

UK COVID-19 INQUIRY

EXHIBIT LC/3 CHRONOLOGY OF LONG COVID

Date	Event
05/04/2020	Elaine Maxwell, (subsequently a member of Long Covid Support) who worked for NIHR, spoke to David Bathurst, General Manager of the NIHR Office for Clinical Research Infrastructure about the importance of post-covid sequelae.
02/05/2020	Long Covid Support Facebook group set up
07/05/2020	SAGE recognised longer-term health sequelae for the first time
15/05/2020	NERVTAG discussed <i>"ongoing clinical issues post-COVID"</i> at first birdtable meeting
29/05/2020	NERVTAG discussed <i>"patients with long-term health sequelae who will require ongoing care"</i> at third birdtable meeting
June 2020	Members of Long Covid Support were interviewed by Dr Elaine Maxwell to understand their lived experience as part of the first NIHR Living with Covid19 review on the evidence base for 'post-covid syndrome',
05/06/2020	DHSC acknowledges sequelae of Covid-19 (in the post-hospitalisation context)
17/06/2020	Steve McCabe MP tabled a written question about Long Covid in the House of Commons in response to a letter written to him by a constituent, a founding member of Long Covid Support
17/06/2020	Long Covid Support members met with Shadow Public Health Minister Alex Norris.
25/06/2020	Private Secretary to CSA and CMO first acknowledges long term sequelae in email correspondence to Covid-19 Comms team
03/07/2020	Long Covid SOS sent a letter to Prime Minister Boris Johnson copied to all sitting Members of Parliament and Chief Medical Officer Professor Chris Whitty and UK Government Chief Scientific Advisor Patrick Vallance
05/07/2020	Post-hospitalisation COVID-19 study (PHOSP-COVID) announced
09/07/2020	Academy of Medical Sciences report <i>'Preparing for a challenging winter 2020/21'</i> presented at SAGE
14/07/2020	Academy of Medical Sciences report <i>Preparing for a challenging winter 2020/21'</i> published: <i>"Although there is a paucity of data to accurately estimate the extent of postCovid-19 sequelae, post-viral syndromes are well documented following other viral infections including severe acute respiratory syndrome (SARS), Chikungunya and Ebola. SARS resulted in chronic widespread musculoskeletal pain, fatigue, depression and disordered sleep in chronic post-SARS syndrome."</i> (p.24)

15/07/2020	DHSC, Home Office, Government's Actuary's Department (GAD) and ONS publish report on <i>Direct and indirect impacts of COVID-19 on Excess Deaths and Morbidity</i> . The report includes brief mention of longer term effects
August 2020	Long Covid Support gave evidence to the APPG on Coronavirus
August 2020	Long Covid Support members met with Prof Sally Singh about Your Covid Recovery website
06/08/2020	Long Covid Support members met with Greater Manchester Mayor Andy Burnham
28/08/2020	Long Covid Support and partners sent a letter to Jeremy Hunt, chair of the Health & Social Care Committee, to call for the UK Government to assemble a multi-disciplinary Long Covid task force. This letter was forwarded by Mr Hunt to Matt Hancock, then Secretary of State for Health and Social Care
September 2020	Long Covid SOS met with Professor Stephen Powis, Medical Director of NHS England and his team. This was the start of a regular and ongoing dialogue about achieving better care for people with Long Covid. It was critically important meeting because up until that point there had been little public acknowledgement from the NHS about Long Covid
September 2020	The WHO emergency use International Classification of Diseases (ICD) codes were designated for Long Covid/post-Covid conditions
01/09/2020	Long Covid SOS attend a meeting with Dr Sally Singh to discuss the development of the NHSE 'Your Covid Recovery' website
03/09/2020	Public Health England produces proposed text for <i>COVID-19 Long Term Effects for inclusion in Clinical Guidance</i>
04/09/2020	First mention of Long Covid at a full NERVTAG meeting
07/09/2020	Public Health England published guidance: <i>COVID-19: long-term health effects</i>
11/09/2020	Long Covid SOS met with Professor Stephen Powis, Medical Director of NHS England and his team. This was the start of a regular and ongoing dialogue about achieving better care for people with Long Covid. It was critically important meeting because up until that point there had been little public acknowledgement from the NHS about Long Covid
15/09/2020	Committee on Science and Technology (Lord's) hears evidence for its inquiry, <i>The science of Covid-19</i> , on the long-term consequences of the Covid-19 pandemic, including Long Covid
18/09/2020	Significant discussion of Long Covid at NERVTAG
25/09/2020	Long Covid SOS attend a meeting with Cathy Hassell NHS England Director of Clinical Policy and Nikki Kanini NHSE Medical Director for Primary Care
October 2020	Long Covid Kids met with Andrew Gwynne MP
01/10/2020	Written evidence on Long Covid published for Committee on Science and Technology (Lord's) , includes recommendations for research and treatment
01/10/2020	First mention of Long Covid at a SAGE meeting
02/10/2020	Long Covid Support were asked by the NIHR to recruit volunteers for a film about Long Covid.
02/10/2020	Long Covid mentioned for the final time at NERVTAG
13/10/2020	Long Covid SOS and Long Covid Support attended the first Long Covid Ministerial Roundtable chaired by Lord Bethell
13/10/2020	Long Covid SOS attended a meeting with the Clinical Policy team at NHS England to discuss Post-Covid clinics
15/10/2020	First NIHR review into Long Covid published
16/10/2020	Long Covid SOS emailed ONS about the urgent need to count Long Covid and its absence from the national Covid-19 statistics as a measure of the impact of the pandemic

21/10/2020	DHSC released a public health campaign video on Long Covid featuring Long Covid sufferers. Guidance accompanying the video from SSDHSC warns 10% of 18–49 year olds will be affected by the “ <i>debilitating long-term impact of COVID-19</i> ”.
22/10/2020	Long Covid SOS were invited by the Head of Clinical Policy to review NHSE commission guidance for post Covid clinics
23/10/2020	The Royal Society's SET-C group publishes a report: <i>Long Covid: what is it and what is needed?</i>
23/10/2020	The founder of Long Covid SOS was invited by the NIHR and the Medical Research Council (MRC), to be a member of the COVID Expert Group to work on the first Long Covid funding call
28/10/2020	Long Covid SOS met with NHS London Clinical Reference Group
29/10/2020	Long Covid SOS and Long Covid Support attended the first NHS Long Covid Task force meeting
29/10/2020	Long Covid SOS attended a meeting with ONS to discuss ‘counting’ Long Covid cases
30/10/2020	Long Covid SOS attended a meeting of the COVID Expert Group to work on the first Long Covid funding call
02/11/2020	Long Covid SOS met with NHS London – Sprint workshop on Long Covid services
04/11/2020	Long Covid SOS met with NHS London – Sprint workshop on Long Covid services
05/11/2020	Long Covid SOS met with NHS London – Sprint workshop on Long Covid services
05/11/2020	Long Covid SOS met with NHSE Director of Clinical Policy
09/11/2020	Long Covid SOS met with NHS London – Sprint workshop on Long Covid services
12/11/2020	Long Covid SOS met with NHS London – Sprint workshop on Long Covid services – 2 meetings
12/11/2020	Long Covid SOS and Long Covid Support attended the second NHS Long Covid Taskforce meeting
16/11/2020	Long Covid SOS and Long Covid Support attended the second Ministerial Roundtable on Long Covid, chaired by Lord Bethell
17/11/2020	Long Covid SOS met with NHS London Clinical Reference Group
26/11/2020	Long Covid SOS and Long Covid Support attended the third NHS Long Covid Task force meeting
01/12/2020	Long Covid SOS met with NHS London Clinical Reference Group
03/12/2020	Long Covid SOS met with NHS England Director of Clinical Policy and Senior Programme Manager for Long Covid
14/12/2020	The Long COVID Assessment Clinics Sitrep collection started on behalf of NHS England to capture data on patient volumes, activities undertaken when assessing Long Covid patients, and patient demographics
16/12/2020	Long Covid SOS attends the Post COVID National Taskforce- Subgroup on Long Covid assessment services rollout and feedback
17/12/2020	DHSC, Home Office, Government's Actuary's Department (GAD) and ONS publish report on <i>Direct and indirect impacts of COVID-19 on excess deaths and morbidity</i> . In this report there is detailed consideration of Long Covid and acknowledgement of Long Covid as a <u>direct health impact of Covid-19</u>
18/12/2020	NICE publishes <i>Covid-19 rapid guidance: managing the long term effects of Covid-19</i>
18/12/2020	Announcement of Long Covid clinics experience survey by Long Covid Support
21/12/2020	Long Covid Support responded to consultation on NICE guidelines on Long Covid.

23/12/2020	Long Covid Kids had an email exchange with Chris Loder MP about Commons debate on Long Covid in January 2021
07/01/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended the fourth NHS Long Covid Task force meeting
07/01/2021	Long Covid Kids sent an email to Layla Moran MP
09/01/2021	Long Covid Support founder Claire Hastie sent a letter to all MPs urging them to participate in the Commons debate on Long Covid scheduled for 14 January 2021
11/01/2021	Long Covid Kids sent an email to Layla Moran MP with briefing from Parents United Against Unsafe Schools regarding Commons debate on Long Covid
12/01/2021	Long Covid SOS wrote to the Prime Minister Boris Johnson stating that: <i>"The risk of Long Covid must be a primary consideration in policy decisions"</i> . This followed his announcement on 4 January 2021 regarding the vaccination programme and lifting of restrictions.
15/01/2021	Long Covid SOS attends the Post COVID National Taskforce- Subgroup on Long Covid assessment services rollout and feedback
25/01/2021	WHO adds 'long-term consequences of Covid-19' to clinical management guidance
26/01/2021	Long Covid Kids give evidence to the APPG on Coronavirus
29/01/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended the Ministerial Roundtable on Long Covid
03/02/2021	ONS includes the following question in its Coronavirus (COVID-19) Infection Survey (CIS) for the first time: <i>"Would you describe yourself as having 'long COVID', that is, you are still experiencing symptoms more than 4 weeks after you first had COVID-19, that are not explained by something else?"</i>
04/02/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended the NHS Long Covid Task force meeting
04/02/2021	Discussion of Long Covid at SAGE
07/02/2021	Long Covid Support sent an email to ONS, DHSC and NHSE
08/02/2021	Long Covid SOS attends meeting with NHSE chair of Long Covid Taskforce to discuss role of patient public voice partners
10/02/2021	Long Covid SOS attends the Long Covid Services subgroup meeting
12/02/2021	Long Covid Support member Claire Hastie sent an email to the DHSC, NHSE and ONS
12/02/2021	Long Covid SOS met with ONS to discuss progress on counting Long Covid cases
19/02/2021	Long Covid Support met with the DHSC Long Covid Team
22/02/2021	Long Covid Support member Claire Hastie sent an email to ONS about phrasing of survey questions
23/02/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended the Ministerial Roundtable chaired by Secretary of State for Health and Social Care Matt Hancock and Lord Bethell.
23/02/2021	Long Covid Support had email exchanges with Name Redacted Head of Long Covid NHS Policy and Performance Group at DHSC re patient and public voice participation
24/02/2021	Long Covid Support email exchanges with Name Redacted , Head of Long Covid NHS Policy and Performance Group at DHSC
25/02/2021	Long Covid SOS sent a letter to Secretary of State for Health and Social Care Matt Hancock regarding lack of research and funding for clinical trials
25/02/2021	Discussion of Long Covid at SAGE
04/03/2021	Long Covid Kids sent an email to Chris Loder MP with their Schools Pack

04/03/2021	Long Covid SOS received response from DHSC to 12 January 2021 letter to Boris Johnson
16/03/2021	Second NIHR review into Long Covid published
29/03/2021	Long Covid SOS received response from Matt Hancock to 25 February 2021 letter
01/04/2021	ONS publishes its first bulletin on Long Covid: <i>Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK</i>
12/04/2021	Long Covid Kids sent a joint letter (with Safe Ed for All) to Matt Hancock
13/04/2021	A response to a written question from Colleen Fletcher MP to DHSC confirmed DHSC had no plans to centrally collect data on the number of people experiencing Long Covid symptoms at constituency or local authority level
20/04/2021	Long Covid SOS met with NHS England Director of Clinical Policy and Senior Programme Manager for Long Covid
22/04/2021	Long Covid Support were invited to present at the Westminster Health Forum event: <i>Long Covid - priorities for research and improving patient care, treatment and support</i>
24.02.2021	Long Covid Support had email exchanged with [Name Redacted], Head of Long Covid NHS Policy and Performance Group at DHSC re patient and public voice participation
04/05/2021	Long Covid Kids sent a letter to Gavin Williamson, Secretary of State for Education
21/05/2021	Members of Long Covid Support met with Dean Russell MP, member of the Health & Social Care Select Committee
June 2021	Members of Long Covid SOS and Long Covid Support joined Patient and Public Voice partners for NHS England between June 2021 and June 2022
09/06/2021	Long Covid Kids , Long Covid SOS and Long Covid Support attended NHS Long Covid Specialist assessment service subgroup meeting
13/06/2021	Long Covid Support responds to DHSC's call for evidence on "Women's Health Strategy"
15/06/2021	NHS announces it is setting up specialist Long Covid services including services for children and young people across 15 new paediatric hubs
16/06/2021	Long Covid Kids , Long Covid SOS and Long Covid Support attended the Ministerial Roundtable on Long Covid chaired by Lord Bethell
18/06/2021	Long Covid SOS had a telephone call with the Therapeutics Policy and Engagement Lead at DHSC
21/06/2021	NHS England published their guidance to GP practices on the Enhanced Service provisions for Long Covid sufferers. Long Covid, ongoing symptomatic Covid-19 and Post-Covid-19 are all defined
22/06/2021	Long Covid SOS had a meeting with the Therapeutics Policy and Engagement Lead at DHSC and Deputy Director of Therapeutics and Antivirals Taskforce at DHSC
22/06/2021	First meeting of the DHSC Long Covid Oversight Board
01/07/2021	Long Covid Kids had an Email exchange with Wera Hobhouse MP about Long Covid in children with another group Safe Ed for All
03/07/2021	Long Covid Kids sent a joint email with Safe Ed for All to Neil O'Brien MP
07/07/2021	Long Covid Kids , Long Covid SOS and Long Covid Support attended NHS Long Covid Specialist assessment service subgroup meeting
08/07/2021	Long Covid Support wrote to Sajid Javid urgently requesting that when evaluating policy, he takes account of the impact of Long Covid on people
09/07/2021	Long Covid Kids wrote letter to Sajid Javid raising concerns about long covid in children
15/07/2021	Long Covid SOS wrote to Sajid Javid, Secretary of State for Health and Social Care asking that Long Covid be considered when easing restrictions

20/07/2021	DHSC Long Covid Oversight Board meeting regarding long covid and the lifting of restrictions
22/07/2021	Discussion of Long Covid at SAGE
27/07/2021	Paper for the COVID-O meeting titled <i>High Prevalence: Summer Response</i> refers to Long Covid as a Category C impact " <i>not in scope for discussion</i> "
28/07/2021	Long Covid SOS met with Logan Graham, advisor to Prime Minister Boris Johnson to discuss the economic impact of Long Covid and future plans to model the likely effects
04/08/2021	Long Covid SOS attended the NHS Long Covid Taskforce Research Subgroup
08/08/2021	Long Covid SOS met with Name Redacted DHSC Operational Researcher Covid-19 and Health Protection Analysis to discuss the economic cost of Long Covid and ongoing research by DHSC/SAGE
01/09/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended NHS Long Covid Taskforce Research subgroup meeting and NHS Long Covid assessment clinics subgroup meeting
02/09/2021	Letter of response from DHSC to Long Covid Support
02/09/2021	Long Covid SOS, Long Covid Support and Long Covid Kids attended the NHS Long Covid National Taskforce Research subgroup
03/09/2021	Long Covid first acknowledged as a "risk" on DHSC Strategic Risk Register
09/09/2021	Long Covid Support sent an email to Clinical Policy NHSE raising concerns about the appointment of National Specialty Advisor Graham Burns who had previously publicly stated that Long Covid was fuelled by insomnia and anxiety
09/09/2021	DHSC and ONS publish report on <i>Direct and Indirect health impacts of COVID-19 in England</i> . The report includes an acknowledgement of Long Covid as a direct health impact of Covid-19
17/09/2021	Long Covid SOS met with ONS to discuss recent data published by ONS on Long Covid prevalence
21/09/2021	Long Covid SOS gave evidence at the Health and Social Care Committee into Clearing the Backlog caused by the pandemic, giving evidence that sufferers of Long Covid had to fight to get recognition of their illness and were struggling to get referred to LC Clinics.
23/09/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended Ministerial Roundtable on Long Covid
29/09/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended NHS Long Covid Specialist assessment service subgroup meeting
06/10/2021	Long Covid SOS and Long Covid Support attended the NHS Long Covid National Taskforce Research subgroup
11/10/2021	Long Covid SOS met with National Clinical Specialist Advisor Respiratory (including Long COVID), Personalised Care Group NHSE
11/10/2021	Long Covid SOS met with NHS England Clinical Policy team (Director of Clinical Policy, Senior Programme Manager for Long Covid and others)
21/10/2021	Long Covid SOS attended the National Suicide Prevention Strategy Advisory Group – Covid-19 Sub Group to present on lived experience of those with Covid and risk of suicide.
03/11/2021	Long Covid Support and Long Covid SOS attended the NHS Long Covid National Taskforce Research subgroup
04/11/2021	Long Covid Support, Long Covid SOS and Long Covid Kids attend the NHS Long Covid Taskforce Meeting
17/11/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended NHS Post Covid National Taskforce Subgroup
22/11/2021	Long Covid SOS met with NHS England Clinical Policy team (Director of Clinical Policy, Senior Programme Manager for Long Covid and others)

24/11/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended NHS Long Covid Specialist assessment service sub group meeting
29/11/2021	Long Covid Kids, Long Covid SOS and Long Covid Support meet with Jeremy Hunt to discuss problems faced by people with Long Covid and issues around treatment and research
07/12/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended the Ministerial Roundtable on Long Covid
07/12/2021	Long Covid SOS attended a roundtable with Maria Caulfield, Minister for Patient Safety and Primary Care
07/12/2021	Long Covid Kids sent an email to DHSC response
10/12/2021	Long Covid Kids sent a letter to Dame Rachel Souza Children's Commissioner
15/12/2021	Long Covid SOS and Long Covid Support attended NHS Long Covid Specialist assessment service subgroup meeting
03/02/2022	Long Covid Kids, Long Covid SOS and Long Covid Support attended NHS Long Covid Task force meeting
14/02/2022	Long Covid SOS met with NHS England Clinical Policy team (Director of Clinical Policy, Senior Programme Manager for Long Covid and others)
02/03/2022	Long Covid Support and Long Covid SOS attended the NHS Long Covid National Taskforce Research Subgroup
04/03/2022	Long Covid Kids received an email from Dr Anne Cox CAMHS Intensive Support Team
07/03/2022	Long Covid Kids received a letter from Dr Anne Cox CAMHS Intensive Support Team
10/03/2022	Long Covid SOS and Long Covid Support attended a Ministerial Roundtable on Long Covid
11/03/2022	Long Covid Kids sent letters to Andrew Gwynne MP and Layla Moran MP about visit to Downing Street
16/03/2022	Long Covid Kids, Long Covid SOS and Long Covid Support attended NHS Post Covid Specialist Services subgroup meeting
17/03/2022	Long Covid Kids sent an email to Damien Hinds MP about visit to Downing Street
22/03/2022	Long Covid Support were invited to present at Westminster Health Forum event: <i>Long Covid - improving patient care and access to support, progress in service development, and priority areas for research</i>
22/03/2022	Long Covid Kids receives response from Damien Hinds MP
31/03/2022	Long Covid SOS met with NHS England Director of Clinical Policy and Senior Programme Manager for Long Covid
01/04/2022	A cohort of children and young people with Long Covid delivered the Long Covid Kids support guide to Downing Street, along with a letter to the Prime Minister
06/04/2022	Long Covid SOS and Long Covid Support attended the NHS Long Covid National Taskforce Research Subgroup
07/04/2022	Long Covid SOS attended the NHS Long Covid National Taskforce Meeting
20/04/2022	Long Covid SOS and Long Covid Support attended NHS Post Covid Specialist Services subgroup meeting
23/04/2022	Long Covid Kids member I&S sent a letter to Boris Johnson
09/05/2022	Long Covid SOS met with NHS England Director of Clinical Policy and Senior Programme Manager for Long Covid
30/05/2022	Long Covid Kids had an email exchange with the office of Jeremy Miles, Member of Senedd, re effects of Long Covid on children and education
01/06/2022	Long Covid Kids received an email from DHSC in response to the letter delivered during visit to Downing Street
01/06/2022	Long Covid Kids met with Stephen Morgan MP

20/06/2022	Long Covid SOS met with NHS England Director of Clinical Policy and Senior Programme Manager for Long Covid
28/06/2022	Long Covid Kids sent a letter to Prime Minister Boris Johnson responding to DHSC response
01/08/2022	Long Covid SOS met with NHS England Director of Clinical Policy and Senior Programme Manager for Long Covid
04/08/2022	DHSC and ONS publish report on <i>Direct and indirect health impacts of COVID-19 in England: emerging Omicron impacts</i> – report includes an acknowledgement of Long Covid as direct health impact of Covid-19
06/09/2022	Long Covid Support wrote a letter to the Prime Minister regarding adopting measures to prevent spread of Covid-19
06/09/2022	Long Covid Kids received a letter from James Morris MP, DHSC on behalf of Prime Minister responding to Downing Street visit
21/09/2022	Long Covid SOS wrote to the Secretary of State for Health and Social care
02/11/2022	Long Covid Kids sent an email to Neil O'Brien MP
November 2022	Response to Long Covid Kids from Neil O'Brien MP