

COVID-19 PUBLIC INQUIRY

SPEAKING NOTE ON BEHALF OF LONG COVID KIDS, LONG COVID PHYSIO, LONG COVID SOS AND LONG COVID SUPPORT

MODULE 3 SECOND PRELIMINARY HEARING Hearing Date – 27 September 2023

1. My Lady, as you are aware, I address you on behalf of the Long Covid Groups.
2. I have two preliminary points to make, followed by some procedural points.
3. Overarching my submissions is this one simple point: Long Covid is **a direct** consequence of Covid 19 and must not be syphoned off into a separate investigation. To investigate the pandemic is to investigate Long Covid. With that overarching point in mind I make these short points which I hope assists My Lady:

Vaccines and Therapeutics

4. First, the Long Covid Groups raise, with concern, **a topic that appears to have been raised by other Core Participants, that is the division of the topic of vaccines and therapeutics over Modules 3 and 4. The Long Covid Groups are concerned specifically about** the issue of vaccines and therapeutics in so far as they are significant to the incidence and severity of **Long Covid**. There **is** evidence that vaccines are efficient at reducing the impact of Long Covid on the overall population, and in reducing the harm felt by individuals suffering from Long Covid., matters to be considered in Module 3. Specifically, there is evidence that vaccinated individuals are less likely to develop Long Covid from an acute infection, that vaccines alleviate pre-existing symptoms of Long Covid and that vaccines reduce the overall severity of Long Covid symptoms, **thereby reducing** the overall prevalence of Long Covid in the UK's population.

5. The Long Covid Groups have not been granted Core Participant Status in Module 4, and they have expressed their concern to you. Module 4 covers this topic as a whole and it is noted that the Decision Letter refusing them Core Participant status suggests that the “diagnosis and treatment” of Long Covid falls within the provisional outline scope for Module 3. The Long Covid Groups wish to ensure therefore that the scope for Module 3 will accommodate the use of pharmaceutical interventions, that is vaccines and therapeutics, for the **prevention and treatment** of Long Covid. It is both **necessary and proportionate** that this issue is investigated during the course of the Inquiry. People are continuing to suffer from Long Covid; it endures. The Long Covid Groups seek to understand when and how the Inquiry will investigate how vaccines and therapeutics can best be used to prevent and treat this illness.

CHILDREN AND YOUNG PEOPLE

6. Turning to my second submission, My Lady I am mindful that the experiences of children and young people is one that is close to your heart and you have on several occasions raised the importance of hearing and understanding the experiences of children and young people to your inquiry.
7. The inquiry needs to grapple with the roulette of Covid-19: whilst most children suffer short mild illness, some do not. It is very important that the experiences of the children and young people that suffered from, and in some cases continue to suffer from Long Covid, are not forgotten.
8. As we have said those children suffered the dual harms of the general impact that isolation and the loss of education had during the pandemic, as well as the physiological harms of Long Covid.
9. I refer you to the public testimonies of families, children and young people shared on the Long Covid Kids website. I have two, brief examples to share. One from the perspective of a child, and one from the perspective of their family:
 - a. C, a child **aged 8** said: *“On big days out I now have to use my wheelchair because otherwise I get too tired and I would have an energy crash”*

- b. The family of J, **aged 12**, said: *“his life is unrecognisable now compared to pre-covid. He has spent the last 2 years seeing doctors, visiting hospitals, taking supplements and medication, having physiotherapy and pacing. Covid literally knocked him off his feet.”*
10. I am sure you are cognisant of the profound impact that the sudden loss of health, and enduring disability, have on previously healthy children and young people.
11. We have three requests on behalf of children with Long Covid:
- one that there is proper paediatric evidence
 - second that the list of issues is amended to reflect the investigation into adults **and** children with Long Covid, and
 - third concerns Every Story Matters.
12. Turning to the first point, the expert report of Dr Brightling and Evans, whilst recognising the harm caused by Covid to children that developed into Long Covid, it is candid in its acceptance that those experts are not paediatricians and are not expert clinicians who are hands on and treat children with Long Covid. My Lady, this leaves a gap in the evidence **for this Module of** the Inquiry, which is the absence of a properly resourced paediatric expert opinion. **Children cannot and should not be compared to adults** – their experience is unique, as is their physiology. It is over a year until Module 3 starts and we would reiterate our request on behalf of our clients that the Inquiry instructs paediatric expert on Long Covid. I note this is likely to assist your investigation in the future module on children and education. My instructing team remain very open to meeting the inquiry team to discuss this constructively and offer suggestions.
13. Second, the List of Issues should be amended at paragraph 12 (a) to include “definition and diagnosis of Long Covid in **adults and children.**” I suggest it is important to specify the unique experience of children.
14. Third, in relation to Every Story Matters, 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. As matters stand, children and young people will not be heard either in the hearings or through Every Story Matters. The Long Covid Groups are concerned that those children with Long Covid will be hidden in plain sight as a minority group under the crushing

weight of the experiences of other children and young people. Our clients, Long Covid Kids, have proposed that the Listening Exercise collects accounts from children in a personal manner. As your Lady recognised, children's memories fade, but it seems taking children's accounts whether that is individualised or otherwise, has still not yet happened. Long Covid Kids have further noted that younger children may not have the language to express their experiences and artwork could be submitted instead. Our clients continue to work with the Listening Exercise team and would invite consideration of these proposals.

PROCEDURAL MATTERS

15. My Lady, I will now turn to procedural matters. I have four submissions in regard to the List of Issues, expert evidence and witness evidence.

List of Issues

16. On the List of Issues, we proposed some amendments at paragraph 6 and 7 of our written submissions which we hope are of assistance to the Inquiry and will ensure there is no misunderstanding of the scope of investigation. **We understand from Ms Carey KC's submissions this morning that the List of Issues is iterative and we welcome this approach. At this stage, I raise only this:** Long Covid is at the end of the list of issues and I take no point with this other than to simply ask that 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. This is borne out by the submissions from other Core Participants, (RCN, TUC, CVF), that all refer to their members with Long Covid.

17. The centrality of Long Covid as being a direct harm requires the following **specific** amendments to the List of Issues:

- That the investigation of Long Covid under para 12 includes “**the recognition of Long Covid as a disability**”, as called for by the TUC and Royal College of Nurses, **and “recognition of Long Covid as an occupational health disease.”** This is in line with the approach in other countries like the USA where Long Covid was recognised as a disability under the Americans with Disabilities Act as early as **July 2021.**
- That 4b “Access to and Use of Primary Care” be amended to include Long Covid sufferers’ access to primary care especially in the early stages of the pandemic and

- That 7a “ impact of the pandemic on doctors, nurses and other healthcare staff” be expanded to **expressly include the impact of Long Covid**. I note and commend to your team that compelling report from the British Medical Association “*Over exposed and under protected the long term impact of Covid 19 on Doctors*”, which sets out the brutal impact of Long Covid on doctors as just one example.
18. I invite detailed consideration of the amendments proposed at para 6 of our written submissions regarding further lines of inquiry with Long Covid, which we trust are of assistance to you and the Inquiry Legal Team.
19. My final point on the List of Issues **circles back to my first submission** - that there has been no confirmation that Module 3 will consider treatments, anti-virals and impact of vaccines **in reducing the incidence and severity of Long Covid**. The Long Covid Groups invite the Inquiry to confirm that these pressing issues will be investigated in Module 3, or to confirm that they will be investigated in Module 4.

Expert evidence

20. **We are grateful to the update on the Long Covid expert report outlined earlier this morning and look forward to receiving the Module 3 part of the expert report.** In regard to Professor Brightling’s and Dr Evans’ further report on Long Covid for module 3, we understand that this will address the treatment of Long Covid, research and long-term management of the illness, their role in advising healthcare systems across the UK on their response to the Covid 19 pandemic, and any further lessons learned (p.47). **Whilst it is understood that the Module 3 sections are in the process of being finalised,** we ask that the Inquiry ensure the following points **will also be** covered by the Long Covid expert reports:
- (a) First Interventions to prevent the incidence of Long Covid:
- a. Being (a) Impact of vaccinations on the incidence of, and severity of, Long Covid and effect of vaccinations on existing Long Covid patients;¹

¹ 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 the treatment of Long Covid.

- b. And (b) Impact of treatments for acute Covid-19 infections (such as antivirals) on the incidence of Long Covid;²
- (b) Second, Surveillance systems for Long Covid in patient electronic health records.

Witness Evidence

21. We agree with the Bereaved Families for Justice that there is a need for appropriate witness evidence in this Module from those with lived experience. We note that the BFFJ propose to provide a schedule of families to provide evidence. Our clients have provided an extensive composite statement reflecting the experiences of their members and supporters of thousands, representing the estimated 2 million people that have suffered from Long Covid. We would urge that our clients are also called to give oral evidence. They reflect the diverse experiences of accessing healthcare systems as an individual with Long Covid, from ordinary working families to frontline healthcare workers as represented by Long Covid Physio.

Every Story Matters

22. We would ask that the ESM lines of enquiry are amended to include Experiences of having Long Covid:
- i. The impact of lack of recognition of Long Covid on people suffering with Long Covid;
 - ii. 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.

PRACTICAL SUGGESTIONS

The Long Covid Groups note, with concern, the delays outlined by Ms Carey KC this morning, of certain key Government bodies responding to Rule 9 requests. Specifically, the significant

² 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/>.

delays by DHSC and UKHSA, key to this Module. At this stage we simply share the Inquiry Team's observation that this delay is unreasonable and is unnecessarily delaying the important work of this Inquiry.

The Long Covid Groups also note the submissions advanced by other Core Participants, namely the Bereaved Families for Justice in regard to the hearing timetable. The Long Covid Groups have one simple observation in this regard, which is that the timetable be agile enough to adequately accommodate the number of issues listed as being investigated in the scope, and that there is sufficient time allocated to hear impact evidence from those affected. The Long Covid Groups note that the timetabling of impact evidence was strained in Module 2, and hope that Module 3 will allot sufficient time to properly accommodate the hearing of this important evidence. At this stage and without a clear sense of the number of witnesses to be called, that is all the Long Covid Groups wish to raise about the final hearings.

My Lady, that is all I wish to say, now unless I can assist you any further?