
COVID-19 INQUIRY MODULE 2
CLOSING SUBMISSIONS OF THE LONG COVID GROUPS
13 December 2023

1. My Lady, I appear with Sangeetha Iengar and Shanthi Sivakumaran on behalf of the Long Covid Groups, instructed by Jane Ryan of Bhatt Murphy.

LONG COVID VOICES

2. Our clients are angry. They have been disbelieved, dismissed and ignored, and suffered the ignominy of hearing Mr Johnson’s testimony last week. My Lady began this module by hearing from those impacted by Covid 19, and it is apt to return now to the voices of our clients.
3. Orli Summers, a Covid frontline nurse who contracted Covid in the first wave said: *“Long Covid had not been mooted as a thing. As a result, my ongoing symptoms were often met with scepticism and a degree of gaslighting...”* She was sadly not an anomaly. Kim Horstmanshof said: *‘I thought it was going to be a cold because I was 37, went to the gym several times a week and all the messaging was that Covid was nothing to worry about if you were young...(my family) find it hard to accept that I’m disabled... Its hugely isolating.’*
4. Many lost their livelihoods. Oonagh Cousins was a professional athlete who was pre-selected for the Olympics as part of the British Rowing team. After developing Long Covid, she was *‘struggling with cooking, showering and getting out of bed,’* all the basic daily tasks. Long Covid has forced Oonagh to retire completely from her rowing career.
5. Parents were not warned that Long Covid could debilitate and disable their children. Jessica, a 10 year-old who has lived with Long Covid since November 2021 describes how: *“no one at school or in health believed me until I ended up in crisis in hospital with a feeding tube.”* Jessica was very active and loved to roller skate with her family. Now, she needs a wheelchair and can’t walk or attend school.

6. You heard from our client Sammie McFarland during the impact films. In her statement, she said: *“it has been extremely distressing to watch my child who had been previously completely healthy, happy and dancing around being unable to move and full of self-doubt. It was like watching my child fade away – she is no longer the child she was.”*
7. New voices continue to be added to the collective Long Covid experience. Today, people will develop Long Covid from new Covid-19 infections. They will lose their physical health; their ability to work; to go to school. They will lose their lives as they know them. The lessons to be learnt from government decision-making matter **now**, as much as they do for the future.
8. The voices of people with Long Covid have been represented by the Long Covid Groups - Long Covid Kids, Long Covid SOS and Long Covid Support – who have followed the hearings closely.
9. They have sought answers to questions they have carried with them since they began suffering from the long-term effects of Covid-19. Their suspicions have been confirmed:

First, the Long Covid Groups have heard evidence of the unfounded dismissal of their illness exemplified by the attitude of the former Prime Minister, Boris Johnson.

Second, the evidence is that Long Covid was, at best, an accepted ‘trade-off’ when decisions were made about easing restrictions, and at worst, entirely ignored as an inconvenient truth.

Third, the evidence demonstrates that there was a wholesale failure to use what Mr Johnson calls the ‘most important tool’ of public messaging, to communicate the indiscriminate risk of long-term harm to the public, which covers the risk to children and adults of all ages.
10. These cumulative errors have caused the avoidable injury and enduring suffering experienced by the Long Covid Groups.

DISBELIEF IN LONG COVID

11. The Long Covid Groups have sought to understand how and why there was an inexplicable delay in the Government's recognition of Long Covid, when longer-term sequelae were foreseeable and well-established from other recent coronaviruses such as SARS and MERS. We now know from the evidence that the risk of long term sequelae was in fact foreseen. The Secretary of State for Health and Social Care, Matt Hancock, and the Prime Minister's most senior advisor, Dominic Cummings, both recalled being advised by Professor Sir Chris Whitty, the CMO and Sir Patrick Vallance, the GCSA, that Covid-19 was likely to have long-term effects on a significant number of people. **Yet it took patient advocates**, already suffering from Long Covid, to advocate for action. Long Covid is a patient-made term, it did not need to be.
12. Mr Johnson's attitude to Long Covid exemplifies the biases that the Long Covid Groups were formed to counter. He doubted that people with Long Covid had a 'real condition.' This is not true: the scientific evidence and lived experience of people suffering from debilitating long-term symptoms caused by Covid-19 is very clear.
13. Mr Johnson now claims that his scrawl of BOLLOCKS on a box grid in October 2020, this **one obscene** word, was his attempt to request advice on Long Covid. My Lady, there are glaring holes in his belated claims that he was seeking advice on Long Covid:

First, and significantly, Mr Johnson only came up with the suggestion that he was asking for advice in oral evidence. His witness statement tells an entirely different story, of a man who dismissed the suffering of millions, despite the wide range of people who were trying to open his mind to the worrying reality. He waited until late May 2021 to ask his CMO for further information on Long Covid.

Second, the box grid he was presented with outlined the NIHR report on Long Covid commissioned by Professor Sir Chris Whitty, which reviewed scientific and clinical data on long-term sequelae. He did not ask to see the full report, which he knew was available.

Finally, Sir Patrick Vallance said that he made the Prime Minister aware of Long Covid. This is supported by his diaries which record Mr Johnson repeatedly referring to gulf war syndrome when Long Covid was raised.

14. The evidence overall, including that from Mr Johnson's own witness statement, makes plain that Long Covid was an inconvenient truth that Mr Johnson chose to ignore. **This choice** caused great harm and immeasurable suffering.

AVOIDABLE HARM

15. My Lady, a crucial question is whether nearly 2 million adults and children with Long Covid was avoidable. Decisions around the introduction of and release of NPIs were matters of life and death, of health and sickness. The long-term harm caused by Covid-19 was a relevant outcome from those decisions. Put plainly, **Long Covid was not considered in the decisions taken in response to the pandemic**. Sir Christopher Wormald confirmed as much saying that the sole factors under consideration were hospitalisation rates, the spread of disease and the death rate. Is it not simple common sense that long term harm from a virus is relevant to how a pandemic is managed?
16. Sir Patrick Vallance explained the lack of consideration of Long Covid by saying that *“the Covid pandemic was running at high levels all the way from August through to the end of that year, and so the recommendation was: keep the prevalence low. That was not happening and the consequence of that is more people with Long Covid. And I don't think that was something that policy makers were keen to factor in.”*
17. Professor Sir Chris Whitty in his witness statement observed that recognising Long Covid could occur at any age, had important practical implications as it made him more cautious to the effects of Covid-19 in the young and in otherwise healthy adults. It is extraordinary that he thought that long-term harm was **not** something the Prime Minister needed to know in 2020, when Sir Patrick Vallance was warning the Prime Minister and the Cabinet that this **was** a material consideration. Sir Patrick advised that strategies like segmentation or the Great Barrington Declaration proposal which allowed high rates of transmission amongst the young would result in large numbers of people contracting Long Covid.

18. The failure to consider Long Covid when making decisions on NPIs had three stark consequences:

First, before the second wave, the Prime Minister wanted to be the Mayor of *Jams* and was actively trying to **keep the beaches open** while delaying the decision to take a second lockdown. He entertained strategies where he thought by keeping the known vulnerable off the beaches, the rest of the population could go out to sea. As Dame Angela McLean said, there were **'unknown vulnerable'** who could develop Long Covid. The Prime Minister ignored the fact that the shark in the water could maim anyone.

Second, as restrictions were eased, there was little, if any, focus on the need to prevent Long Covid. This meant that strategies which allowed high prevalence of Covid-19 in 2021 did not include mitigation measures to encourage preventative behaviours so people could avoid the risk of Covid-19 and its concomitant risk of Long Covid. To the extent that Long Covid was considered, Mr Javid told us that it was at best, an accepted trade-off for the release of restrictions. If the risk of Long Covid was factored in at all, our clients are entitled to question why simple, uncostly, mitigation measures were not kept in place to lower that risk.

Third, regarding the financial burden of the disease. The socio-economic costs of a virus cannot be fully quantified and planned for if the long-term impact of the virus is not measured and factored into decision-making. The OBR recognised there would be an economic cost associated with increased cases of Long Covid in 2020, but this cost was not factored into Government advice until the Covid Task Force Paper in April 2021. Even then, the economic cost of Long Covid was still not a feature of Treasury advice on NPIs. Mr Sunak admitted on Monday that the impact of Covid on the labour market was *mis-estimated*. The Treasury was disproportionately focused on the **costs of measures** in response to Covid-19, rather than the **costs of the virus** itself.

19. Decision-making that had factored in Long Covid when unlocking NPIs would have:

Prioritised public messaging warning people, of all ages, of the indiscriminate risk of Long Covid,

AND -

Maintained mitigation measures to prevent transmission of Covid-19 such as guidance on mask wearing, improving air filtration and ventilation in public buildings, supporting policy recommendations on clean air, supporting employers with health and safety risk assessments and ensuring free lateral tests remained available.

20. One of the many clear examples of the failure to incorporate Long Covid into decision-making **is in relation to children**. As at March 2023, there are at least 62,000 children with Long Covid. Mr Johnson called schools ‘reservoirs of risk.’ In May 2021, there was agreement between DHSC, PHE, NHS and DfE that messaging in schools should signpost for any child experiencing long-term symptoms following a Covid 19 infection.¹ Yet messaging, and other adequate Covid-19 safety measures, weren’t put in place. Schools, public buildings and hospitals still don’t have adequate Covid-19 safety measures.
21. Long Covid could, and should, have been considered in decision-making around NPIs.

PUBLIC COMMUNICATIONS OF THE RISK OF LONG COVID

22. Mr Johnson, Mr Hancock and Sir Christopher Wormald have all emphasised that public communications are an important NPI in the toolkit of responses to a pandemic. Yet there was an unacceptable absence in communications on Long Covid. During the pandemic, we watched daily press conferences and looked to our Prime Minister and his closest advisers to provide us with accurate, timely and reliable information on how to protect ourselves, our families and our communities. The Prime Minister did not mention Long Covid once. Indeed, we now understand that there was no Government communications strategy for Long Covid. This left people believing that if they were otherwise healthy, they would recover quickly when they fell sick, as they had been reassured would be the case for the majority of people.

¹ INQ000283448

23. Mr Hancock acknowledged the role that the Long Covid Groups played in drawing his attention to the impact of Long Covid and the need for better communication. Yet the one video with its single accompanying press statement issued by DHSC on Long Covid in October 2020 was simply not enough. It came months after public recognition of Long Covid in the US by Dr Anthony Fauci and Dr Tedros Ghebreyesus from the WHO.
24. After October 2020, there were no slogans, no public health messages and no campaigns on Long Covid - by DHSC, or across Government. On being pressed by Ms Cecil, Mr Javid admitted that there was no communications campaign on the risk of Long Covid to the public under his watch. In the absence of public messaging, people felt frustrated and abandoned.
25. Professor Sir Chris Whitty has admitted that it would have been helpful to acknowledge Long Covid at an earlier stage. The overwhelming picture is that people were not warned that they were all, including previously fit, healthy, active people, indiscriminately at risk of suffering from long-term ill-health from Covid 19.
26. The public deserved to know the risk that Long Covid posed to them, so that they could take steps to protect themselves from it. Decision-makers could, and should, use the preventative tool of public messaging to communicate the risks of Long Covid.

RECOMMENDATIONS

27. My Lady, the long-term impacts of Covid-19 are but one aspect you will need to consider in relation to the response to the pandemic. We have heard evidence which sheds light on the inner workings of Government at the height of the crisis. You may conclude that the decision-makers at the heart of government could not be trusted to make rational, consistent, strategic decisions to guide the country through this crisis.
28. Looking forward, we hope that this Inquiry will make findings and recommendations that will ensure that we are better prepared to respond to pandemics; it is simple common sense that long term harm from a virus must be a relevant consideration for Government to protect the public.

29. The unjustifiable delay in imposing NPIs including the first and second lockdowns meant that people needlessly contracted Covid-19 and developed Long Covid. Suffering has been the avoidable cost of delay and indecision. The evidence you have heard suggests that maintaining low levels of transmission of a novel virus is better for economic, health and social outcomes and it means that lockdowns can be introduced with more notice and shorter duration, reducing the economic impact of those measures.
30. However, the experiences of those with Long Covid have illustrated that it is not enough to focus exclusively on the short-term impacts of a virus. When challenged about the lack of consideration of Long Covid, decision-makers fall back on the defence that preventing Covid-19 meant preventing Long Covid. Aside from the obvious point that decision-makers failed to prevent high transmission of Covid-19 and indeed came to accept it as part of their policies in Summer 2021, this approach fails to grasp that there are additional considerations to preventing Long Covid. The twin considerations are the indiscriminate risk of Long Covid and the need to maintain measures to minimise that risk as social distancing measures are released to the public.
31. My Lady, we invite you to recommend that the long-term health consequences of a novel virus are planned for, identified, monitored, measured and factored into any response to a pandemic. These recommendations are equally relevant today; the Covid 19 pandemic endures yet Long Covid is no longer being counted or reported on.
32. Recommendations relevant to long-term sequelae could fall within **four broad categories**, all drawn from the evidence related to Long Covid:
1. **First**, surveillance systems should be in place from the outset of the pandemic, preferably in the form of sleeping studies, to identify and monitor data on the impact of longer-term sequelae so that long-term health implications can be recognised early;
 2. **Second**, the long-term health consequences of a novel virus must be factored into decisions made in response to the transmission of the virus and included in assessments of the necessity for NPIs and PIs, as they may have a different risk profile to acute infections and add to the burden of the disease;

3. **Third**, decision-makers should take a preventative approach and provide clear, timely and consistent public messaging on the long-term consequences of infection throughout a pandemic to raise awareness of the risk of long-term consequences to encourage protective behaviour, and signpost available treatment resources; and
 4. **Fourth**, Adult and Child Patient Voices should be involved from an early stage of any pandemic response to ensure that policies are responsive to people's needs.
33. These four categories of recommendations would ensure that the avoidable on-going suffering of nearly 2 million adults and children in this country, is never repeated.
34. Thank you.

[End]
