COVID-19 PUBLIC INQUIRY

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

MODULE 2 THIRD PRELIMINARY HEARING

Hearing Date – 6 June 2023

I. INTRODUCTION

- 1. These submissions are made on behalf of three Long Covid Groups in relation to the third preliminary hearing for Module 2. The Long Covid Groups have limited submissions in relation to the agenda for the third preliminary hearing in Module 2; we address here matters related to the witness list for Module 2 hearings; outstanding disclosure and the listening exercise.
- 2. A preliminary point which the Long Covid Groups consider it necessary to return to is the substantial relevance of Long Covid to the Module 2 investigations. The absence of any reference to long-term morbidity or Long Covid in the draft List of Issues exposes a significant gap in the investigations for Module 2 which we consider is necessary to resolve before delving into the procedural issues related to the proceedings.

II. THE RELEVANCE OF LONG COVID TO MODULE 2

3. The overarching theme that characterised the Long Covid Groups' experience during the pandemic was one of being overlooked and underappreciated. The organisations were all formed out of necessity as patient advocacy groups in direct response to the apparent

failure of Government decision-makers to recognise the risks of Long Covid and to consider those risks in relation to decisions taken in response to the pandemic.¹

- 4. The Long Covid Groups are reminded through this process of their pandemic experiences as the Inquiry appears to mirror the same error of approach by failing to appreciate the relevance of Long Covid in relation to decisions taken to prevent the spread of Covid-19. The need for repeated correspondence over the past months has caused them to recall in visceral detail their experiences during the pandemic of advocating key decision makers to recognise and respond to the risk of Long Covid.
- 5. This Inquiry provides a novel and necessary opportunity to learn from the experience of Long Covid sufferers and prevent the avoidable suffering of long-term morbidity in future pandemics. The Long Covid Groups' hope is that their experiences of being dismissed, undermined, and overlooked will not be repeated. This will not be possible if the Inquiry's investigation replicates the very mistakes made by key government and administrative decision-makers during the pandemic that is, overlooking the relevance of long-term morbidity, including Long Covid, to decision-making in response to the spread of Covid-19 during the pandemic.
- 6. The Long Covid Groups re-iterate that a critical issue which should be subject to investigation in Module 2 is whether the UK's core political and administrative decision-makers adequately considered Long Covid and its impact in coming to their decisions. It was understood that this view was shared by the Chair who said she would "investigate the extent to which risks associated with long Covid were considered under other parts of the terms of reference for example, consideration of 'how decisions were made, communicated and implemented' will include investigation of how long Covid was considered in decisions on the implementation of lockdown measures." This position was then confirmed by CTI who accepted that the extent to which consideration was

¹ Long Covid Support {INQ000099721}; Long Covid SOS {INQ000099720}; Long Covid Kids {INQ000099699}

² Baroness Hallett, Terms of Reference Consultation – Summary Report, May 2022 p.18 available at: https://covid19.public-inquiry.uk/wp-content/uploads/2022/05/FINAL-Consultation-Summary-Report.pdf

given to Long Covid when making decisions would be investigated within the scope of Module 2.³

7. Despite these express assurances, references to Long Covid are markedly absent in disclosed corporate statements, expert reports and most revealingly of all, the draft List of Issues.

Rule 9 Requests

- 8. After receiving the first corporate statements disclosed by the Inquiry, the Long Covid Groups responded by making representations to the Inquiry Legal Team, explaining the significance of Long Covid to the Inquiry's investigations in Module 2, suggesting possible lines of questioning and encouraging them to include questions related to Long Covid when drafting Rule 9 requests. The Long Covid Groups have also provided an Annex of suggested witnesses and reasons why they are relevant to the Inquiry's work. The Long Covid Groups are encouraged that several of these suggestions have been taken up by the Inquiry but remain greatly concerned that key corporate statement providers and individuals will not be asked to provide evidence on their understanding of Long Covid or on the advice they gave to Government on the risk of long-term sequelae, including Long Covid, which we now know impacts almost two million people in the UK.
- 9. We do not seek to repeat the reasons we have provided to the Inquiry Legal Team for identifying the relevant Rule 9 recipients, however we make the general point that this Module requires Rule 9 recipients to provide evidence on their understanding, advice and response to Long Covid in order to scrutinise whether the risk of long-term sequelae and Long Covid was adequately factored into government decision making. Government decision making was informed by and implemented by a significant number of interrelated government departments and bodies which was complicated by the

³ 'Rule 9s which we have recently sent to key decision makers include questions about the extent to which consideration was given when making decisions about NPIs to the risk of Long Covid or health sequelae from Covid 19 infections' Module 2 PH held on 1 March 2023, transcript p26 §§ 2-6

⁴ Annex to Bhatt Murphy letter dated 26 April 2023

⁵ Letter from Inquiry Team dated 24 May 2023

⁶ The latest ONS data on the prevalence of Long Covid estimates that 1.9 million people were suffering from Long Covid as at 30 March 2023. Available online at

 $[\]underline{https://www.ons.gov.uk/people population and community/health and social care/conditions and diseases/bulletins/prevalence of ongoing symptoms following coronavirus covid 19 in fection in the uk/30 march 2023$

replacement of Public Health England by UKHSA in April 2021. As the Inquiry is well aware, the broad scope of Module 2 has necessitated the investigation into all those interrelated bodies.

- 10. The Long Covid Groups maintain that key decision-makers should be asked to provide an explanation of the extent to which they considered the risk of Long Covid in their corporate witness statements including UKHSA, the Department for Education, the Department for Work and Pensions, the British Medical Association, NHS Digital and the Office of the Children's Commissioner. They consider that this is necessary in order to properly investigate issues relevant to Long Covid in the context of Module 2. Limited additional questions should not impose a disproportionate burden on the Inquiry nor the respective witnesses as they have already been approached to provide witness statements and the request extends to limited additional questions. The limited cost of asking these additional questions are outweighed by the risk of an incomplete investigation in Module 2 should these simple questions not be asked.
- 11. In the same vein, identified individuals who have evidence relevant to Long Covid in relation to Module 2 issues should be invited to give evidence to the Inquiry. Some of the witnesses who the Inquiry has declined to ask questions about Long Covid are already providing witness statements in Module 2 and/or are likely to provide statements in Module 3.7 Additional questions about Long Covid in the context of Module 2 is a limited and discrete request which would not impose an additional burden on the Inquiry nor the witnesses.
- 12. The Long Covid Groups have considered it necessary to raise these concerns at this stage so that the Inquiry is not impeded in its investigations by the identification of significant gaps at a later time.

Expert Reports

13. The Inquiry Legal Team's position that the expert reports are drafted at too high a level to consider Long Covid specifically has been met with surprise and considerable

⁷ Andrew Hayward has already been asked to provide a more detailed witness statement under Rule 9 for Module 2. It is anticipated that Dr Melissa Heightman and Professor Anthony Costello are likely to be approached for a witness statement for Module 3 given the nature of their work. Limited questions relevant to Module 2 could be added to those requests for further evidence.

disappointment. We have made submissions in response to Professor Hale's report about why long-term morbidity and Long Covid should be considered alongside mortality which encourages the Inquiry to reconsider that approach. The Long Covid Groups submit that long-term morbidity, including Long Covid, should also be a relevant consideration in Gavin Freeguard's report given that he is instructed to report on access to and use of data by the UK Government and devolved administrations. The failure to record data about individuals with Long Covid was identified in December 2020 by the APPG on Coronavirus Interim Report and recommendations were provided to Government to remedy this. Accordingly, this is anticipated to be a potential line of enquiry to be pursued in Module 2.

- 14. The last point that the Long Covid Groups raise in relation to experts applies to the expert on Long Covid instructed for Module 3.9 It is understood that the same expert will be relied upon in Module 2¹⁰. This is a positive development. The Long Covid Groups ask that:
 - i) instructions to the expert are expanded to specifically address issues relevant to Module 2 and are not limited to Module 3;
 - ii) disclosure of the report takes place before the Module 2 hearing when it can be of assistance in influencing the development of those hearings.
- 15. The Long Covid Groups remain willing to assist the Inquiry in developing a focused framework of instructions and detailed lines of questioning.

The List of Issues

16. Given the history of correspondence, and the Long Covid Groups' earlier representations at the preliminary hearings, the Long Covid Groups are alarmed to see that Long Covid and long-term morbidity were not recognised as issues to be investigated in Module 2

https://static1.squarespace.com/static/61c09c985b6cc435c9948d88/t/6329d9329b34c00400d1e445/1663686965123/APPG+on+Coronavirus+Interim+Report+December+2020.pdf

⁸ APPG on Coronavirus Interim Report December 2020

⁹ Long Covid Groups have proposed a number of potential experts on Long Covid for Module 3.

¹⁰ Confirmed in letter from Inquiry dated 24 May 2023: "Module 3 is taking steps to instruct an expert specifically on Long Covid and we anticipate that this will be disclosed and relied upon in Module 2."

within the draft List of Issues. Long Covid and long-term morbidity had seemingly been entirely overlooked.

- 17. Submissions on behalf of the Long Covid Groups in relation to the List of Issues have been provided to the Inquiry and it is understood that they are being considered. The Long Covid Groups strongly encourage the Inquiry to review its approach to Long Covid by remedying this omission in the next iteration of the List of Issues for Module 2 which set the framework for the Inquiry's investigations in this Module.
- 18. The opportunity for the Inquiry to investigate and learn from government decision-making around Long Covid, and by extension, government decision-makers' recognition of post-acute sequelae and consideration of long-term and chronic illness post infection in a pandemic, arises only in Module 2. The scope of Module 3 and the list of future modules published on the Inquiry website provide very distinct opportunities to assess concerns relevant to Long Covid. As an example, Long Covid sufferers' experience of accessing healthcare and the investigation of decision-making on Long Covid within the healthcare system, falls within the purview of Module 3, whereas government decision makers' recognition and consideration of Long Covid in relation to the spread of Covid-19 falls squarely within the remit of Module 2.
- 19. The Long Covid Groups' firm hope is that their experiences of being dismissed, undermined and overlooked will not be repeated. They remain willing to assist the Inquiry with its investigations and offer their views with the objective of ensuring important lines of investigation are not missed and critical lessons are learnt in relation to long-term morbidity.

III. RULE 9 REQUESTS AND WITNESS LIST

20. The Long Covid Groups have noted with care the comments by CTI in the Note for the Third Preliminary Hearing in Module 2 ('CTI's Note'). They are led to understand that the majority of signed statements and exhibits will not be disclosed to Core Participants until the end of July 2023 (§11 and 38 of CTI's Note), and there are particular delays in receiving draft corporate witness statements from the Department for Health and Social Care (DHSC) and the UK Health Security Agency (UKHSA) (§26 of CTI's Note).

- 21. Core Participants will therefore be asked to make observations on a provisional witness list in June 2023, (§44 of CTI's Note) without sight of the majority of witness statements. The Long Covid Groups raise two concerns in this regard. First, they will only be able to provide limited observations on the witness list without the context of the witness statements. Secondly, in the event that further relevant witnesses are only latterly identified after reviewing the witness statements, there is concern that they may not be accommodated within the current timetable.
- 22. The Long Covid Groups recognise that the Module 2 Inquiry Legal Team has been working under significant pressure to ensure that the current hearing dates are effective but are concerned that late disclosure of witness statements and documents will impact on their ability to effectively participate in the Inquiry. The Long Covid Groups invite the Inquiry Legal Team to introduce the following measures to assist Core Participants to best prepare for the hearings in the limited time available:
 - a. The early disclosure of all relevant witness statements where possible;
 - b. Disclosure of a full list of all witnesses who have been requested to provide a
 witness statement under Rule 9 of the Inquiry Rules 2006 to assist Core
 Participants when providing observations on the proposed list of witnesses to be
 called;¹¹
 - c. Disclosure of draft corporate witness statements to Core Participants in advance to ensure that they have sufficient time to prepare for Opening Statements and Rule 10 requests. It is noted that draft expert reports have been disclosed without issue and it is suggested that the disclosure of draft corporate witness statements follow the same approach;
 - d. Plan a measure of flexibility into the hearing timetable in order to accommodate relevant witnesses likely to be identified only at a late stage in the proceedings.

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¹¹ At §9 of CTI's note, it says that the Module 2 Legal Team has issued more than 400 R9 requests for evidence including 200 questionnaires. The helpful updates from the Inquiry include which witnesses have received further Rule 9 requests but do not provide confirmation of all the names of witnesses who have received a request for a witness statement pursuant to Rule 9 of the Inquiry Rules 2006.

IV. DISCLOSURE

- 23. The Long Covid Groups are grateful to the Inquiry Legal Team for their helpful monthly updates and further details about disclosure in CTI's Note which reveal first concerns about disclosure from the Cabinet Office and secondly, general delays in disclosure.
- 24. It is understood from CTI's Note that the Cabinet Office's disclosure has revealed a number of issues including (i) delayed disclosure (§§23 and 25 of CTI's Note), (ii) excessive redactions contrary to the redactions protocol (§14 of CTI's Note), (iii) an application pursuant to section 21(4) of the Inquiries Act 2005 to revoke a section 21 Notice (§18 of CTI's Note) and (iv) an intended application for (potentially wide ranging) restriction orders under section 19 of the Inquiries Act 2005 (§32 of CTI's Note).
- 25. The Cabinet Office first applied to the Chair to withdraw her section 21 Notice on 15 May 2023 on the basis that information within the documents that was unambiguously irrelevant should be redacted. Only after the Chair refused their application on 22 May 2023, did the Cabinet Office inform the Chair on 26 May 2023 that they did not in fact possess the requested documents for the Rt Hon Boris Johnson MP which was the subject of their application of 15 May 2023. On 30 May 2023, the Chair granted an extension of time for compliance until 2 June 2023. Apart from two of nearly 30 Cabinet Office witnesses, The Cabinet Office has not complied with the requirements for disclosure of potentially relevant material (§21 of CTI's note).
- 26. The Long Covid Groups have also noted with concern CTI's comments that delays in disclosure of corporate statements from DHSC and UKHSA have the "potential to disrupt the Inquiry's process" (§13 of CTI's note).
- 27. In summary, the Long Covid Groups make the following observations. They:
 - (i) support the Chair's rulings of 22 and 30 May 2023;
 - (ii) request the opportunity to make representations in response to any application under section 19 of the Inquiries Act 2005; and
 - (iii) raise concerns about the impact of delayed disclosure on their ability to fully and adequately prepare for the Module 2 hearings.

- 28. The Long Covid Groups' support the Chair's issuance of a notice under section 21 of the Inquiries Act 2005 requiring provision of a range of documents in unredacted form, her subsequent ruling of 22 May 2023 refusing the Cabinet Office's application subject to section 21(4) of the Inquiries Act 2005 to withdraw that notice and the Notice of 30 May 2023 varying the Section 21 Notice and requiring the Cabinet Office to confirm and provide detail on whether the requested material is or was in its possession. The Inquiry must be uninhibited in its role to independently and robustly scrutinise the decision making of the Cabinet Office; in order to carry out its functions, the Inquiry should have access to timely and unredacted material.
- 29. Disclosure from the Cabinet Office encompasses the core of decisions made in response to the pandemic and the failure to ensure relevant disclosure is completed will inevitably impact on the ability of the Inquiry to meet its terms of reference. Given the central importance of this body of disclosure to the Inquiry's investigations, the Long Covid Groups applaud the robust approach taken by the Chair to the disclosure of redacted material to the Inquiry. The Chair's commitment to ensuring timely and complete disclosure including from the Cabinet Office gives considerable confidence to the Long Covid Groups that her investigation will be thorough and independent with no favour given to any party subject to investigation.
- 30. Whilst the Cabinet Office has now informed the Inquiry on 27 May 2023 that they do not have possession of Mr Johnson MP's WhatsApp messages and notebooks, Mr Johnson MP has stated in a letter to the Inquiry dated 24 May 2023 that he has always "sought to comply with all disclosure requests from the Inquiry..." It is anticipated that Mr Johnson MP will therefore be able to assist the Inquiry where the Cabinet Office is not seemingly able to do so.
- 31. The Long Covid Groups note that despite requests being made in December 2022 and January 2023, to date only two of nearly 30 Cabinet Office witnesses have provided potentially relevant communications to the Inquiry. Of further and serious concern, some witnesses claim to "not currently hold such materials". ¹³

¹² Letter from Rt Hon Boris Johnson MP to the Chair of the Covid-19 Public Inquiry dated 24 May 2023

¹³ §21 of CTI's Note.

- 32. The Cabinet Office's claims to be permitted to apply selective redactions of relevance to documents which fall for disclosure effectively proposes that they should not be subject to the same processes and procedures as other Core Participants. Given the role that they played during the pandemic, the mainstay of the Inquiry's investigations in this Module, decision-makers within the Cabinet Office during this period should be open to transparency and to the Inquiry's mandated scrutiny, rather than laying claims to exceptionalism. The Long Covid Groups respectfully support the Chair's Rulings and endorse the position that the Cabinet Office should comply with the disclosure requests without any further delay.
- 33. In respect of any potential application under section 19 of the Inquiries Act 2005 for a restriction order, the Long Covid Groups would ask for the opportunity to make submissions in response. They note that the Chair has a wide discretion to determine the procedure or conduct of the Inquiry which is only restrained by her duty to "act with fairness and with regard also to the need to avoid any unnecessary cost (whether to public funds or to witnesses or others)" (s.17(3) of the Inquiries Act 2005).
- 34. It is noted that the proposed section 19 application has the potential to have a wide reach affecting a significant body of evidence subject to scrutiny in Module 2. As the ramifications of any section 19 order in these circumstances may have a profound impact on this Module, it is submitted that fairness requires that Core Participants are provided the opportunity to respond to the section 19 application. They invite the Inquiry to ensure that these issues are properly ventilated through written applications and hearings.
- 35. Finally, in respect of general disclosure, on the premise that there are no further delays, Core Participants will be required to review the witness statements and enclosed exhibits and a substantial proportion of disclosure in order to prepare Opening Statements within less than two months before hearings in October 2023. Any later disclosure to Core Participants could significantly impede the Long Covid Groups' and other Core Participants' ability to participate in the Inquiry in the intended 'collaborative, forensic process.' 14

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¹⁴ Module 1: Second Preliminary Hearing held on 14 February 2023, Page 9 lines 12-13

- 36. The Long Covid Groups are concerned that issues regarding approaches to disclosure of potentially relevant material have not yet been resolved five months after disclosure requests were raised in December 2022 and January 2023. At this juncture, they observe with regret that, akin with other relevant documents, further delays to disclosure from the Cabinet Office could have the potential to impact on adequate preparations for Module 2.
- 37. In order to facilitate preparation within this very tight timescale, the Long Covid Groups would be grateful for further information from the Inquiry Legal Team to clarify (i) how many documents in total the Inquiry has received to date¹⁵, (ii) what the total number of documents that are likely to be disclosed to Core Participants approximates to and (iii) a timescale for that further disclosure.¹⁶ This is so that Core Participants can plan an effective review of the documents within what is a relatively short timeframe.
- 38. The Long Covid Groups commend and support the Chair's robust approach to the timetable of the Inquiry and her determination to deliver a timely and thorough process. Nonetheless, it is urged that expediency should not prioritised at the expense of a full, fair and inclusive investigation.

V. THE LISTENING EXERCISE

39. The Long Covid Groups welcome the updates in relation to the progress of the Listening Exercise, 'Every Story Matters.' We return to and reiterate a point that we raised at the First Preliminary Hearing for Module 3 regarding the inclusion of children and young people in this important process.

¹⁵ It is understood from CTI's Note of 17 May 2023 at § 39 that over 13,000 documents across 19 tranches of material have been disclosed to Core Participants to date.

¹⁶ Paragraphs 34 and 35 of CTI's Note do not mention how many documents the Inquiry has received and how many will be disclosed to CPs before the hearings in October 2023. Although it is unlikely that the Inquiry will know the exact number of documents to be disclosed while relevance reviews are ongoing, it is anticipated that the Inquiry may be able to estimate the proportion of documents which are relevant and disclosable to CPs from those ongoing relevance reviews. For example at paragraph 39, CTI says that the Inquiry will disclose a further 20,000 documents from DHSC alone.

40. At that hearing we raised concern that the online webform under 'Share your experience' excluded anyone under the age of 18 from sharing their perspectives. The webform remains unchanged. We were assured that steps would be taken to create safe and inclusive ways to incorporate children's experiences into the Listening Exercises and we hope that this will soon be facilitated to ensure that the Listening Exercise captures the widest possible range of experiences, as is intended.

31 May 2023

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