



RECOGNITION FOR LONG COVID CHARITIES REPRESENTING VICTIMS OF COVID-19 AS THEY ARE GRANTED CORE PARTICIPANT STATUS IN MODULE 2 OF THE UK COVID INQUIRY

Three key Long Covid charities - Long Covid SOS, Long Covid Kids and Long Covid Support - announced today they have been granted core participant status in Module 2 of the UK Covid-19 Inquiry, meaning they now form part of the official inquiry into the Government's handling and decision-making around the Covid pandemic.

All three organisations have been fighting for recognition and providing support for the millions of adults, children and young people across the UK - victims of Covid infections, either mild or severe – who went on to develop Long Covid, a multi-system condition which can cause life-changing illness.

Latest figures from [ONS](#) suggest that 2.3 million people in the UK currently have Long Covid. Included in this figure are [101,000](#) children aged 16 and under and almost 1 million people aged 25-49 in the prime of their working lives. 1.1 million have been sick for over a year.

Standing together with Covid-19 Bereaved Families for Justice in seeking justice for lost and radically changed lives, the groups are calling for the inquiry to focus on the following key questions:

- Why was there no acknowledgement early in the pandemic that SARS-CoV-2 could cause a devastating chronic illness despite evidence from previous pandemics? As a result, those with Long Covid were not believed and have struggled ever since to get care.
- Why has the impact of Long Covid been consistently ignored in government policy making decisions? This has led to a lack of awareness among the general public regarding the true risks of Long Covid, preventing them from making informed decisions about taking necessary precautions.
- Why is healthcare funding for Long Covid so inadequate in the face of a huge and growing demand? There are still no validated treatments for Long Covid and it remains poorly understood by many medical professionals, resulting in unsatisfactory care or no treatment at all.
- Why are there no public health measures in place to stop more people from joining the Long Covid statistics? This is a preventable health condition which currently has no cure.
- Why were children's Covid-19 infections, hospital admissions and deaths analysed against adult data rather than the paediatric population?

Speaking today, Long Covid SOS co-founder, **Ondine Sherwood** said:

"We are glad that the UK Covid Inquiry has recognised the reality of Long Covid and granted us Core Participant status.

"We are determined to work together to act as one voice on behalf of the millions of people with Long Covid, the surviving victims of this pandemic - stuck, trapped, and unwell and still struggling to be recognised or get any form of effective treatment.

"Since 2020 we have been highlighting both the risks and the lived reality of Long Covid to the UK Government, to the WHO, to NHS England and many others - that it is not only the elderly or those severely unwell that develop this debilitating condition, but fit and active children, young people and working age adults who are sadly still joining our numbers every day.

"Lessons need to be learned - and quickly - so that we can find ways to prevent people from developing Long Covid and to fast-track research on treatments. The growing numbers of people with long term illness and shortages of key frontline staff show how the cost of inaction on Long Covid, on both a personal, individual level and economically as a country is extremely damaging."

Ami Banerjee, Long Covid SOS Trustee and Professor of Clinical Data Science and Honorary Consultant Cardiologist at University College London said:

“The pandemic continues to cause avoidable harm, whether through short-term direct and indirect effects or Long Covid. It is essential that people with lived experience are front and centre of this inquiry, and are heard, so I am pleased to see Long Covid patient organisations such as Long Covid SOS playing their part in the inquiry.”

Michael Rosen, Patron, Long Covid Kids said:

“If Long Covid Kids are able to submit evidence to the Covid Inquiry, I would be delighted. Covid reaches sections of the population who sometimes do not hit the headlines - very young long term sufferers of Long Covid being amongst these groups. I very much hope the Inquiry will hear what young people have been and are still going through”

Sammie McFarland, Chief Executive Officer & Founder Long Covid Kids said:

“Long Covid Kids are committed to ensuring that all children should be able to thrive and look forward to a positive future. Children are our future. We welcome the opportunity to participate collaboratively as core applicants in the Covid Inquiry to represent the growing community of families, children and young people living with long term health effects of SARS-CoV-2. It is time to bring Long Covid and Paediatric Multisystem Syndrome (PIMS) to the forefront of the public conversation.

“Long Covid is a preventable condition; there is no time to lose to reduce the risk of repeated SARS-CoV-2 infection and minimise the incidence of Long Covid. We sincerely hope participation in the Inquiry will assist the government to this end. Children are the victims of the early false narrative that said children and young people were not a risk from Sars-CoV-2. Their families are living with the heart-breaking reality that this reassurance was wrong.

“Families are significantly impacted. Increased caring duties prohibit employment opportunities, crippling household incomes at a time when the cost of living is already hurting families. Children are unable to access education and often miss out on social activities.

“Our recent [reinfection survey](#) in collaboration with Long Covid Support, makes clear that reinfection makes Long Covid worse in 58% of CYP who were in recovery or remission. It also highlights that each repeat infection poses a risk of Long Covid. Paediatric biomedical research is a priority.”

Natalie Rogers, Long Covid Support Founding Trustee said:

“We stand by those bereaved due to Covid-19 in campaigning for lessons to be learned swiftly in order to save lives. The legacy of the pandemic is sadly not only those who have already lost loved ones but the long-term damage that the SARS-CoV-2 virus has had and is still having on huge numbers of people of all ages.

“Whilst death or survival were the two publicised outcomes, the long-term effects were barely communicated. Despite Long Covid being brought to the attention of the government back in Spring 2020 there has been little in terms of public awareness campaigns. The best way to avoid Long Covid is to avoid infection.

“Long Covid is resulting in permanent organ damage, shortened life expectancy, life changing disabilities, people taking their own lives, loss of work, a reduced workforce and additional pressure on the NHS. The true extent of these ramifications, in both health and economic terms, will continue to be felt long after the Inquiry has reached its conclusion.

“It is important that the Inquiry recognises and acknowledges the mistakes that have been made on behalf of the families already affected. It is equally important that a rapid review is conducted and that those in charge act now to avoid these mistakes impacting lives on a catastrophic scale for generations to come.”

Danny Altmann, Long Covid Support Trustee and Professor of Immunology at Imperial College London said:

“It sends out a critical message for Long Covid groups to have Core Participant status. There are many ways to measure the tragedies of the pandemic, the costs and the appropriateness of measures adopted. The national burden of Long Covid that has ensued, including the 700,000 additional cases accrued during

Omicron in 2022 while learning to 'live with the virus' is a huge aspect of the pandemic that will still be with us for years to come. That is, even when those early horrors of the initial waves are for many a dim memory, we will still be grappling the Long Covid cost in lost lives, educations, jobs, livelihoods - not to mention the long term strain on NHS resources of a patient load equivalent again to all of cardiology or rheumatology.”

Anthony Metzger KC of Goldsmith Chambers, lead counsel for the Long Covid groups, said:

“Long Covid SOS, Long Covid Kids and Long Covid Support are grateful that Baroness Hallett has recognised that Long Covid Groups are well placed to assist Module 2 of the Inquiry as Core Participants and welcome this opportunity to help the investigation into government decision-making during the pandemic.

“These three Groups are representative organisations of tens of thousands of adult and child surviving victims of Covid-19 who have suffered life-changing illness and /or disability following infection. The organisations have 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 with Covid-19. It is of vital importance that the Inquiry includes the perspectives of Long Covid survivors, who presently include 2.3 million people comprising 3.5% of the population”.

Jane Ryan, Partner at Bhatt Murphy Solicitors said:

“It is imperative that the evidence of those that have suffered Long Covid is at the heart of this Inquiry. As victims of Covid-19 my clients will assist the Inquiry to ensure that there is accountability, justice and change for the future”

Background

- NHS England has set up 90 Long Covid clinics however there are currently **no validated treatments, no cure and only symptom relief**. Families consistently report varied challenges gaining access to the paediatric hubs. These clinics are accepting no more than [5000 new referrals](#) each month which means it will take more than five years for the currently most severely impacted in England to be seen. There are currently no Long Covid clinics in Scotland with only patchy provision in Wales and Northern Ireland.
- Long Covid is having a direct impact on the economy. The Bank of England [highlighted](#) the contribution Long Covid has made towards an estimated 440,000 missing workers and more than [10,000 long term absences](#) among NHS staff are Covid related. The Institute of Fiscal Affairs recently [reported](#) that 110,000 workers are on sick leave due to Long Covid.
- Many with Long Covid are unable to work and support their families and are being forced to sell their homes. Social care, healthcare and education are the sectors [most impacted](#) but as yet the condition has not been classified as an [Occupational Disease](#).
- Impact on education is not being recorded. Children and young people living with Long Covid face cognitive, physical and logistical difficulties accessing education and sitting exams. At present there is no method to document these children, their needs or absences.
- The [UK Covid-19 Inquiry](#) is an independent public inquiry set up to examine the UK’s response to and impact of the Covid-19 pandemic, and learn lessons for the future. It was officially launched on 21st July 2022 by Baroness Hallett. Module 2 will examine political and administrative decision-making of the UK and devolved governments, with a particular focus on early 2020. Preliminary hearings for module 2 will begin on Monday 31 October.

About the core participants:

Long Covid SOS was established during the early months of the pandemic, staffed entirely by volunteers with lived experience of Long Covid. It is now a registered charity and has played a major role in generating awareness of the condition, initiating dialogues with the [WHO](#) and [NHS England](#) in August/September 2020. The written and oral evidence Long Covid SOS [submitted](#) to the Health and Social

Care Select Committee Inquiry into the NHS backlog formed the basis for the NHS England [Long Covid improvement plan](#) for 2022/23. The charity focuses on the need for recognition, research and rehabilitation for people with Long Covid through social media and press campaigning, advocacy, and involvement in research.

Long Covid SOS produces original research and collaborates with researchers, including and promoting the voice of those with lived experience in a number of publicly-funded research projects. The charity advocates for appropriate, inclusive and relevant research and has representation on expert panels informing research priorities. Their [peer reviewed](#) survey into the impact of Covid-19 vaccines on Long Covid symptoms has been cited by institutions worldwide including UKHSA, NICE, ONS, SAGE and the CDC.

For more information:

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Long Covid Kids was founded in October 2020 by people living with Long Covid. In 2021 LCK became the first registered charity advocating for families, children and young people living with Long Covid anywhere in the world. Currently supporting 11,000 families, LCK's vision is to achieve recognition, support and recovery for Long Covid and related illnesses in children and young people. Their mission is to increase understanding, aid early diagnosis and improve response and intervention.

LCK volunteers have worked tirelessly to raise awareness and effect change throughout the pandemic. Their [Annual Report 2021-2022](#) spotlights their impact.

LCK's award winning guidebook '[Shining a light on Long Covid in Children. A Guide to Recognition. Support. Recovery](#)' was created in response to the increase in demand for their support services. The guide contains practical and helpful information for health and education professionals, and families Designed to support and inform on recovery alongside their popular resources; [Pacing Penguins](#) and [Cautious Tortoise](#).

For more information:

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Long Covid Support was founded by people with Long Covid. It is a registered charity advocating for better health, welfare and employment policy for those affected. Through its Research Involvement Group, the charity ensures that the experience of the Long Covid community informs medical research into diagnosis and treatment. Long Covid Support runs an international peer support group with over 56,000 members. Since May 2020, the organisation has been calling for recognition of the impact on individuals, employers and society and for measures to prevent more people developing Long Covid.

Long Covid Support partners with key policymakers and stakeholders, including the WHO, NHSE, NIHR, CIPD and TUC, sharing insights from surveys and feedback from their support group. In December 2020 Long Covid Support partnered with ISARIC and GLOPID-R to organise the [Long Covid Forum](#), the first international research conference on the condition. In conjunction with Imperial College London they co-created the [VOICE Global Long Covid Research Involvement Hub](#). Long Covid Support and Long Covid Kids jointly produced an [Information Leaflet](#), and conducted research on the [effect of reinfections in Long Covid](#). The charity runs an on-going survey into [patient experience of accessing care in England](#).

For more information:

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Sammie McFarland, Ondine Sherwood, Jane Murphy and members of the legal team will be in attendance at the Inquiry Module 2 hearing in London on Monday 31st October

Interviews and case studies available on request