



Long Covid SOS

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Covid-19 inquiry: We must not ignore the long term health impacts of covid

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Module 1 of the UK covid-19 inquiry reported on 18 July 2024. The report is rightly critical and does not hold back from emphasising the devastating truth. Far from the UK being one of the most prepared countries for a pandemic—as was erroneously thought—“the processes, planning, and policy of the civil contingency structures across the UK failed the citizens of all four nations,” said Heather Hallett, chair of the inquiry.

As the report underlines, the lack of resilience and preparedness was acutely felt by those on the front lines, many of whom lost their lives. Entrenched health inequalities meant that those from minority and marginalised groups were especially vulnerable. But the risk of long term health impacts, which particularly affected both of those groups, was ignored in the face of lessons which could—and should—have been learned from SARS-1 and MERS. The report from this module does not highlight this huge oversight, which is regrettable, but acknowledges that “there was a failure to learn sufficiently from past civil emergency exercises and outbreaks of disease.”

“Long covid was both foreseeable and foreseen, yet decision makers chose to overlook the known risk it posed.”

These are the words of KC Anthony Metzger, made in the long covid groups’ closing statement for module 2 of the UK covid-19 inquiry.

Long covid groups were not granted core participant status in module 1 and so were unable to emphasise to the inquiry the important issue of the country’s lack of preparedness for post viral illness. Fortunately, our participation in module 2 gave us the opportunity to question witnesses on this topic and bring this concern directly to the notice of the inquiry.

We and our legal team witnessed first hand how the question of long term ill health as a result of covid, which impacts so many, moved from being considered a side issue to becoming a significant concern.¹ Towards the end of the module, Hallett interjected with questions for witnesses on the topic of long covid.

It was during these module 2 hearings that experts acknowledged that the country should have been prepared to treat people with ongoing symptoms. Expert witness evidence from Christopher Brightling, clinical professor in respiratory medicine and Rachael Evans, clinical associate professor and honorary consultant respiratory physician, underlined the existing understanding of potential long term sequelae from other coronavirus outbreaks saying: “it was foreseeable that there were going to be

long-term sequelae from covid-19 extrapolated from previous coronavirus pandemics and previous knowledge of post-viral syndromes.”²

Graham Medley, former chair of SPI-M (the pandemic preparedness committee in UK Department of Health) agreed questioning that “we knew from the outset that there were likely to be post-infection sequelae, I think clinically they’re known as, the consequence of infection.”³

The evidence I provided to the inquiry, both in writing and in person, emphasised that despite prior knowledge of post viral syndromes, the lack of information available to health professionals, particularly in the early stages of the pandemic, had a detrimental impact on those who did not recover from their covid-19 infection.⁴ The struggle for recognition, to access appropriate care, diagnosis, and treatment was compounded by a frequent tendency for medical staff to interpret the symptoms as anxiety. Patients were not believed, their concerns were dismissed and their experiences invalidated, despite facing debilitating and often frightening symptoms. It was left to groups such as Long Covid SOS and others to advocate on their behalf, to bring to the attention of the NHS and policymakers something that was happening in plain sight: many people do not recover from covid in two weeks and this phenomenon is not at all rare.

Being disbelieved has frequently been described by patients as one of the most profoundly traumatic aspects of their experience. A survey carried out by our charity in 2020 revealed that a 23% of patients were not believed or told their symptoms were due to anxiety⁵:

“The first GP I spoke to via 111 in April told me I couldn’t have been sick with covid for more than 14 days and so I must have had two separate illnesses. One GP suggested my neurological symptoms were down to stress/ anxiety.”

“I had one GP tell me I should seek counselling, another that post covid doesn’t exist, a couple that were sympathetic but not offering anything else, finally I spoke to one end of July that believes in post covid and referred me”

It is concerning that this attitude persists.^{5,6} Adequate preparation and education in the early days of the pandemic and during the critical period before it emerged could have avoided neglect and distress for so many.

It also underlines the importance of representation at the inquiry. Long Covid SOS and the other long covid groups have been unsuccessful in our applications for module 4 (Vaccines and

Therapeutics), module 7 (Test, Trace and Isolate) and provisionally (a renewed application has been submitted) module 8 (Children and Young people). It is imperative that the inquiry continues to fully investigate the failings throughout the pandemic which impacted all those harmed by covid-19.

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- 2 Brightling C, Evans R. Expert Report for the UK Covid-19 Public Inquiry. Module 2: Long Covid. <https://covid19.public-inquiry.uk/wp-content/uploads/2023/10/13171432/INQ000280198.pdf>
- 3 Transcript of Module 2 Public Hearing on 12 October 2023 <https://ukcovid19inquiry.dra-cos.co.uk/module-2/2023-10-12/>
- 4 Sherwood OUK. Covid-19 inquiry. Witness Statement of Ondine Sherwood on behalf of Lond Coivd SOS. <https://covid19.public-inquiry.uk/wp-content/uploads/2023/10/13171427/INQ000280196.pdf>
- 5 Long Covid SOS. GP Survey Report. <https://www.longcovidosos.org/gp-survey-2020>
- 6 Life BJGP. Long COVID: why are people still struggling to access care? <https://bjgplife.com/long-covid-why-are-people-still-struggling-to-access-care/>