

NOTICE OF DETERMINATION CORE PARTICIPANT APPLICATION

MODULE 4 - LONG COVID GROUP COMPRISING LONG COVID KIDS, LONG COVID PHYSIO, LONG COVID SOS AND LONG COVID SUPPORT ("LONG COVID ORGANISATIONS")

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 5 June 2023, the Inquiry opened Module 4 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 30 June 2023.
- 2. The Inquiry has published the <u>Provisional Outline of Scope</u> for Module 4, which states that this module will consider a range of issues relating to the development of Covid-19 vaccines and the implementation of the vaccine rollout programme in England, Wales, Scotland and Northern Ireland. Issues relating to the treatment of Covid-19 through both existing and new medications will be examined in parallel. Further modules will be announced and opened in due course, to address other aspects of the Inquiry's Terms of Reference.
- 3. On 30 June 2023 the Inquiry received an application from Long Covid Group Comprising Long Covid Kids, Long Covid Physio, Long Covid SOS and Long Covid Support ("Long Covid Organisations" or "LCOs") ("the Applicant") for Core Participant status in Module 4.
- 4. I made a provisional decision not to designate the Long Covid Organisations as a Core Participant in Module 4, thereby declining their application ("the Provisional Decision"),

- on 17 July 2023. The Long Covid Organisations were provided with an opportunity to renew the application in writing by 4pm on 24 July 2023.
- On 24 July 2023, the Long Covid Organisations submitted a renewed application for Core Participant status in Module 4. This notice sets out my determination of the Long Covid Organisations' application for Core Participant status in Module 4.

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 Core Participant Protocol, 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 4.

Summary of Application

8. In its original application, the LCOs relied on Rules 5(2)(a) and 5(2)(b).

- 9. In respect of Rule 5(2)(b) the LCOs said that their significant interest in Module 4 arises as a victim cohort that has suffered physical harm and interference with bodily integrity sufficient to engage Article 3 ECHR. The application was put on the basis that, having been directly affected by the disease, they had a significant interest in the development of available therapeutics for Long Covid and the impact of vaccines on preventing Covid-19 and Long Covid. The LCOs said they could assist the Inquiry on issues relating to vaccine confidence, namely through provision of relevant information and counter evidence relevant to the stance perpetuated by what the LCOs describe as "anti-vaccine groups" that Long Covid is caused by vaccine injury. The LCOs also said they could assist the Inquiry in relation to vaccine prioritisation for children and young people in that they submitted that it is clear that vaccination could prevent Long Covid in children.
- 10. As to Rule 5(2)(a), the LCOs said they have played a direct and significant role given their (i) advocacy; (ii) evidence and submissions to the Long Covid National Taskforce, APPG and others; and (iii) role in collating, researching and providing an evidence base used by the Government and public health bodies.
- 11. In their renewed application, the LCOs say that the investigation of vaccines and therapeutics for the prevention and treatment of acute infections of Covid-19 cannot be artificially separated from the investigation of the use of the same vaccines and therapeutics to treat Long Covid. The LCOs say that they have a significant interest for the purposes of Rule 5(2)(b) given that (i) the only known means to avoid Long Covid is to avoid an acute infection of Covid-19 and that vaccines are a core preventative measure; (ii) vaccines reduce an individual's chances of developing Long Covid and there is evidence that vaccines alleviate pre-existing Long Covid symptoms; and (iii) vaccines reduce the severity of Long Covid symptoms. The LCOs also say that they have a significant interest in therapeutics. In particular, they have an interest in (i) the development of new therapeutics for treatment of acute infections of Covid-19 as they relate to the development of Long Covid; and (ii) it would be reasonable and proportionate for the Inquiry to investigate the development of new therapeutics for Long Covid alongside therapeutics for acute infections of Covid-19 in Module 4. The LCOs further point to the fact that (i) LCOs represent a large proportion of people with Long Covid; (ii) they have a direct interest in how their collective interests as sufferers and potential future sufferers of Long Covid were recognised and responded to; (iii)

they actively advocated for the development of vaccines and therapeutics during the relevant period; (iv) they are unable adequately to represent their collective interests as Long Covid sufferers without Core Participant status as alternative mechanisms are insufficient; and (v) representation of Core Participants in the Inquiry will be skewed towards Government representatives without balancing representation from affected organisations with a direct and significant interest.

Decision for the Applicants

- 12. I have considered with great care everything that is said in the Applicant' 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 as a whole. Having done so, in my discretion, I have decided not to grant the Applicant Core Participant status in Module 4 of the Inquiry.
- 13. I am grateful to the Applicant for taking care to set out more detail in its renewed application. As a group which has raised various concerns about Long Covid in relation to both vaccines and therapeutics, the Applicant can be said to have an interest in matters relevant to Module 4. However, this in itself does not amount to a significant interest for the purposes of Rule 5(2)(b).
- 14. I am determined to run the Inquiry as thoroughly and as efficiently as possible, bearing in mind the Inquiry's wide-ranging terms of reference and the need for the Inquiry process to be rigorous and fair. Given the vast numbers of people who were involved with, or adversely affected by, the Covid-19 pandemic, very many people in the United Kingdom could potentially have an interest in it.
- 15. In reaching my decision, I reiterate that the characterisation and identification of Post-Covid Condition (including Long Covid) and its diagnosis and treatment falls within the provisional outline of scope for Module 3 and that the Applicant have been granted Core Participant status in that Module.
- 16. I will keep the scope of Module 4 under review. My decision not to designate the Applicant as a Core Participant in Module 4 does not preclude it from making any

further applications in respect of later modules. I will consider any future applications the Applicant may wish to make on their merits at the time they are made.

Rt Hon Baroness Heather Hallett DBE
Chair of the UK Covid-19 Inquiry
4 August 2023