

# NOTICE OF DETERMINATION

# **CORE PARTICIPANT APPLICATION**

# MODULE 1 - LONG COVID KIDS, LONG COVID PHYSIO, LONG COVID SOS AND LONG COVID SUPPORT

#### Introduction

- 1. In my Opening Statement on 21 July 2022, I explained that Modules would be announced and opened in sequence, with those wishing to take a formal role in the Inquiry invited to apply to become Core Participants for each module. On the same day, the Inquiry opened Module 1 and invited anyone who wished to be considered as a Core Participant to that Module to submit an application in writing to the Solicitor to the Inquiry by 16 August 2022.
- The <u>Provisional Outline of Scope</u> for Module 1 provides that this module will examine
  the resilience and preparedness of the United Kingdom for a Coronavirus pandemic.
  Further modules will be announced and opened in due course, to address other
  aspects of the Inquiry's Terms of Reference.
- On 15 August 2022 the Inquiry received an application from Long Covid Kids, Long COVID Physio, Long Covid SOS and Long Covid Support ("the Applicants") for Core Participant status in Module 1.
- 4. I made a provisional decision not to designate the Applicants as Core Participants in Module 1, thereby declining their application ("the Provisional Decision"), on 7 September 2022. The Applicants were provided with an opportunity to renew the application in writing by 4pm on 16 September 2022.



5. On 13 September 2022 the Applicants submitted a renewed application for Core Participant status in Module 1. This notice sets out my determination of their application for Core Participant status in Module 1.

# **Application**

- 6. Applications for Core Participant status are considered in accordance with Rule 5 of the Inquiry Rules 2006, which provides:
  - 5.—(1) The chairman may designate a person as a core participant at any time during the course of the inquiry, provided that person consents to being so designated.
  - (2) In deciding whether to designate a person as a core participant, the chairman must in particular consider whether—
    - (a) the person played, or may have played, a direct and significant role in relation to the matters to which the inquiry relates;
    - (b) the person has a significant interest in an important aspect of the matters to which the inquiry relates; or
    - (c) the person may be subject to explicit or significant criticism during the inquiry proceedings or in the report, or in any interim report.
  - (3) A person ceases to be a core participant on—
    - (a) the date specified by the chairman in writing; or
    - (b) the end of the inquiry.
- 7. In accordance with the approach set out in my Opening Statement and the Inquiry's <u>Core Participant Protocol</u>, I have considered whether the application fulfils the requirements set out in Rule 5(2) in relation to the issues set out in the Provisional Outline of Scope for Module 1.

# **Summary of Application**

8. The Applicants' original application is made on behalf of four organisations. The application states that they are representative bodies providing support for, and



advocacy on behalf of, thousands of people suffering from Long Covid. The application explains that those represented by the applicants have suffered serious physical illness, harm and distress as a consequence of Covid-19: such that whilst they have survived infection, they remain victims of the virus as they suffered/continue to suffer chronic illness and/or disability following infection.

- 9. The Applicants say that their representation of many people who have suffered chronic illness and/or disability as a consequence of Covid-19, along with their involvement in raising reasonable, legitimate and evidenced concerns to the Government, NHSE and others about Long Covid, means that they each played a direct and significant role in relation to the matters to which the Outline of Scope for Module 1 relates for the purposes of satisfying Rule 5(2)(a). The Applicants also say that their desire to understand what, if any, consideration was given to the potential chronic effects of an illness in a pandemic in terms of emergency planning and preparedness means that they have a significant interest in an important aspect of the matters to which the Outline of Scope for Module 1 relates for the purposes of satisfying Rule 5(2)(b). The original application sets out in detail those aspects of the Outline of Scope for Module 1 in which the Applicants cite having a particularly significant interest.
- 10. The renewed application elaborates on the Applicants' concerns regarding, and wishes to have fully ventilated, the extent to which the Government recognised that chronic illness was a possible outcome of a pandemic and played a direct or significant part in the Government's pandemic preparedness and planning. In particular, they contend that their experience is central to Module 1's assessment of whether Public Health Services were properly prepared to anticipate and respond to longer term or chronic health related challenges, as well acute illness in a pandemic.
- 11. The Applicants assert that as persons who have suffered life changing chronic illness and/or disability, the Long Covid Groups are akin to survivor groups, and should be



treated as having sufficient interest in the matters for investigation under Module 1. They contend that Long Covid is self-evidently not death, but that for this cohort of people, the harm caused by the virus has been catastrophic with overwhelming harm and loss associated with severe illness. They say it is not appropriate to compare sufferers of Long Covid with other people that have been adversely affected by the pandemic because this cohort's position created by the disease, unlike others who may have been adversely affected by the measures taken in response to the pandemic, is much more akin to the bereaved.

12. The Applicants set out how they say their experience of the core symptoms and effects of Long Covid are crucial to Module 1's understanding of the basic characteristics and epidemiology of SARS-CoV-2 and Covid-19 and that they therefore have a significant interest in ensuring that the Inquiry's examination of epidemiology fully considers the potential mechanisms contributing to the pathophysiology of Long Covid.

# **Decision for the Applicant**

- 13. I wish to extend my deep sympathy to all those represented by the Applicants who have suffered, and continue to suffer, from adverse health, illness and disability as a result of the Covid-19 pandemic. I acknowledge that Long Covid sufferers have plainly been seriously affected by the pandemic.
- 14. I have considered with great care everything that is said in the renewed application. I have also reminded myself of what was said in the original application to enable me to assess the merits of the application for Core Participant status as a whole.
- 15. It has been helpful to understand more about how the Applicants consider themselves to have an interest in applying for Core Participant status in Module 1 and I appreciate the time and care taken in providing the further detail set out in their renewed



application. I also acknowledge that the Applicants bring a representative and valuable voice to those suffering from Long Covid. However, given the wide impact of the pandemic there will inevitably be a very significant number of organisations and groups whose members were impacted by the pandemic and accordingly, and understandably, have a very real interest in understanding how that impact could or should have been mitigated by planning in advance.

- 16. I do not doubt that the Applicants are organisations with a deep and genuine concern for the extent to which past planning for pandemics considered the potential outcome of individuals suffering from chronic illnesses. However, Module 1 is primarily concerned with the core systems and structures within the United Kingdom for preparedness and resilience for an event such as the Covid-19 pandemic and with high-level pandemic resilience, preparedness and planning. It will examine whether the correct structures, bodies, procedures and policies were in place at UK and at regional and national levels and look at their history, development, co-operation, and performance. In terms of inquiring into pandemic planning, this will include examination of the forecasting processes, the extent to which lessons were learned from knowledge of actual events and simulated exercises, the degree of readiness preparation and the general resources that were available. The Module is therefore concerned with how the relevant entities prepared and whether they were ready by way of general response.
- 17. In order to manage the investigative work of the Inquiry in as proportionate manner as possible and to ensure the timely publication of my findings, lessons learned and recommendations for the future, it is not possible for Module 1 to consider the state of preparedness by reference to the potential impact of an event such as the Covid-19 pandemic on all kinds of eventualities. I will of course keep the Provisional Outline of Scope for Module 1 under review and, as I explained out in my Opening Statement, other aspects of the Inquiry's Terms of Reference will be covered in future modules for which Provisional Outlines of Scope will be prepared and published in due course.



- 18. I have carefully considered the Applicants' characterisation of their distinct nature as survivor groups. In that connection, I note that the renewed application also makes detailed submissions based on the Inquiry having obligations under the European Convention on Human Rights ("ECHR"), including the duty to conduct a prompt and effective investigation of apparent breaches of Articles 2 and 3 ECHR and the right of participation of victims' families in the course of carrying out that investigation. I have considered these submissions with great care. However, regardless of the extent to which the Applicants' Articles 2 and 3 rights are engaged in the context of this Inquiry, there is no obligation under Articles 2 and 3 for the Applicants to be designated as Core Participants in it and Articles 2 and 3 do not require me to grant the Applicants Core Participant status in Module 1.
- 19. I do not accept the Applicants' contention that if they are not granted Core Participant Status in Module 1, "the Inquiry will fall into the same errors as the Government when it comes to investigating the pandemic. That is, that Long Covid will become an afterthought, rather than forming a key part of the investigation particularly bearing in mind the massive public health, economic and social burden caused by Long Covid". I have not yet heard any evidence, let alone made findings and retain a completely open mind at this stage as to whether or not the Government did make any errors, as alleged by the Applicants or otherwise. More generally, however, and to the extent that the issues raised by the Applicants are intended to be addressed by Module 1 as opposed to later modules, I have every confidence in the Inquiry's independent legal team to pursue all legitimate lines of inquiry with the investigatory and analytical rigour that a statutory inquiry of this scale and importance demands. This extends both to the points raised in the renewed application about the preparedness of the UK in relation to chronic illnesses, as well as the basic characteristics and epidemiology of SARS-CoV-2 and Covid-19.



- 20. Further, there are a number of ways in which the Applicants can participate in Module 1 without being Core Participants. For example, it is not necessary for an individual or organisation to be a Core Participant in order to provide evidence to the Inquiry. The applicants may have relevant information to give in relation to matters being examined in the Inquiry and the Inquiry will be seeking evidence in due course from a large number of individuals, organisations and bodies.
- 21. The Inquiry will also listen to and consider carefully the experiences of those who have suffered hardship or loss as a result of the pandemic, through its listening exercise. I made clear in my Opening Statement that this listening exercise is a significant and important task which will lead to summary reports of the impact of the pandemic to be used as evidence during the Inquiry's module hearings. The Applicants and those they represent will have the opportunity to contribute to the Inquiry, through the listening exercise if they choose.
- 22. For all of those reasons, having considered all of the information provided by the Applicants in light of the Provisional Outline of Scope for Module 1, I consider that the Applicants did not play a direct and significant role in relation to the matters sought to be investigated in Module 1, nor do they have a significant interest in an important aspect of the matters to which Module 1 relates. Accordingly, in my discretion I decline to designate them as Core Participants in Module 1.
- 23. My decision not to designate the Applicant as a Core Participant in Module 1 does not preclude the Applicant from making any further applications in respect of any later modules. The Applicants are encouraged to consider making an application for Core Participant status in a future module dealing directly with healthcare and Long Covid and with health inequalities. I will consider any future applications the Applicant may wish to make on their merits at the time they are made.



24. Finally, I acknowledge the Applicants' concluding submission that if I decide to refuse their renewed application, they "respectfully and exceptionally request an oral hearing". In my Provisional Decision I expressed my intention to determine any applications on paper without oral submissions, other than in exceptional circumstances. I have been greatly assisted in my determination by the significant amount of further evidence and explanation that has been provided by the Applicants in their renewed application. In light of the considerable information with which I have been provided in support of the applications, I am not persuaded that the renewed application raises sufficient reasons to justify the exceptional need to hear oral submissions.

Rt Hon Baroness Heather Hallett DBE
Chair of the UK Covid-19 Inquiry
28 September 2022