hope the brief reference to Long Covid at the end of the List of Issues is not reflective of Long Covid being an afterthought to the Inquiry's principal investigations. We make three short observations on the List of Issues as they pertain to people suffering with Long Covid:
  - i. Our concerns emanate from the more detailed specification of lines of investigation in other aspects of Module 3, which are not reflected at paragraph 12. We appreciate that this may not indicate any differentiation in the degree of investigation to be carried out. Nonetheless, we observe that further elucidation is helpful to understand the extent and nature of relevant lines of enquiry. We have therefore proposed some amendments which we hope are of assistance to the Inquiry and will ensure there is no misunderstanding of the scope of investigation.
  - ii. As the Chair is well aware, the Long Covid Groups were surprised and disappointed to be refused Core Participant status in Module 4 where the development of therapeutics and vaccines will be investigated. It is noted that in the refusal of Core Participant Status in Module 4, the Chair stated, "*In reaching my decision, I bear in mind that the characterisation and identification of Post-Covid Condition (including Long Covid) and its diagnosis and treatment falls within the provisional outline of scope for Module 3, and that the Applicants have been granted Core Participant status in that Module.*" (§12 of the Notice). We understand from this decision that matters relevant to Long Covid will therefore be properly investigated in Module 3. We ask that the

Inquiry investigate interventions which limit the incidence of and severity of Long Covid; this includes treatments which reduced the risk of Long Covid such as paxlovid and metaformin and anti-virals<sup>1</sup> and the impact of vaccines in reducing the incidence of and severity of Long Covid.<sup>2</sup> We understand from the Chair's decision that these are not matters subject to investigation in Module 4. The Inquiry is urged not to ignore these pressing issues given their immediate relevance to the present situation where there are increasing numbers of Covid-19 cases, and thereby an increased risk of Long Covid. We invite the Inquiry to ensure these issues are properly investigated in Module 3 so that important lessons on the impact of vaccinations and antivirals on Long Covid are not overlooked.

- iii. Finally, we have consistently urged the Inquiry Legal Team to ensure Long Covid is not treated as a stand-alone, discrete issue, but as an important thread underlying the investigation in this Module. The consequence of investigating Long Covid separately and tagging it on to the end of the outline scope and List of Issues, is that an artificial line is drawn between Covid-19 and Long Covid. Long Covid is a long-term chronic or disabling illness *caused* by infection from Covid-19. We ask for reassurance that the Inquiry will not siphon off Long Covid as a discrete matter to be investigated as an adjunct to the rest of Module 3, but rather that it is considered as an intrinsic part of the people's experience of healthcare during the pandemic. We encourage the Inquiry to consider the impact of Long Covid where relevant to other strands of the Inquiry's investigation. For example, investigations in relation to the impact of the

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<sup>1</sup> Xie et al, "Association of Treatment with Nirmatrelvir and the Risk of Post-Covid-19 Condition," JAMA Intern Med 2023 Jun 1; 183 (6): 554-564 [10.1001/jamainternmed.2023.0743](https://doi.org/10.1001/jamainternmed.2023.0743); Bramante et al, "Outpatient treatment of Covid-19 and incidence of post-Covid-19 condition over 10 months (Covid-Out): A multicentre, randomised, quadruple-blind, parallel-group, phase 3 trial," published online 8 June 2023, [https://doi.org/10.1016/S1473-3099\(23\)00299-2](https://doi.org/10.1016/S1473-3099(23)00299-2). See German et al, "Treatment of Long-Haul COVID Patients With Off-Label Acyclovir"; National Library of Medicine April 2023. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10205150/>.

<sup>2</sup> See paragraph 4.5 of the draft report of Professor Brightling and Dr Evans on Long Covid; Notarte et al, "Impact of Covid-19 vaccination on the risk of developing long-COVID and on existing long-COVID symptoms: A systematic review," The Lancet Volume 53, 101624, November 2022 published on 26 August 2022 <https://doi.org/10.1016/j.eclinm.2022.101624>. Krishna et al, "Reduced Incidence of Long Coronavirus Disease Referrals to the Cambridge University Teaching Hospital Long Coronavirus Disease Clinic," Clinical Infectious Diseases, Volume 76, Issue 4, 15 February 2023, pp.738-740. <https://doi.org/10.1093/cid/ciac630>.

pandemic on doctors, nurses and other healthcare staff, should include the impact of Long Covid on those medical professionals.<sup>3</sup>

6. Further to these submissions, we would invite the Chair to include the following limited amendments to the List of Issues:
  - iv. §2 Core decision-making and leadership:
    - i. The extent to which long-term consequences of Covid-19 were considered as part of core-decision making processes.
  - v. §12(a) Definition and diagnosis of Long Covid in adults and children and how it came to be recognised.
  - vi. § 12 (a)
    - i. How Long Covid affects individual's body systems;
    - ii. The response to Long Covid by healthcare professionals; and
    - iii. Public health messaging about the risks of Long Covid.
  - vii. §12 (b) Treatment for and prevention of Long Covid
    - i. How treatment of Long Covid changed throughout the course of the pandemic and what informed the changes, with particular consideration of the guidance on pacing;
    - ii. National guidance on treatment for Long Covid and how it was disseminated;
    - iii. The treatments for acute infections of Covid-19 that reduced the risk of Long Covid such as anti-virals; and
    - iv. The impact of vaccines on the incidence of and severity of Long Covid.
7. As set out above, we ask the Inquiry to consider Long Covid when investigating other relevant areas and provide the following list of inexhaustive examples of where Long Covid is relevant to other strands of Module 3 investigations:
  - i. § 4 (b) Access to and use of Primary Care:
    - i. Long Covid sufferers' access to primary care especially in the early stages of the pandemic
  - ii. § 7(a) Impact of the pandemic on doctors, nurses and other healthcare staff:

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<sup>3</sup> BMA, "Over-exposed and under-protected: the long-term impact of COVID-19 on doctors", July 2023 <https://www.bma.org.uk/media/7318/bma-long-covid-report040723.pdf>

i. the impact of Long Covid

8. We expressly reserve the right to make further submissions on the List of Issues once it is developed further.

**Every Story Matters**

9. We commend the Inquiry's early disclosure of the key lines of enquiry for Every Story Matters and the express inclusion of Long Covid within these lines of enquiry.
10. However the Long Covid Groups are concerned that the current plan to research and review the experiences of children and young people will dilute and depersonalise the experiences of children and young people with Long Covid, who will be hidden in plain sight as a minority group under the crushing weight of the experiences of other children and young people. Children who have suffered life changing long-term harm as a consequence of Covid-19 infection should be afforded a specific opportunity to be heard.
11. Again, we understand that the terms set out at § 38 (a) to (c) of CTI's Note need to be broad at this stage. We anticipate that § 38 (a) includes both the impact of accessing healthcare on Long Covid patients who were hospitalised for acute infections of Covid-19 and the impact of accessing healthcare on Long Covid sufferers in the community who were not hospitalised and had a distinct experience.
12. We request the Inquiry to amend the key lines of enquiry to include the following:
- i. Experiences of having Long Covid;
  - ii. The impact of lack of recognition of Long Covid on people suffering with Long Covid;
  - iii. Experiences of accessing healthcare for Long Covid, including primary and secondary care and the differential experiences of those who were hospitalised for Covid-19 and those who experienced infections in the community.

## **Expert Witnesses**

13. We welcome the confirmation that Professor Chris Brightling and Dr Rachael Evans will be providing an expert report on Long Covid.
14. Further to our correspondence with the Inquiry dated 15 June 2023, we note that CTI's Note at § 24 does not cover paediatric expertise on Long Covid. The first reference in SAGE minutes to the need to understand the long-term effects of Covid-19 arose in the context of reports of a "Kawasaki-like syndrome in children" with a probable link to Covid-19 (§12 and 14 of SAGE 29 on 28 April 2020).<sup>4</sup> We therefore respectfully remind the Inquiry not to overlook the consequences of Long Covid on children. It is evident from Dr Brightling and Dr Evans' report in Module 2 that they are not able to address paediatric long covid and have relied upon discussions with two practitioners. We repeat our request for an expert with expertise on paediatric Long Covid to provide an expert report on this discrete issue. We would welcome the opportunity for a discussion with the Inquiry Legal Team to share our insights on appropriate paediatric experts on Long Covid.
15. On 11 September 2023 the Long Covid Groups received disclosure of Dr Brightling's and Dr Evans' report on Long Covid for Module 2. This helpful report should be disclosed in Module 3. It states that the further report for Module 3 will address Treatment of Long Covid, research, long-term management, their role in advising healthcare systems across the UK on their response to the Covid 19 pandemic and any further lessons learned (p.47). In addition to the outline points at § 24 of CTI's Note and page 47 of the draft Module 2 report, we invite the Inquiry to ensure the following points will be covered by the Long Covid expert reports:
  - (a) Interventions to prevent the incidence of Long Covid:
    - a. Impact of vaccinations on incidence of and severity of Long Covid and effect of vaccinations on existing Long Covid patients;<sup>5</sup>

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<sup>4</sup> Covid-19 infections have been associated with a post-covid-19 outbreak of severe "Kawasaki-like" multi system inflammatory syndromes in children. See Shakeel et al, *Post-Covid-19 Outbreak of Severe Kawasaki-like Multi system inflammatory Syndrome in Children*, Malays J Med Sci, 2021 Feb; 28(1): 109-116/  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7909350/>

<sup>5</sup> Although vaccinations are touched upon at paragraph 4.5 of the draft Module 2 report this important preventative measure should be expanded upon in the Module 3 report which will be considering treatment of Long Covid.

- b. Impact of treatments for acute Covid-19 infections (such as antivirals) on the incidence of Long Covid;<sup>6</sup>
- (b) Surveillance systems for Long Covid in patient electronic health records.

### **III. CONCLUSION**

- 16. The Long Covid Groups remain willing to assist the Inquiry with their investigations at all stages.

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**12 September 2023**

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<sup>6</sup> Xie et al, “Association of Treatment with Nirmatrelvir and the Risk of Post-Covid-19 Condition,” JAMA Intern Med 2023 Jun 1; 183 (6): 554-564 [10.1001/jamainternmed.2023.0743](https://doi.org/10.1001/jamainternmed.2023.0743); Bramante et al, “Outpatient treatment of Covid-19 and incidence of post-Covid-19 condition over 10 months (Covid-Out): A multicentre, randomised, quadruple-blind, parallel-group, phase 3 trial,” published online 8 June 2023, [https://doi.org/10.1016/S1473-3099\(23\)00299-2](https://doi.org/10.1016/S1473-3099(23)00299-2). See German et al, “Treatment of Long-Haul COVID Patients With Off-Label Acyclovir”; National Library of Medicine April 2023. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10205150/>.