COVID-19 PUBLIC INQUIRY

MODULE 2:
JOINT WRITTEN SUBMISSIONS
ON BEHALF OF
LONG COVID KIDS, LONG COVID SOS AND LONG COVID SUPPORT

Hearing Date - 31 October 2022

I. Introduction

1. The Long Covid Groups welcome the Chair's recognition that Long Covid SOS, Long Covid Kids and Long Covid Support have a significant interest in Module 2 and are well placed to assist the Inquiry in relation to their investigations in this Module.

2. This note addresses the following topics on the Agenda:
    a. Long Covid Group's Interest in the Inquiry;
    b. The Scope of Module 2;
    c. Rule 9 Requests;
    d. Disclosure from Core Participants;
    e. Experts;
    f. The Listening Exercise.

II. Long Covid Groups Interest in the Inquiry

3. The Long Covid Groups are representative of tens of thousands of adult and child surviving victims of Covid-19 who have suffered life-changing illness and /or disability following infection. They remain victims of the virus as they continue to suffer chronic illness and/or disability. Many previously fit and healthy individuals have suffered profound changes to their lives as they experience the continuing effects of the disease..

4. It is now understood that the physiological experiences of Long Covid survivors are diverse and that infection of Covid-19 can have wide-ranging long-term health impairment and organ damage. Beyond acute respiratory disease, Covid-19 can affect the proper functioning of the heart and cardiovascular system, the brain, the kidneys and gut.[1]

5. "Long Covid" is defined by NICE as signs and symptoms that develop during or after an infection consistent with Covid-19, continue for more than 12 weeks and are not explained by alternative diagnosis.[2] Long Covid usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body.

6. The current ONS survey shows that as at 3 September 2022, Long Covid symptoms adversely affected the day-to-day activities of 2.3 million people (that is 3.5% of the population).[3] This is a significant cohort of people whose lives have been, and continue to be, directly affected by Covid-19.

7. The Long Covid groups wish to underscore that they are suffering from the effects of the disease itself. Therefore, it is key that the Inquiry recognises that individuals suffering from Long Covid are victims of the disease who have suffered life- changing illness and /or disability. Further, as survivors of Covid-19 who are suffering from life-

[1] Puntmann VO, Carerj ML, Wieters I, et al. Outcomes of Cardiovascular Magnetic Resonance Imaging in Patients Recently Recovered From Coronavirus Disease 2019 (COVID-19). JAMA Cardiology. Published online July 27, 2020. del Rio C, Collins LF, Malani Long-term Health Consequences of COVID-19. JAMA. 2020;324(17):1723. Huang Y, Pinto MD, Borelli JL, et al. COVID Symptoms, Symptom Clusters, and Predictors for Becoming a Long-Hauler: Looking for Clarity in the Haze of the Pandemic. medRxiv. Published online March 5; Dennis A, Wamil M, Alberts J, et al. Multiorgan impairment in low-risk individuals with post-COVID-19 syndrome: a prospective, community-based study. BMJ Open. 2021;11(3); .Davis HE, Assaf GS, McCorkell L, et al. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. EClinicalMedicine. 2021;38.

[2] NICE, Covid-19 rapid guideline: managing the long term effects of Covid-19: https://www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-longterm-effects-of-covid19-pdf-51035515742#:~:text=In%20addition%20to%20the%20clinical,(12%20weeks%20or%20more).

[3] ONS, Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 21October 2022: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19latestinsights/infections#long-covid

changing illness, the Long Covid Groups are victims of Covid-19 and anticipate that the Inquiry will recognise the Long Covid groups as victim groups.

8. During the Covid-19 Pandemic, individuals suffering from Long Covid felt overlooked by Government decision-makers who failed to recognise Long Covid at an early stage and to respond to their needs. This led to those suffering from Long Covid establishing grassroots organisations seeking to advocate on their behalf with relevant Government bodies.

9. Long Covid Support was established in March 2020 as a Facebook Group and grew quickly. Their support group now has over 56,000 members globally with 23,000 in the UK. The organisation has 26,500 Twitter followers, 10,100 followers on Instagram.

10. Long Covid SOS was established in June 2020 as a volunteer-run patient advocacy and campaign group. The organisation has 21, 800 Twitter followers, 7556 followers on Instagram and 3980 individuals have signed up to their website.

11. Long Covid Kids was established in September 2020 by a group of families whose children became victims of Long Covid. The organisation continues to support 10,000 families through its support services and has 27,300 Twitter followers, 3214 followers on Instagram.

12. All three Long Covid Groups are representative organisations of victims of Long Covid. They all have also been important public voices for the Long Covid community by advocating for the recognition of chronic illness and/or disability caused by infection, and the risk of long-term illness from infection of Covid-19. They have all participated in multiple stakeholder forums since 2020 to advocate for the recognition of Long Covid and rehabilitation and research into treatments.

13. Indeed, many Long Covid victims who are members of the Long Covid groups have suffered as a direct consequence of the Government's failure to adequately recognise that chronic illness and/or disability was an outcome for the pandemic.

14. The Long Covid Groups have made direct interventions to the highest levels of Government on the risks of Long Covid, the need for public recognition of chronic illness and/or disability from infection, the importance of including Long Covid in public messaging and have provided recommendations on the need for decision makers to implement NPIs and other mitigation measures.

15. Long Covid Groups have needed to campaign at every stage of the pandemic for Long Covid to be recognised as a condition and to be considered in Government decision making. They welcomed the establishment of this Public Inquiry as they seek answers as to why in their view Long Covid was not adequately recognised and why the risks of long-term or chronic illness and/or disability were not factored into the Government response to the pandemic, and ongoing to date.

16. On seeing the draft terms of reference, the Long Covid Groups wish to record that they were disappointed that Long Covid only appeared to be recognised in the provision for Long Covid in respect of the health and care sector.[4] The Final Terms of Reference were not amended in respect of Long Covid.[5]

17. The Chair's comments were noted in her Final Consultation Summary Report on the Terms of Reference where she said that she could not recommend the Terms of Reference be amended in respect of Long Covid because 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."*[6]

18. The Long Covid Groups have been reassured by the Chair's commitment and they anticipate that the risks associated with Long Covid will be fully investigated in Module 2 (as well as other relevant modules). The Long Covid Groups are well able to assist

[4] UK Covid-19 Inquiry Draft Terms of Reference – March 2022 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1059952/covid-19-inquiry-draft-terms-of-reference-march-22.pdf

[5] Covid-19 Inquiry Terms of Reference https://covid19.public-inquiry.uk/wp-content/uploads/2022/06/Covid-19-Inquiry-Terms-of-Reference-Final.pdf

[6] 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

the Inquiry by providing evidence of their efforts to advocate for the recognition of the risks of Long Covid during the pandemic. Given their experience advocating on behalf of those with Long Covid during the pandemic and as one of the few non-governmental core participants in Module 2, their unique perspective should materially assist the Inquiry on government decision- making during the relevant period.

19. The following observations on the procedure of the Inquiry are made with the intention of assisting the Inquiry with its work in Module 2.

III. Scope

20. The Long Covid Groups agree with CTI that the provisional scope of Module 2 is ambitious and introduces a wide range of topics. With this in mind, the Long Covid Groups are encouraged by CTI's commitment to develop the issues once the majority of the Rule 9 requests have been received. They ask that this be in the form of a List of Issues which would be provided to Core Participants with an early opportunity to provide comments.

21. The List of Issues will help to focus minds given the broad scope of the terms of reference and scope of the Module. As well as providing structure to an investigation in the Module informing decisions on relevance of evidence, lines of inquiry and identification of witnesses to be called, it can also assist Core Participants to understand how the Inquiry has interpreted the extent of their investigations in the Module. Core Participants can on review invite the Inquiry to pursue additional lines of Inquiry and tailor opening and closing statements to the list of issues.

22. For example, the Long Covid Groups ask respectfully whether Topic (3) on the Scope of Module 2 will investigate decision making relating to the lifting of non-pharmaceutical interventions (NPIs) as well as decision making in relation to their imposition. This is a specific consideration.

23. In broader terms, the Long Covid Groups are concerned to ensure that the political and administrative decision making about the chronic impacts of Covid-19 (and not only acute illness) should be investigated in Module 2. A draft List of Issues could easily

allay their concerns and provide an early opportunity for Long Covid Groups to assist the Inquiry with proposing further lines of inquiry drawn from their experience of the events subject to investigation in this Module.

24. The development of a List of Issues in consultation with Core Participants has become good practice in Public Inquiries.[7] Public Inquiries with broad terms of references to investigate events over a long period of time and affecting a wide number of people have disclosed Lists of Issues: Post Office Horizon IT Inquiry,[8] Grenfell Tower Inquiry,[9] The Undercover Policing Inquiry,[10] the Infected Blood Inquiry.[11]

25. The Long Covid Groups would invite the Inquiry Team to consider early disclosure of a draft List of Issues. This would be followed by a process of consultation before finalising the List of issues. This final list of issues would be a working document open to further revision, aligned with the Inquiry's iterative process.[14]

26. Noting that the Inquiry has committed to an ambitious timetable setting hearings in Summer 2023, we suggest that a draft List of Issues be shared before the next procedural hearing. It is anticipated that a significant number of Rule 9 responses may have been received by this time and early disclosure of a list of issues would be helpful in the event that any further lines of inquiry or gaps in the list of issues are identified which would require further Rule 9 Requests.

IV. Rule 9 Requests

27. The Long Covid Groups note that all the organisations listed at §40 who have been issued Rule 9 requests to provide a chronology and a corporate statement setting out a narrative of relevant events and the lessons learnt [§45 and 50 of CTI's Note].

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[7] Beer KC, *Public Inquiries*, Oxford, OUP, 2011 at §5.21
[8] Post Office Horizon IT Inquiry Completed List of Issues: https://www.postofficehorizoninquiry.org.uk/publications/completed-list-issues
[9] Grenfell Tower Inquiry Updated List of Issues: https://assets.grenfelltowerinquiry.org.uk/inline-files/List%20of%20Issues%2025%20September%202019%20%281%29.pdf
[10] UCPI has published four issues lists for Module 1 and 2 after consultation with core participants to date https://www.ucpi.org.uk/evidence/#issues-lists
[11] Infected Blood Inquiry – Revised List of Issues https://www.infectedbloodinquiry.org.uk/sites/default/files/2020-09/2020-10/Amended%20List%20of%20Issues%2027.9.2021.docx.pdf

28. We also note the Chair's comments in her Ruling following Module 1's Preliminary Hearing [§8] that the corporate statements will serve a similar purpose to position statements *'the Inquiry has already requested the Rule 9 recipients to provide a corporate statement setting out a narrative of relevant events and of the lessons learned. These will serve a similar purpose to position statements.'*

29. Building on the comments of the Chair, the Long Covid Groups suggest that corporate statements also address the organisation's understanding of their responsibilities, remit, processes, policies and resources in place at the time. These are important considerations for understanding the Organisations' position in relation to the narrative of relevant events as well as putting into context any lessons learnt.

V. Disclosure from Core Participants

30. The Long Covid Groups are grateful for the Chair's indication in her Ruling on Module 1's Preliminary Hearing [§ 10] that *'the Inquiry will be as open as possible with the Core Participants and with the public in relation to the disclosure of documents.'*

31. The Long Covid Groups further welcome the Chair's clarification that the test for disclosure will be relevance [§ 11 Ruling on Module 1] and we respectfully agree that this is the correct test for disclosure to be applied.

32. We are however concerned that in the absence of a disclosure policy, the CTI's Note for Module 2's Preliminary Hearing appears to move away from the strict legal test of 'relevancy' to 'proportionality.'

33. At [§ 44] of the Note CTI states that '*rather than requiring all documents potentially relevant to particular themes or areas to be provided, it has instead sought documentation relevant to the key narrative events, the decision-making procedures of those bodies and persons relevant to the core political and administrative decision-making and the core decisions themselves.'*

34. It is respectfully submitted that this marks a procedural shift in the Inquiry Team's approach to disclosure from asking what is relevant to matters examined under Module

2, to asking more limitedly, what is relevant to key narrative events of Module 2. This necessarily results in a restriction of scope of matters to be examined under Module 2, which concerns the Long Covid groups.

35. The Long Covid Groups are concerned that Core Participants have not been consulted on the 'key narrative events' and that there is no agreed list of key narrative events from which all document providers and Core Participants are working from.

36. Indeed, where the outline scope of Module 2 remains very broad, it is submitted that there is a real risk that disclosure as per [§ 44 of CTI's Note] would exclude relevant material and would not permit the Inquiry to examine alternative key narrative events within their scope.

37. These concerns could be allayed by (i) the transparent publication of a list of key narrative events for Module 2 with an accompanying note of who identified those events and (ii) the publication of a disclosure policy.

38. We therefore suggest that, as with the Scope of the Module 2, Core Participants be invited to feed into the list of key narrative events to ensure there are no gaps in disclosure.

39. As with the Redactions of Document Policy which the Inquiry's Legal Team helpfully published on 18 October 2022, a disclosure policy would detail in greater specificity the test and procedure to be consistently applied.

40. The Long Covid Groups note with interest the Chair's reference, in her Ruling on Module 1 preliminary matters, that document providers are being asked to provide [§ 16 Module 1 Ruling]: *'an account setting out details of the nature of the review carried out, how the documents were originally stored and the search terms used or other processes used to locate documents.'*

41. It is noted that as part of this process, the Inquiry may be assisted by Document Providers confirming if relevant information was deleted before they were asked to take

steps to retain material potentially relevant to the Inquiry. This may include information that was shared on WhatsApp, Signal and Cabinet Office instant chat application.

42. The Long Covid Groups would ask that these documents are disclosed to Core Participants as a matter of course. Disclosure of the documents will achieve the twin objectives of ensuring transparency and confidence in the Inquiry process.

43. This is especially relevant in this context as the Inquiry is not seeking disclosure of all relevant documents to the Module but has limited their request to documents which are relevant to "*key narrative events, decision making procedures of those bodies and persons relevant to the core political and administrative decision-making and the core decisions themselves."* [§44 of CTI's Note].

44. The Inquiry (and other Core Participants) will have to place a significant amount of trust in the document provider to undertake a thorough disclosure review. In circumstances where some document providers may not be forthcoming with disclosure or may simply be overwhelmed (where there are tens of millions of documents §43 of CTI's Note), the document providers' process for identifying relevant documents must, naturally, be subject to close scrutiny.

45. Core Participants would be assisted in their confidence in the Inquiry processes if the methodology employed by document providers identifying documents is transparent.

VI. Experts

46. The Long Covid Groups recognise that the Inquiry will be assisted by expert evidence on a wide range of topics in Module 2 and that work in identifying experts will be well underway to realise the listing in Summer 2023.

47. The Long Covid Groups welcome CTIs commitment to disclose the identity of expert witnesses and the questions and issues that they will be asked to address. They note that Core Participants will be provided with an opportunity to provide observations on the expert witnesses and their instructions which we agree will ensure effective participation.

48. It is appreciated that the Inquiry will be alive to the difficulty of instructing an expert in the present context where many of the relevant experts were involved in the events under investigation or may have publicly expressed a view on the matters within scope of Module 2. Additionally, the subject matter itself has been subject to polarising views within relevant disciplines.

49. In view of these sensitivities, Long Covid Groups would appreciate an early opportunity to provide observations on the expert witnesses that have been instructed (or are intended to be instructed) and on the scope of their instructions. Early disclosure of the experts and their CVs will assist the Inquiry in so far as any objections can be made known and any further experts identified. Any submissions will have little weight if work by the experts is already well advanced. In addition, it would serve no useful purpose for the Long Covid Groups to offer further experts if an adequate alternative has already been identified.

50. In relation to the specialist areas which lay and expert witnesses will be giving evidence on in Module 2 [§67 of CTI's note], Long Covid Groups would ask that §68(b) include systems for measuring and estimation of post-covid sequelae (Long Covid) and the overall figures for Long Covid.[15] This would assist the Inquiry in understanding what information was available to the government about the risks of Long Covid as well as the steps they took to measure that risk.

VII. Listening Exercise

51. Long Covid Groups have noted the early indications of the design and process for the Listening Exercise in CTI's Note and in STI's Note regarding the Listening Exercise and Commemoration.[16] While they welcome the opportunity for individual experiences to be recorded in the listening exercise, they would invite the Inquiry to adopt a consultative approach in designing and setting up the process. Consultation with the Long Covid Groups and other Core Participants in the design of the Listening Exercise could ensure that a breadth of perspectives are captured as well as ensuring that the process will be as constructive and accessible as possible for those who are affected by it.

52. The Chair has confirmed that 'those who suffered during the pandemic will be at the heart of the Inquiry' [§ 33 Ruling on Module 1 Preliminary Hearing] and as a victim group, the Long Covid Groups would also emphasise that the Listening Exercise should not replace evidence being gathered and heard in Module 2 from the Long Covid Organisations as well as a sample of representative individuals affected by Long Covid.

53. It is suggested that the evidence of Long Covid groups will usefully assist the Inquiry in its investigations in two key respects. First, witness statements from representatives of the organisations can speak to their efforts in trying to influence government decision making as it affected those with Long Covid and at risk of contracting Long Covid during the relevant period. Their evidence is not of individual experiences but rather of the organisational history and knowledge of government decision making from their perspective. Secondly, individual evidence of Long Covid suffering is relevant to systemic failings in addressing their particular concern.

54. Long Covid Groups note the Chair's observation in the Ruling of 17 October 2022 following Module 1 Preliminary Hearing at §30-31 and CTI's comments in the Note for Preliminary Hearing Module 2 at §75 that evidence of individual deaths may be relevant where it relates to systemic failings. Long Covid Groups would remind the Inquiry that many individuals who suffer from Long Covid have had their lives profoundly affected by the disease. The government response to Long Covid has in many cases compounded their suffering. Individual evidence of experiences of those suffering from Long Covid may also assist the Inquiry to address whether there were systemic failings in decision- making which affected their cohort.

55. Long Covid Groups note that the initial intention around the Listening Exercise is that it will be a non-legal process and evidence will be provided in a non-legal process which will be reviewed, anonymised and then fed into the Inquiry modules. While the Listening Exercise has an important function to serve, it is imperative that it does not replace the need for individual evidence to be heard in the Inquiry.

VIII. Conclusion

56. The Long Covid Groups are willing to assist the Inquiry with their investigations at all stages and if there are any queries which they are able to address, please do not hesitate to contact us.

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