

COVID-19 PUBLIC INQUIRY

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

MODULE 2 SECOND PRELIMINARY HEARING

Hearing Date – 1 March 2023

I. INTRODUCTION

1. These submissions are made on behalf of the Long Covid Groups – Long Covid Kids, Long Covid SOS and Long Covid Support – in relation to the second preliminary hearing for Module 2.
2. This note addresses the following topics on the Agenda:
 - i. Witness List, Timetable and Rule 9 Process;
 - ii. Experts;
 - iii. Parliamentary privilege;
 - iv. Rule 10;
 - v. Relativity; and
 - vi. Commemorations and Listening Exercise.

II. SUBMISSIONS

- i. Witness List, Timetable and Rule 9 Process**
3. The issues of witness lists, timetabling and the Rule 9 process are addressed together as they are inter-linked.

4. The Long Covid Groups support CTI's helpful commitment to providing a list of issues in April 2023 and to sharing a provisional list of witnesses shortly thereafter, in recognition that Core Participants' early observations will assist the Chair and her team (§§23-26).
5. The Long Covid Groups seek greater clarity about the Rule 9 process in order to ensure effective assistance to the Inquiry. It is understood that the Inquiry has issued preliminary requests for assistance pursuant to Rule 9 in the form of questionnaires and that these requests and the responses are only intended to identify potential witnesses who will then receive a further substantive Rule 9 request, if necessary.
6. The Long Covid Groups responded on 16 December 2022 to Rule 9 requests for initial assistance sent to them. Each response clarified that they were providing provisional information only and that they would be willing to provide more detailed statements to the Inquiry. The Long Covid Groups have not been provided any further information on the Rule 9 process; they do not know whether the Inquiry intends to ask for substantive Rule 9 witness statements from them, when this might be, or if this is the extent of the evidence they can expect to provide to the Inquiry for this module.
7. It is recognised that there are less than two months until the list of issues and witness list are circulated. It is respectfully submitted that further clarity on the Rule 9 process adopted by CTI would allow Core Participants to maximise the available time in preparing witness statements that are sufficiently detailed to best assist the Inquiry. CTI's comments at (§ 12) that Core Participants have not to date suggested that there are any significant gaps in the issuance of the Rule 9 requests, are noted. A clear understanding of the Rule 9 process would allow Core Participants to make informed observations on the substantive Rule 9 requests issued.
8. The January 2023 Update Note does not illuminate the position on the Rule 9 process for substantive witness statements for "at risk or vulnerable Groups". It simply states that 75 Rule 9 requests have been made to organisations and bodies representing at-risk or vulnerable Groups (§ 12 of the January 2023 Update Note for Module 2). There is

no indication if those organisations, including the Long Covid Groups, will receive follow up requests for substantive witness statements.

9. It is understood that the Inquiry is operating under time pressure and that further requests may be under consideration. However, the Long Covid Groups take this opportunity at the preliminary hearing to invite the Inquiry to share the process for seeking further evidence from those with Long Covid following the Directions issued by the Chair on 9 November 2022.
10. At the first Module 2 preliminary hearing, our clients were grateful to receive reassurances from the Chair that she intended to hear from individuals about the circumstances they experienced as they related to systemic issues in the modules concerned. The Chair also recognised that she would hear from those with Long Covid if they had evidence that might relate to systemic failings.¹
11. In directions issued on 9 November 2022 following the preliminary hearing, the Chair directed the Inquiry team to work on ways in which some ‘impact evidence’ can be admitted to some of the ‘system modules’ but said that the focus of Modules 2, 2A, 2B and 2C will be on key decision making at a high level and the "*extent to which decision makers were obliged to have, but may not have had, regard to the likely impact of their decisions*". The Chair also said: "*some issues, for example the impact on... Long Covid sufferers...are not therefore directly in issue.*"²
12. The Long Covid Groups respectfully submit that their lived experience of the pandemic, their testimony on the impact that decision making had for Long Covid sufferers, their experience of the need to advocate for the condition and their ongoing experiences advocating for its recognition, fall firmly within the scope of investigation of Module 2.

¹ PH 30.10.2022 p. 113. l. 22 – p.114 l.18.

² §§4-5 Directions dated 9 November 2022 regarding Modules 2, 2A, 2B and 2C.

13. It has been suggested that “*Long Covid is the first illness to be made through patients finding one another on Twitter and other social media.*”³ The etymology of the term Long Covid can be traced to social media posts in May and June 2020.⁴ Patients extended their advocacy to recognition of Long Covid in medical journals and mainstream media.⁵
14. Minutes of a SAGE meeting show that SAGE had noted the “*existence of longer-term health sequelae*” and “*the importance of monitoring these impacts through longer-term cohort studies*”. This was at the thirty-fourth meeting of SAGE on 7 May 2020.⁶ At the forty-eighth meeting of SAGE on 23 July 2020, the risks of long-term sequelae were again recognised in relation to discussions about age-structured segmentation and it is minuted “*Although under 45s are at less risk from COVID-19, including lower risk of death, they are nonetheless at some risk and long-term sequelae are not yet well understood.*”⁷ However, it was only on 1 October 2020 that the first reference to Long Covid was documented in SAGE minutes where it was minuted “*UKRI to consider a clear pathway for enabling viral phenotyping capability in the UK and clinical phenotyping of mild disease, including Long-COVID.*”⁸
15. The acknowledgement of long-term sequelae in May 2020 did not result in public recognition by the Government of Long Covid. Further, the apparent delay within the advisory group in characterising and recognising Long Covid was also discordant with widespread public reporting in national and international media and on social media

³ Callard and Perego *How and Why Patients Made Long Covid*, Social Science & Medicine 268 (2021) 113426, 7 October 2020 <https://doi.org/10.1016/j.socscimed.2020.113426>

⁴ Callard and Perego *How and Why Patients Made Long Covid*, Social Science & Medicine 268 (2021) 113426, 7 October 2020 <https://doi.org/10.1016/j.socscimed.2020.113426>.

⁵ See BMJ Opinion, *Patients’ experiences of “long Covid” are missing from the NHS narrative*, 10 July 2020 <https://blogs.bmj.com/bmj/2020/07/10/patients-experiences-of-longcovid-are-missing-from-the-nhs-narrative/> ;

⁶ 34th Meeting of SAGE on Covid-19, 7 May 2020

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1065937/S0404_Thirty-fourth_SAGE_meeting_on_Covid-19_1.pdf

⁷ §17 of 48th Meeting of SAGE on Covid-19, 23 July 2020

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/921187/S0656_Forty-eighth_SAGE_meeting_on_Covid-19.pdf

⁸ 60th Meeting of SAGE on Covid-19, 1 October 2020

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/931034/S0798_Sixtieth_SAGE_meeting_on_Covid-19.pdf

about individual experiences of Long Covid and its impact on them from Summer 2020.⁹

16. The delay in Government and administrative decision makers to respond to early reports of Long Covid led to the formation of the Long Covid Groups over the course of 2020. Their advocacy was wide-reaching and instrumental in raising awareness of the need for formal recognition, research and publicly funded treatment for Long Covid sufferers and the need to factor Long Covid into any response to the pandemic.

17. For example, Long Covid Support was set up from May 2020. On 16-17 June 2020, two UK parliamentarians Baroness Bennett of Manor Castle and Rt Hon Steve McCabe tabled written questions about Long Covid following questions from Long Covid Support member Claire Hastie¹⁰. On 28 August 2020, Long Covid Support and partners wrote to Rt Hon Jeremy Hunt MP, Chair of the Health and Social Care Committee to ask for the UK Government to assemble a multi-disciplinary Long Covid task force, as well develop and disseminate information on treatment, management of symptoms and rehabilitation.¹¹

18. In June 2020, Long Covid SOS created a campaign “#messageinabottle” gathering video evidence of individuals experiencing Long Covid. They wrote to key decision-makers in the UK Government in July 2020 sharing experiences of people living with Long Covid. In August 2020, the WHO invited them to set up the first conference on Long Covid where Dr Tedros Adhanom Ghebreyesus spoke. On 21 August 2020, Dr Ghebreyesus’ opening remarks at the press briefing about the meeting spoke about patients suffering from “*long term effects from Covid-19 infection.*”¹² He noted that there was a need for “*recognition of their disease, appropriate rehabilitation services*

⁹ Callard and Perego *How and Why Patients Made Long Covid*, *Social Science & Medicine* 268 (2021) 113426, 7 October 2020 <https://doi.org/10.1016/j.socscimed.2020.113426>

¹⁰ Question for Department of Health and Social Care UNI60680 <https://questions-statements.parliament.uk/written-questions/detail/2020-06-17/60680> HL 5748; <https://questions-statements.parliament.uk/written-questions/detail/2020-06-16/hl5748>

¹¹ <https://drive.google.com/file/d/1XCoTs1Q9eOy7LEg7Y0QmxF0mFfr36hj/view>

¹² WHO Director-General’s opening remarks at the media briefing on COVID-19 – 21 August 2020 <https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---21-august-2020>

and more research to be done into the long term effects of this new illness.”¹³ By September 2020, the WHO had issued guidance on Long Covid.¹⁴

19. In September 2020, Long Covid Kids launched a video testimony from children who had contracted Covid-19 and had not recovered, suffering serious debilitating illness: *“Our unhappily ever after.”*¹⁵ Long Covid Kids called for the Government to publish a more comprehensive list of Covid symptoms for children and young people and raised concerns that a lack of clarity was putting vulnerable adults and young people at risk¹⁶.

20. On 7 September 2020, Public Health England published guidance *“Covid-19: long-term health effects”* where they recognised that in 10% of “mild” coronavirus (COVID-19) cases, people reported symptoms lasting more than four weeks.¹⁷ However, it was only on 18 December 2020 that NICE issued *Covid-19 rapid guidelines: managing the long-term effects of COVID-19.*¹⁸ This was after the All-Party Parliamentary Group (APPG) on Coronavirus Interim Report published in December 2020 found that the UK Government *“is not counting the number of individuals who are left with long-lasting effects of Covid-19 as a measure of the severity and impact of the pandemic”* and *“Long Covid has not yet received full recognition, sufficient research funding or adequate rehabilitation support.”* The APPG interim report also found that *“there are very few guidelines for employers or for GPs on recognising and managing Long Covid.”*¹⁹ This,

¹³ BMJ, *We have heard your message about Long Covid and we will act says WHO*, 3 September 2020 <https://blogs.bmj.com/bmj/2020/09/03/we-have-heard-your-message-about-long-covid-and-we-will-act-says-who/>

¹⁴ WHO Coronavirus update 36, 9 September 2020, “What we know about the long term effects of COVID-19 – the latest on the Covid-19 Global Situation & Long-Term Sequelae”.

¹⁵ Long Covid Kids Our Unhappily Ever After <https://www.youtube.com/watch?v=RiIambG8vs0>

¹⁶ i News, 22 September 2021 *Covid Symptoms: Government update on common signs of coronavirus ‘in process’ as calls for new guidance grow*; <https://inews.co.uk/news/ovid-symptoms-common-signs-coronavirus-government-update-calls-better-guidance-1210877>

¹⁷ PHE, *Guidance Covid-19: long-term health effects*, published 7 September 2020, updated on 30 April 2021 and withdrawn on 1 April 2022.

¹⁸ NICE, Covid-19 rapid guideline: managing the Long term effects of COVID-19, NG188 <https://www.nice.org.uk/guidance/ng188>.

¹⁹ See also the recommendations on page. 14 APPG Group on Coronavirus *Interim Report December 2020* p.41 available at: <https://static1.squarespace.com/static/61c09c985b6cc435c9948d88/t/6329d9329b34c00400d1e445/1663686965123/APPG+on+Coronavirus+Interim+Report+December+2020.pdf>

and other delays in decision making, has increased the harm and suffering felt by victims of Long Covid.²⁰

21. These are only brief examples of some of the Long Covid Groups' advocacy. However, as the Inquiry is aware, the Long Covid Groups have been involved in multiple forums and platforms to advocate for better recognition for and understanding of Long Covid, including attending ministerial roundtables. Their initial Rule 9 questionnaires provide an overview of this. Their interest in participating in this module is derived from their experiences and concerns that administrative and government decision makers failed to have regard to Long Covid when considering the impact of their decisions.
22. The Long Covid Groups commend the Inquiry's comprehensive approach to evidence gathering through initial questionnaires issued pursuant to Rule 9. However, they underscore that the Government and administrative decision makers' perspective provides only one facet of the context in which decisions were made. The experiences of those living with Long Covid and advocating for its recognition provides a crucial element to the narrative of administrative and government decision making on Covid-19. They respectfully submit that it is necessary to hear further evidence from Long Covid Groups to provide a complete picture of Module 2.
23. The Long Covid Groups are uniquely placed to assist the Inquiry in this module by providing evidence of the extent of the advocacy interventions made to governmental and administrative decision-makers on the risks of Long Covid and the need for its due recognition and consideration in decision-making. Their evidence is important for learning lessons from the experiences of patient advocacy Groups during a pandemic where decision-makers have potentially failed to respond to their particular concerns to the detriment of a wide cohort of people directly impacted by the pandemic. They are therefore not purely witnesses to the 'impact' of the pandemic but also relevant witnesses to the administrative and governmental decision-making processes during the pandemic. Our clients consider that as a result of their advocacy during the pandemic,

²⁰ Evidence on 5 August 2020 to the APPG Coronavirus (Interim Report) <https://www.appgcoronavirus.uk/home/interim-report-2020>; p.41-41

decision-makers were “*obliged to have... regard to the likely impact of their decisions.*” on people with Long Covid and the risk of people acquiring Long Covid.

24. The Long Covid Groups make these early observations in advance of any draft witness list in order that they can fully understand the Inquiry’s approach to evidence gathering whilst there is an opportunity to substantively assist the Inquiry.

ii. Experts

25. The Long Covid Groups welcome the indication that draft reports for the four experts to Module 2 will be shared in March 2023. They appreciate that the Inquiry team has been working at pace and that this early disclosure of reports is evidence of considerable effort on the part of the Inquiry to be prepared for the Module 2 hearings. The Long Covid Groups also anticipate contributing a limited number of observations to the draft reports when they are disclosed.

26. Whilst recognising that the focus of this module is on administrative and government decision-making, those decisions can only properly be understood in the context of what advice was being given and the appropriateness of following that advice. The expert advice that has been sought is the exclusive preserve of political scientists and, while important in its own right, it will not be of assistance in understanding whether the advice given to administrative and political decision makers was appropriate.

27. As the initial disclosure is being reviewed, an emerging consideration has been the need for expert reports from appropriate epidemiologists and public health experts. In Module 1, expert reports have been sought from public health experts and epidemiologists who can speak to pandemic preparedness. Their evidence speaks to the first stage in the narrative of decision-making. It is respectfully requested that these relevant Module 1 reports be disclosed to Core Participants of Module 2 at an early stage. While the reports will no doubt be published at the time of the Module 1 hearing, given the pace that the Inquiry is progressing at, Core Participants in Module 2 would be considerably assisted by understanding the expert views in respect of Module 1 as they pertain to Module 2 in good time to advance preparation for Module 2.

28. The Long Covid Groups respectfully suggest that it may be of assistance to the Inquiry to seek similar reports from public health experts and epidemiologists on their opinions on the development of the pandemic and advice on responding to the different stages of the pandemic. The Long Covid Groups appreciate that the leading epidemiologists in the UK will be giving evidence as witnesses of fact in Module 2 in respect of advice that they gave the government during the pandemic. Their witness statements may not be sufficient to address this gap in evidence in Module 2 as they are not independent i) they will be motivated to defend the advice without recognising any oversights or mistakes in approach and ii) they do not have the same duties to the court²¹.
29. From the perspective of Long Covid Groups, the Inquiry may well be assisted by an expert who specialises in the study of long-term sequelae, their characterisation in a pandemic context and developing research methods and responses to them.

iii. Parliamentary privilege

30. The Long Covid Groups have noted with interest the observations made in respect of Parliamentary Privilege in CTI's Note for the Second Preliminary Hearing (§§27-40) and the Chair's ruling of 17 February 2023 following the second M1 preliminary hearing (§§15-19). The Long Covid Groups reserve the right to make submissions on the application of parliamentary privilege at a later date as and when it may be relevant.

iv. Rule 10

31. CTI's proposal set out at §§42-50 of the Note for the Second Preliminary Hearing in Module 2 is supported and the Long Covid Groups welcome the staged process to

²¹ The Long Covid Groups recognise that pursuant to Rule 17 of the Inquiries Act 2005, the procedure and conduct of the Inquiry is a matter for the Chair although she must act with fairness and regard to the need to avoid any unnecessary cost in doing so (whether to public funds, witnesses or others). In certain circumstances witnesses of fact can give evidence of opinion in civil proceedings (governed by the distinct framework established by the Civil Procedure Rules) if it is within their knowledge or experience. However, this evidence will not be independent and may be considered "self-serving or unreliable, particularly if not supported by documents" and should not seek to circumvent the absence of any expert evidence. See for example *Mad Atelier International BV v Manes* [2021] EWHC 1899 at [13]. The Long Covid Groups are able to expand on these legal submissions should that be of assistance to the Inquiry.

afford Core Participants “*a meaningful opportunity to engage in the process*” of gathering evidence from witnesses.

32. The only additional observation that the Long Covid Groups make is that the Inquiry consider reasonable adjustments for Long Covid Groups when setting deadlines for responses.
33. CTI at present suggests that CPs respond to evidence proposals within 7 days. This is a very short period of time for the Long Covid Groups to review the evidence proposals and respond. As the Chair is aware, the Long Covid Groups are all volunteers. Long Covid has resulted in profound, disabling changes to their health which requires management of their activities to avoid triggering a relapses and adverse symptoms.²² Many of those in the Long Covid Groups would meet the definition of disabled under the terms of section 6(1) of the Equality Act 2010 and are accordingly entitled to reasonable adjustments pursuant to section 20. They would ask that this is factored into the timetable for witnesses’ evidence proposals and reasonable adjustments are made.
34. The Long Covid Groups do not repeat the general submissions on reasonable adjustments set out in their submissions for the Preliminary Hearing for Module 3 at §§48-52. They rely on those submissions and in the same vein, they invite the Inquiry to provide Core Participants with at least 14 days to respond to the evidence proposals.

v. Relativity

35. During the second preliminary hearing for Module 1 hearing, CTI indicated that a Core Participant “*persuaded the Inquiry team to alter the field tagging system so that documents can be marked with additional fields...*”²³

²² Patients with Long Covid reported the benefits of pacing to avoid relapse as early as 2020 Garner, *Long Covid and self-help pacing Groups – getting by with a little help from our friends*, the BMJ Opinion, 29 September 2020. See also guidance on pacing on Long COVID Physio website <https://longcovid.physio/pacing>. Further studies have found it effective in managing Long Covid. Parker et al, *Effect of using a structured pacing protocol on post-exertional symptom exacerbation and health status in a longitudinal cohort with the post-Covid-19 syndrome*, Journal of Medical Virology, Vol. 95, Issue 1 January 2023

<https://doi.org/10.1002/jmv.28373>

²³ Transcript 14 February 2023 p.17 l. 9-15.

36. The Long Covid Groups apply for similar permission to be granted to them on their Relativity workspace so they can have a coding panel installed.²⁴

37. We fully appreciate that the Inquiry Legal Team is facing a daunting and intensive task in preparing for the Module 2 hearings. We seek to assist in this respect and hope that simple procedural matters like this can be resolved through correspondence.

vi. Commemorations and Listening Exercise

38. The Long Covid Groups note the developments of the Listening Exercise, Every Story Matters, and its aim to gather, analyse, anonymise and summarise the experiences of those affected by the pandemic in a non-legal process. The indications in STI's update of 27 January 2023 that the Inquiry will take a targeted approach to listening and that staff will be trained on trauma informed approaches are welcomed.

39. The Long Covid Groups have set out detailed submissions on this matter in their submissions for the Module 3 preliminary hearing which the Inquiry will be aware of. Those submissions are not repeated here.

vii. Covid-19 Safety Measures

40. The Long Covid Groups welcome the Inquiry's commitment to ensure the health, safety and welfare of all attending the hearing centre published in the Inquiry's Covid Guidance policy document. In their submissions for Module 3 preliminary hearing (§§53-55), they have invited the Inquiry to add a commitment to ensure that HEPA filters, ventilation and CO2 monitors will be introduced in all venues.²⁵ They do not repeat the substance of those submissions but welcome the Inquiry's commitment to consider appropriate ventilation and air filtration while exploring a permanent venue.

²⁴ The Long Covid Groups raised this by letter dated 13 February 2023 to the Inquiry Team

²⁵ Studies have found HEPA filters are effective in reducing the transmission of airborne pathogens including SARS-COV-2 see for example Ueki et al *Effectiveness of HEPA Filters at removing infectious SARS-CoV-2 from the Air*, ASM Journals Vol 7, No.4, 10 August 2022 available at <https://journals.asm.org/doi/10.1128/msphere.00086-22> and Conway Morris et al *The Removal of Airborne Severe Acute Respiratory Syndrome Coronavirus 2 and other Microbial Bioaerosols by Air Filtration on Coronavirus Disease 2019 Surge Units*, Clinical Infectious Diseases, Vol 75 Issue 1, 1 July 2022 p.97-101; 1 July 2022 <https://academic.oup.com/cid/article/75/1/e97/6414657?login=false>.

III. CONCLUSION

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

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