COVID-19 PUBLIC INQUIRY

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

MODULE 3
THIRD PRELIMINARY HEARING

Hearing Date – 10 April 2024

I. INTRODUCTION

1. These submissions are provided on behalf of the four Long Covid Groups ('**LCGs'**), Long Covid Kids, Long Covid SOS, Long Covid Physio and Long Covid Support, in advance of the third preliminary hearing for Module 3.

2. The LCGs are grateful for the updates provided in Counsel to the Inquiry's Note of 13 March 2024 (**'CTI's Note')** and the Module 3 January Update to Core Participants dated 9 February 2024 (**'January Update')**. It is apparent that considerable work has been undertaken by the Module 3 Inquiry Legal Team ('**ILT')** to advance preparation of this Module. These submissions do not address every matter listed on the agenda but focus on the particular points of concern to the LCGs.

II. SUBMISSIONS

3. The LCGs comprise of healthcare workers, patients and carers who have suffered life-changing illness and/or disability as a consequence of infection from Covid-19. Their

experiences of accessing, working for, and receiving healthcare are defined by the overall dysfunction of a healthcare system that was unprepared for a pandemic, resulting in great loss of life and avoidable trauma. The healthcare system was also not prepared to treat the vast numbers of patients with chronic disease and disability from infection, which experts to the Inquiry have stated was a foreseeable consequence of SARS-CoV-2.[1] The healthcare system was equally unprepared to protect healthcare staff from developing Long Covid by providing adequate PPE or ensuring mitigation measures were in place, or to manage and support healthcare staff who did then suffer from Long Covid, those unable to work as a result and those disabled by Long Covid. The LCGs anticipate that this Module will shine a light on how such widespread dysfunction came to endure and offer robust recommendations to remedy these failings.

Draft List of Issues

4. The LCGs make the following three observations on the Draft List of Issues, to assist Inquiry in focusing its areas of enquiry and fulfilling the published aims of this Module.

Treatment of Long Covid (§ 12(b))

5. The LCGs note that the updated List of Issues will only be shared with CPs at the end of Spring and after the third Procedural Hearing. Given the advanced stage of preparation of responses to Rule 9 requests for Module 3, the LCGs reiterate their request for clarification on the Inquiry's approach to (i) exploring the interrelationship between vaccines and the incidence and severity of Long Covid and (ii) the development of therapeutics which reduce the risk of developing Long Covid.

6. In their written submissions for the second Procedural Hearing of 27 September 2023, the LCG's sought confirmation that these matters would be investigated in Module 3. The original request was prompted by the Chair's decision dated 4 August 2023 refusing to grant the LCGs Core Participant status in Module 4 which 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*

[1] Module 2 Public Inquiry Hearings [9/91/1-10] and [9/91/17-23].

granted Core Participant status in that Module" (§12 of the Notice). The LCGs repeat their request that the Inquiry not neglect these issues and that clarity be provided in how they will be explored within Module 3.

7. The impact of vaccines on reducing the incidence and severity of Long Covid is of significant concern to the LCGs. Covid-19 has been, and continues to be, wrongly characterised as a risk only to persons deemed vulnerable. But Long Covid demonstrates the indiscriminate nature of the risks posed by Covid-19 – even the otherwise fit and healthy are at risk of developing Long Covid. It follows that there are an unknowable number of adults and children who were, and continue to be, vulnerable to Long Covid, including those who develop Long Covid after reinfection, having recovered unremarkably from previous infection. This has been acknowledged by witnesses who have already provided evidence in Module 3.[2] The scale of vaccine rollout is therefore of conspicuous importance in reducing the (unknown) incidence of Covid-19, and therefore Long Covid. Decisions on vaccine rollouts, such as limiting the availability to the working age population and imposing fee requirements, continue to have a direct impact on the incidence of Long Covid.

8. The draft List of Issues included treatment of Long Covid at §12(b). A proper investigation into the treatment of Long Covid must include an assessment of whether the indiscriminate nature of Long Covid was factored into decision-making on vaccines. Further, it is submitted that the development of therapeutics for the treatment of Covid-19, which also reduce the risk of developing Long Covid,[3] is an additional issue that falls firmly within the scope of §5(a)(i) of the current List of Issues. The LCGs seek clarification, prior to the publication of the updated List of Issues, that these issues will be investigated within Module 3.

[2] [INQ000410237/65] at § 4.114.
[3] 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; 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.

Preventing the Spread of Covid-19 in healthcare settings (§ 8(d)) and
The Impact of the pandemic on doctors, nurses and other healthcare staff (§ 7 (a))

9. Many of those suffering from Long Covid were healthcare workers: doctors, nurses, physiotherapists, occupational therapists, healthcare assistants, hospital porters and administrative staff who trace their initial infection from Covid-19 to their workplace.[4] The Inquiry propose to investigate RIDDOR reporting requirements for healthcare workers who were infected with Covid-19 (§8(d) LoI), as well as the impact of the pandemic on doctors, nurses and healthcare staff (§7(a) LoI). However, the LCGs note with concern, the Chair's Ruling that *'issues relating to the legal designation of Long Covid as a disability and to the creation of a compensation scheme for workers in the healthcare sector who have long Covid are matters that do not relate to the 'impact of the pandemic on healthcare systems. They are more properly characterised as issues relating to law and policy in the area of state benefits and employment matters and so are not within the scope of Module 3.*[5]

10. As has now been widely reported, Long Covid has a significant impact on individuals' ability to work and support themselves and their family. There is a known heightened risk that healthcare workers are exposed to with SARS-CoV-2, and in turn, the adverse effect that Long Covid has on their ability to work and on the staffing capacity of the healthcare sector is also well known.[6] Any investigation into the impact of the pandemic on healthcare staff must necessarily consider the support, including financial support, provided to healthcare staff in managing long-term illness and disability that has been caused by occupational exposure.

11. Many of our clients risked their lives for their patients. They had inadequate PPE and suffered avoidable occupational exposure. Not only do they suffer the physiological harm of Long Covid, but they are also unable to work, were (and remain) inadequately supported in their employment and did not (and continue not to) have reasonable adjustments made. Some of our clients have had to leave the NHS, their job and the

[4] See for example, BMA survey of doctors with Long Covid revealed that 77% who contracted Covid-19 in the first wave believe they contracted it in the workplace.
[5] Ruling dated 9 October 2023 following the Module 3 Preliminary Hearing on 27 September 2023 §16(a).
[6] [INQ000302497/12].

public service they have given their professional lives to. The All Party Parliamentary Group (APPG) on Coronavirus considered the impact of Long Covid on the workforce finding that "*the UK Government has failed to provide employers with any guidance, funding or support to help manage the impact of Long Covid on the UK Workforce."*[7] The APPG had called on the UK Government to recognise Long Covid as an occupational disease in February 2021 and again in January 2022 noting that the UK was out of step with other European Countries.[8]

12. Any investigation into the impact of Covid-19 on healthcare workers must take into account the support, or lack thereof, for those affected by Covid-19 and those that developed Long Covid. Inherent in this, is an examination of how healthcare staff disabled by occupational exposure to Covid-19 were supported, including through financial support and the provision of employment guidance.

13. The LCGs call for the Inquiry to consider the support provided to healthcare workers who developed Long Covid and to probe the nature and development of discussions on prescribing Long Covid as an occupational disease that were happening by core decision makers within the healthcare sector. The support needed for healthcare workers working at the frontline of a pandemic response – protection from infection as well as support for those infected, both in the short and longer term - is an area which the Inquiry could meaningfully provide guidance and recommendations to ensure learning for the future.

Long Covid Services and Clinics (§ 12(b))

14. Services for Long Covid have varied across the four nations with each taking their own approach in terms of funding, strategy and guiding framework. As set out in their witness statement the LCGs have serious concerns about the adequacy of care for adults and children suffering Long Covid. Further, there was and remains a disparity of

[7] p.7 APPG on Coronavirus, Impact of Long Covid on the UK Workforce, published March 2022 available at: https://shh-uk.org/download/appg-report-on-long-covid/?wpdmdl=16991&refresh=6603e16d557601711530349
[8] *Ibid* at p.8. See also p.34, TUC, Long Covid at Work, published March 2023, available at: https://www.tuc.org.uk/sites/default/files/2023-03/Long%20Covid%20at%20Work%20report%20-%20FINAL%20COLOUR%202.pdf.

services available across and within nations. For example, patients' experience of Long Covid clinics within England varied, and continue to vary widely.

15. The LCGs have consistently raised concerns with central government about the barriers to accessing those specialist services as well as variation in the quality of provision. They anticipate that the Inquiry will make findings as to the inadequacies of those services and will make recommendations as to how this could be improved for future pandemics. The LCGs look forward to hearing how the Inquiry will obtain evidence about referral mechanisms (including rates and delays) to specialist services and the provision of treatment at those services. It may be that an equivalent approach to the spotlight hospitals can be applied to Long Covid clinics. The LCGs remain willing to assist the Inquiry by sharing their insight into the operations of the Long Covid services in the four nations to find a practical approach to drawing out the best evidence on this issue.

16. The LCGs seek to clarify that these three issues of scope, which are fundamental to a proper investigation of Long Covid and the healthcare system, will be covered in Module 3. If the Inquiry do not propose to cover these issues within the purview of Module 3, the LCGs seek confirmation of whether a separate Long Covid specific Module will instead investigate these issues.

Procedural Matters

17. The LCGs raise the following three short procedural points aimed at assisting the Inquiry with its preparation:

Input into Evidence gathering/ Rule 9

18. The LCGs appreciate that preparation for Module 3 is moving at pace and there is a considerable volume of evidence being marshalled to cover the breadth of Module 3 scope. In order to assist the Inquiry, the LCGs have identified further issues and documents relevant to Long Covid to be raised with witnesses, via direct correspondence to the Inquiry. The LCGs do not propose to rehearse those details but raise one general observation in terms of approach.

19. The LCGs note that whilst the Inquiry, by necessity, will focus on the healthcare response at a high level rather than focus on individual cases, the detail must not be lost. The LCGs regret to note that the witness statements to date dealing with Long Covid have provided evidence at such a high level of generality that no meaningful conclusions could be drawn. The LCGs have, in direct correspondence, sought to identify those witness statements that fall within this category and suggested further questions to be asked to ensure that the Inquiry obtains the best possible evidence. The LCGs note the Inquiry's suggestion that additional matters might be addressed via the Rule 10 process. It is submitted that the Rule 10 process cannot supplant the need for supplementary witness statements to address gaps in evidence; first there is limited time allocated for hearings which will limit the number of Rule 10 questions that can be asked and secondly, many corporate witnesses might be better placed to answer further questions in a supplementary statement (e.g. for questions within their department's knowledge but not their personal knowledge). The LCGs submit that sending a number of supplementary requests for evidence will assist the Inquiry to gather the best available evidence and to run focused, effective hearings which will inform its findings and recommendations. The LCGs remain willing to assist the Inquiry further in their evidence gathering.

20. Further, the LCGs are concerned that Rule 9 requests for the 22 Spotlight Hospitals have only been sent to the Medical or Clinical Director or Chief Medical Officer.

21. At §9 of CTI's update, it is noted that Medical/ Clinical Directors evidence is not the only source of evidence on impact of the pandemic on those working and being treated in hospitals. The LCGs seek clarification as to whether this is a reference to the Every Story Matters Report and the impact statements. If so, this body of evidence does not replace the need for direct evidence to be heard from staff on the frontline. The LCGs are concerned that there is a potential gap between the knowledge of Medical/ Clinical Directors in the 22 Spotlight Hospitals and the experience on the ground of frontline staff. The LCGs ask the Inquiry to seek evidence from a range of frontline health workers including those privately contracted by the NHS in those hospitals so that there can be a more informed picture of the matters listed at §13 of CTI's note.

Disclosure

22. The LCGs note the update in respect of disclosure and that the majority of draft statements received by the Inquiry are yet to be finalised. They welcome the commitment to disclose a number of corporate witness statements by April 2024. As CTI notes at §20, "*it is inevitable that reading and assimilating all this material will take some time."* The LCGs have, therefore, noted with concern the need for the Chair to issue Section 21 Notices and that some Rule 9 requests have only recently been sent to relevant witnesses.

23. They ask that disclosure of the remainder of draft statements and statements yet to be received, is made with sufficient time for preparation for the hearings. The LCGs observe that timely disclosure assists all participants in the Inquiry to ensure the more effective running of hearings and focused representations. Given the size and complexity of Module 3, the LCGs' ask the Inquiry to ensure that the majority of disclosure to CPs is completed by the end of June 2024 at the latest. To that end, the LCGs propose that the Inquiry publish a roadmap setting out anticipated dates of receipt of material from disclosure providers and onwards disclosure to CPs. This would assist all CPs in the allocation of resources and time management as well as ensure transparency from document providers who are not complying with agreed deadlines.

Hearing Timetable

24. It is noted that 40 days has been allocated in total for Module 3's public hearings. The LCGs observe that this is likely to be inadequate to cover the issues identified in the draft List of Issues. The LCGs are concerned that this does not provide adequate time for important issues, such as Long Covid, to be covered with sufficient scrutiny.

Experts

25. The LCGs endorse the Frontline Migrant Health Workers' Group request for expert evidence on private sector contracts and outsourcing in the healthcare systems. The LCGs' include amongst their number NHS workers and private sector healthcare workers who contributed to the pandemic response. They agree that the Inquiry will be assisted in understanding the healthcare system's response to the pandemic by an expert report which explains the role of the private sector in the provision of healthcare services.

Recommendations

26. The LCGs welcome the Chair's recommendations for the monitoring process including that the institutions responsible for each recommendation will publish their response within 6 months. People continue to be disabled by and suffer avoidable harm from Covid-19: recommendations are of immediate and ongoing relevance. There is an urgent need for the Chair's prompt recommendations of preventative and supportive measures to minimise the ongoing harm caused by Covid-19.

III. CONCLUSION

27. The LCGs note that the Inquiry does not intend to hold a further procedural hearing for Module 3. They invite the Inquiry to keep this under review as the next six months leading up to the final hearings may reveal further issues which can be more readily resolved through open ventilation at a procedural hearing.

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

SARAH HANNETT KC
SANGEETHA IENGAR
SHANTHI SIVAKUMARAN
JANE RYAN

BHATT MURPHY

27 March 2024