

**MODULE 3:
JOINT WRITTEN SUBMISSIONS ON BEHALF OF
LONG COVID KIDS, LONG COVID PHYSIO, LONG COVID SOS AND LONG
COVID SUPPORT**

Hearing Date – 28 February 2023

I. Introduction

1. These submissions are made by the Long Covid Groups in advance of the first preliminary hearing for Module 3. The Long Covid Groups welcome the Chair's recognition that Long Covid SOS, Long Covid Kids, Long Covid Support and Long COVID Physio have a significant interest in Module 3 and are well placed to assist the Inquiry in relation to their investigations in this Module. They are committed to assisting the Chair and her team by sharing their lived experience and involvement of advocating for recognition, treatment and research for Long Covid.
2. The Long Covid Groups (save for Long COVID Physio) are Core Participants in Module 2. They note that determinations on procedural matters made in Modules 1 and 2 apply equally to Module 3 (see for example references at §§39 and 42 of CTI's Note for CPs- Module 3 Preliminary Hearings). With this in mind, the following submissions address matters specific to Module 3 without seeking to repeat submissions made for earlier Modules.
3. This note addresses the following topics on the Agenda:
 - a. Long Covid Groups' Interest in Module 3;
 - b. The Scope for Module 3;
 - c. Rule 9 Requests;
 - d. Experts and Witnesses;
 - e. The Listening Exercise and Commemoration;
 - f. Reasonable Adjustments; and
 - g. Covid-19 Safety Measures.

II. Long Covid Groups Interest in Module 3

4. The Long Covid Groups are representative organisations of tens of thousands of adults and children who are surviving victims of Covid-19 and who have suffered life-changing illness and/or disability following SARS-CoV-2 infection. Their professional expertise spans all aspects of the health and education sectors, as well as occupational health and those involved in Covid-19/Long Covid research. The groups work closely with other organisations focused on specific employment sectors, such as Long Covid Nurses and Midwives. They were all formed in the first year of the pandemic and have played a direct and significant role in the characterisation, identification, diagnosis and treatment of Long Covid.

5. Long Covid Support began as a Facebook Group in March 2020, registering as a charitable company in May 2021. Membership of the Facebook peer support group grew quickly to over 57,000 members globally (23,400 in the UK), a Twitter following of 28,200 and 11,300 on Instagram. The charity provides support and information and campaigns for equitable access to high quality healthcare, employment and welfare rights and research into treatment. Long Covid SOS was established in June 2020 as a volunteer-run patient advocacy and campaign group; it has 23,300 Twitter followers, 9,330 on Instagram and 4775 individuals who have signed up to their website¹. Long Covid Kids was established in September 2020 by a group of families whose children became victims of Long Covid². The organisation continues to support 11,000 families through its support services and has 28,200 Twitter followers and 3628 on Instagram. Long COVID Physio was formed in November 2020 to connect physiotherapists and allied healthcare professionals living with Long Covid through social media, provide free educational resources and advocate for safe rehabilitation. It has 465 Facebook members of allied health professionals living with Long COVID, 24,300 Twitter followers, a website with more than 30,000 monthly page views, and an online video series watched more than 1 million times across all social media channels. The value

¹ Long Covid SOS became a registered charity in May 2022

² Long Covid Kids became a registered charity in October 2021

of these groups is also found in their gathering of key insights and peoples' experiences since early on in the pandemic.

6. The most recent ONS survey published on 2 February 2023, shows that 2 million people were experiencing Long Covid symptoms (that is 3% of the population), 77% of whom were suffering with symptoms adversely affecting the ability to undertake day-to-day activities³ and 40,000 are children with symptoms lasting more than one year.⁴ The Long Covid groups therefore represent a statistically significant and considerable cohort of the population, who are suffering or have suffered from diverse symptoms that are multi-dimensional, affecting different organ systems, and often episodic and unpredictable in nature. Their lives have been, and continue to be, directly affected by Covid-19.
7. The Long Covid Groups welcome the Chair's recognition of "*the specific impact of the pandemic on those suffering with Long Covid as a consequence of infection by Covid-19*" as well as the Long Covid Groups' role in assisting the Inquiry in "*understanding the experiences and perspectives of those suffering from Long Covid in the UK, as well as the response of healthcare systems in characterising, diagnosing and treating the condition.*" [CP Determination for Module 3 §12].
8. Long Covid is a patient derived term; it was patient advocacy that was instrumental in the formal recognition of Long Covid as a clinical illness.⁵ Individuals suffering from Long Covid struggled to access appropriate care, diagnosis, and treatment during the Covid-19 pandemic, as decision-makers failed to recognise and respond to Long Covid, with many people reporting that their physiological symptoms were disbelieved and disregarded by health care professionals and attributed to a psychological cause. This led to those suffering from Long Covid to come together and establish peer support organisations to fill a lacuna and advocate on their behalf for appropriate recognition by, and access to, healthcare systems in England.

³ ONS, Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK, 2 February 2023

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/latest>

⁴ Table 3, [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/latest)

⁵ Perego and Callard, *How and why patients made Long Covid*, Social Science & Medicine Journal, published on 7 October 2020;

9. Formed for this very purpose, the Long Covid Groups, drawing on the lived experience, evidence and insight from their members and followers, have⁶:
- a. Advocated for recognition of Long Covid and awareness of its impact on people suffering from Long Covid;
 - b. Been key participants in and proponents for research into Long Covid and the underlying biological mechanisms;
 - c. Advocated for safe and effective care, diagnosis and treatments;
 - d. Consistently called for preventative public health measures to reduce the number of people infected by SARS-Cov-2, a significant percentage of whom will go on to develop Long Covid.
10. Many members of the Long Covid Groups are also healthcare workers (including doctors, nurses and allied health professionals) who have the twin experience of being Long Covid patients as well as frontline workers in the pandemic, or parent and caregivers of a child with Long Covid. Their experience speaks to the adequacy of prevention of the spread of Covid-19 within healthcare settings, the accessibility of care and treatment for Long Covid sufferers, and the impact of Long Covid on employment as healthcare workers. Healthcare workers were and continue to be important patient advocates for the recognition of Long Covid in the early stages of the pandemic.⁷
11. The Long Covid Groups' role is therefore central to the Inquiry's scrutiny of the impact of the pandemic on healthcare systems in England. They are well placed to assist the Inquiry by providing evidence of their efforts to advocate for the recognition, characterisation, diagnosis and treatment of Long Covid and share Long Covid sufferers' experiences of both accessing healthcare and working in the healthcare system during the pandemic.

⁶ An overview of the Long Covid Groups activities has been provided in their Rule 9 responses of 30 January 2023

⁷ See for example: Long COVID Physio website with details of their advocacy: <https://longcovid.physio/peer-support> and a Letter to BMJ *From doctors as patients: a manifesto for tackling persisting symptoms of covid-19* published 15 September 2020 available at: <https://doi.org/10.1136/bmj.m3565>

III. Scope

12. The Long Covid Groups have explained their interest in Module 3 to contextualise their submissions on the provisional scope of the Module. The Long Covid Groups have three observations on this topic.
13. First, the Long Covid Groups note that reference to Long Covid appears only in paragraph 12 of the entire Provisional Outline of Scope for Module 3: *“Post-Covid Condition (including the condition referred to as long Covid) and its diagnosis and treatment.”*
14. The Long Covid Groups welcome the Inquiry’s express investigation of Long Covid’s characterisation, diagnosis and treatment and agree that this must be included within this Module. However, they respectfully encourage the Inquiry not to relegate the investigation of Long Covid to a discrete sub-category or footnote of the Inquiry’s overall assessment of the healthcare consequences of the pandemic.
15. As was accepted by the Chair in granting the Long Covid Groups core participant status, they are all well placed to assist the Inquiry in understanding the diverse experiences and perspectives of those suffering from Long Covid.
16. One example of this relates to point 7 of the provisional outline scope for Module 3, the impact of the pandemic on healthcare workers. Long COVID Physio worked closely with its union, the Chartered Society of Physiotherapy, to advocate for fair disability-inclusive return to work programmes. This arose from the organisation’s membership recognising the myriad difficulties facing healthcare workers with Long Covid which include difficulties with fair representation, challenges in being accepted onto the NHS sick pay scheme and a lack of uniformity of approach to healthcare workers suffering from Long Covid. Long Covid Support collaborated with TUC equality to conduct a survey in 2021 into people with Long Covid’s experiences with accessing work. This

survey had over 3000 responses, many of whom were key workers including healthcare workers.⁸

17. People with Long Covid had a distinct and distinguishable experience of healthcare provision and treatment which would warrant further investigation in Module 3.⁹
18. For example, despite widespread reporting about Long Covid from May 2020,¹⁰ as late as December 2020, the All Party Parliamentary Group (APPG) on Coronavirus Interim Report recommended that the UK Government “*formally recognises Long Covid and expand research on the long term effects of Covid-19...*” and that the UK government “*collect and publish figures on the number of people living with Long Covid.*”¹¹ NICE issued *Covid rapid guidelines: managing the long-term effects of COVID-19* on 18 December 2020.¹² The delay in formally recognising Long Covid or counting the number affected (e.g. limited use of RIDDOR reporting in healthcare settings) had an inevitable impact on people with Long Covid who have reported difficulties accessing a diagnosis, treatment and employment support for their condition.¹³
19. The APPG on Coronavirus’s Report on Long Covid published in March 2022 made a number of findings related to access to treatment for people with Long Covid including that the “*UK Government’s failure to establish a comprehensive Long Covid care system has resulted in Long Covid patients turning to the private sector in the absence of NHS care.*” Further, that the UK Government has not “*adequately funded research to identify treatments for Long Covid...*”¹⁴ These are merely examples of matters which

⁸ TUC, *Workers’ experiences of Long Covid*, 20 June 2021, <https://www.tuc.org.uk/research-analysis/reports/workers-experiences-long-covid>

⁹ Ladds et al, *Developing services for Long Covid: lessons from a study of wounded healers*, *Clinical Medical Journal*, January 2021 <https://www.rcpjournals.org/content/clinmedicine/21/1/59>

¹⁰ Perego and Callard, *How and why patients made Long Covid*, *Social Science & Medicine Journal*, published on 7 October 2020; APPG on Coronavirus, *Long Covid Report* March 2022

¹¹ See §§37-39 of APPG on Coronavirus, *Interim Report*, December 2020

¹² NICE, *Covid-19 rapid guideline: managing the Long term effects of COVID-19*, published on 3 November 2020; APPG on Coronavirus, *Long Covid Report*, March 2022

¹³ See patient testimony on page 10 APPG on Coronavirus, *Long Covid Report*, March 2022

¹⁴ APPG on Coronavirus, *Long Covid Report*, March 2022

the Long Covid Groups expect would warrant further investigation in Module 3 of this Inquiry.¹⁵

20. Secondly, the Long Covid Groups note that CTI has identified areas of particular interest in Module 3 at §33 of the note which appear at first glance to prematurely narrow the published provisional scope of the Module (repeated at §32 CTI's Note). The Long Covid Groups observed that there is no explicit reference to Long Covid in the areas identified to be of particular interest to the Inquiry at §33. This would be a glaring omission if not for the fact that Long Covid *could* be read to be included within the areas listed at §33. They seek clarification that this is, and indeed should be, the case.
21. Their experience of Long Covid being overlooked during the pandemic means that the Long Covid Groups cannot assume that Long Covid will necessarily be recognised by the Inquiry. They also respectfully encourage the Inquiry to recognise that the impact of decision making in health care systems on people with Long Covid, and the treatment and quality of care afforded to those with Long Covid was different to that provided to those who experienced acute infections of Covid-19. This distinction will necessarily inform the investigations in Module 3 and, the Long Covid Groups hope, the approach taken to the scope of Module 3.
22. Finally, the Long Covid Groups welcome the indication from CTI that the issues will be further developed following receipt of further evidence and responses to Rule 9 requests [§§31-32 of CTI's Note]. The Long Covid Groups understand that CTI will soon be publishing a list of issues for Module 1 in advance of the Module 1 hearing.¹⁶ The Long Covid Groups would respectfully invite the Inquiry to consider disclosure of a similar list of issues to Core Participants to Module 3 as early as possible followed by a process of consultation before finalising the List of Issues. The development of a List

¹⁵ The Health and Social Care Committee Inquiry into Clearing the Backlog caused by the Pandemic at paragraph 60-61 made recommendations regarding Long Covid, noting that “*during our inquiry we heard heart-rending testimony from people who had struggled to access the care they needed, and who did not feel believed or cared for. This is simply not acceptable.*” HoC Health and Social Care Committee, *Clearing the Backlog caused by the pandemic*, 9th Report of Session 2021-22 7 December 2021
<https://committees.parliament.uk/publications/8352/documents/85020/default/>

¹⁶ Ruling following the Second Module 1 Preliminary Hearing on 14 February 2022.

of Issues in consultation with Core Participants has become good practice in public inquiries.¹⁷

23. While we understand the need to review further disclosure before developing the scope of the Module, the early publication of a draft List of Issues will i) allay any concerns that particular topics may be overlooked, ii) provide an opportunity for Core Participants to assist the Inquiry by identifying any limited issues that may need to be included and iii) focus minds given the broad scope of the terms of reference and scope of the Module. The identification of the absence of any reference to Long Covid in the list of areas of particular interest in Module 3 at §33 of CTI's note is an example of where Long Covid Groups can assist the Inquiry in this task.

IV. Rule 9 Requests

24. The Long Covid Groups note that initial questionnaires have been sent to over 550 organisations [§41 CTI Note] and await the monthly updates to be provided after the preliminary hearing. The Long Covid Groups further note that organisations have been asked to flag important materials [§38 CTI Note]. It is assumed that Rule 9 recipients will continue to be required to provide corporate statements setting out a narrative of relevant events and of the lessons learned, in line with the Chair's Ruling on Module 1 [§8] following the first preliminary hearing. The Long Covid Groups invite clarification that this approach will continue.

V. Experts and Witnesses

25. The Long Covid Groups welcome the Inquiry's confirmation that a number of experts are likely to provide evidence that is specific to Module 3.
26. The Long Covid Groups provide three observations in relation to lay and expert witnesses at this stage of the Inquiry.

¹⁷ Beer KC, *Public Inquiries*, Oxford, OUP, 2011 at §5.21

27. First, 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 [§56 CTI Note]. They note that Core Participants will be provided with an opportunity to provide observations on the expert witnesses and their instructions¹⁸ which we agree will ensure effective participation.
28. 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 issues under investigation or may have publicly expressed a view on the matters within scope of Module 3. Additionally, the subject matter itself has been subject to polarising views within relevant disciplines.
29. In view of these sensitivities, Long Covid Groups would appreciate an early opportunity to provide observations on the expert witnesses that have been, or are proposed to being, instructed and on the scope of their instructions.
30. 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 on this issue 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.
31. Early disclosure of the letters of instruction, well in advance of disclosure of the substantive report itself, will allow Core Participants to identify missing subject matters for the expert to opine upon in their report.
32. Secondly, in relation to the specialist areas which lay and expert witnesses will be giving evidence on in Module 3 [§58 CTI note], Long Covid Groups would strongly suggest that this included expertise on post-covid sequelae - Long Covid - and its recognition, as well as testimony from people who suffered from Long Covid and frontline health workers who became Long Covid sufferers. This would assist the Inquiry in understanding when Public Health England/UK Health Security Agency

¹⁸ Ruling following Module 1 Preliminary Hearing, 17 October 2022 § 22

(UKHSA) and the UK's healthcare systems should have been factoring Long Covid into their decision making and in understanding the risks any delay posed to patients and healthcare workers.

33. Finally, the Long Covid Groups welcome CTI's recognition that lay and expert witnesses will be likely to give evidence in Module 3 [§58 CTI Note].
34. The Long Covid Groups represent the collective interests of the surviving victims of Covid-19 who are the patients and healthcare workers who have suffered life changing illness and/or disability as a consequence of infection from Covid-19.
35. As support and advocacy organisations established to fill the gaps in understanding of the treatment and diagnosis of Long Covid, the Long Covid Groups have direct and relevant experience of the healthcare system's response to the pandemic including primary, secondary and tertiary healthcare¹⁹.
36. They are also able to provide expert evidence on how and why patient advocacy was instrumental to the public and clinical recognition of Long Covid²⁰ and the systemic implications this had on Long Covid sufferers. We submit that this is highly relevant to a proper assessment of the matters under scrutiny in this Module.
37. We invite the Inquiry team to give early consideration to members of the Long Covid Groups providing formal evidence in Module 3.
38. We reserve the right to make further submissions on experts and witnesses at a later stage.

¹⁹ See the preliminary questionnaires filed on 30 January 2023

²⁰ Perego and Callard, *How and why patients made Long Covid*, Social Science & Medicine Journal, published on 7 October 2020

VI. The Listening Exercise and Commemoration

39. 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.
40. The Long Covid Groups wish to assist the Listening Exercise, recognising that it has an important function to serve, whilst also urging that this non-legal process does not replace the need for individual evidence to be heard in the Inquiry.
41. We note that STI's update of 27 January 2023 indicates that the Inquiry will take a more targeted approach to listening to ensure that it is hearing from seldom heard groups. We also note that all staff conducting the Listening Exercise interviews will be trained on trauma-informed approaches. We welcome these indications and ask for clarity on how seldom heard groups will be appropriately engaged, and detail on what bespoke training staff will be provided with.
42. The Long Covid Groups invite the Inquiry team to provide clarity on what reasonable adjustments will be put in place to ensure that people living with disability and the clinically vulnerable are able to meaningfully input and participate in Every Story Matters.
43. The Long Covid Groups would strongly suggest that the Listening Exercise continue to be developed in consultation with Core Participants who have a wealth of experience in this area, including disability inclusion and working with children and young people.
44. Early input from Core Participants with experience in handling trauma survivors of all ages would assist the Inquiry in designing an effective Listening Exercise where the full breadth of perspectives is captured, as well as ensuring that the process will be as constructive and accessible as possible for those who have been affected by the pandemic.

45. In relation to the Commemoration, the Long Covid Groups were pleased to have been included in consultation towards the end of 2022 and ask that this consultative process continues as the Commemoration takes shape.
46. The Long Covid Groups welcome the Chair's decision to include video content at the start of every Module and hope that these videos will also reflect and appropriately represent the experiences of Long Covid sufferers who remain surviving victims of the pandemic.
47. It is noted from STI's note [§4.7] that the assistance of the Bereaved Families has been sought and the Long Covid Groups have offered their additional assistance to progress the tapestry and video content.

VII. Reasonable Adjustments

48. The Long Covid Groups respectfully request the Inquiry to consider reasonable adjustments to the entire process of the Inquiry. The Chair will be mindful of her statutory obligation under section 19(1) of the Inquiries Act 2005 to take reasonable steps to ensure that members of the public can follow the proceedings in person or online and obtain or view a record of the evidence.
49. We remind the Inquiry team that this should include reasonable adjustments for the preparation, as well as the venue, proceedings and publication of evidence, in order to ensure that the Inquiry is adequately accessible to the public.
50. The Long Covid Groups represent previously fit and healthy individuals who have suffered profound, disabling changes to their health and lives caused by the effects of Covid-19. As Long Covid sufferers, the Long Covid Groups find the speed with which they are able to review documents and provide meaningful input compromised.
51. Long Covid Groups wish to raise concern over the tight time frames that they as client groups are expected to review submissions within. There were only six working days from the provision of CTI's Note for Module 3 until the deadline to lodge written submissions in response. This provided minimal time for disabled clients to review

written submissions once drafted and impairs their ability to meaningfully contribute as Core Participants.

52. The Long Covid Groups appreciate that the Inquiry is working at speed. It is respectfully requested that disabled client groups be provided with adequate time to review documents and provide instructions in order to properly assist the Inquiry and fulfil their role as Core Participants.

VIII. Covid-19 Safety Measures

53. 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. They would encourage the Inquiry to add a commitment to ensure that HEPA filters, ventilation and CO2 monitors will be assured in all venues.

54. Studies have found that air filtration using HEPA filters,²¹ and CO2 monitors that assess levels of ventilation, alongside other ventilation methods, successfully reduces the transmission of airborne pathogens including SARS-COV-2.²²

55. The Long Covid Groups have invited the Inquiry team to consider using both in their permanent venue. They welcome the commitment to consider appropriate ventilation while exploring a permanent venue and propose this measure as a simple and relatively cost-effective method of infection prevention and control, to minimise the risk of Covid-19 transmission, to avoid disruption and potential harm for all participants during the hearing process.

²¹ 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>

²² EMG, *Role of Ventilation in Controlling SARS-CoV-2 Transmission*, Considered at SAGE 60 on 1 October 2020 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/928720/S0789_EMG_Role_of_Ventilation_in_Controlling_SARS-CoV-2_Transmission.pdf

IX. Conclusion

56. The Long Covid groups are willing to assist the Inquiry with their investigations at all stages and invite the Inquiry team to contact them should they need any further assistance.

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