

UK COVID-19 INQUIRY

EXHIBIT LC/1

CHRONOLOGY OF SUBMISSIONS TO THE GOVERNMENT AND NHS MADE BY THE LONG COVID CORE PARTICIPANT GROUP

Date	Event	Exhibit
June 2020	Members of Long Covid Support were interviewed by Dr Elaine Maxwell as part of her work at NIHR on the evidence base for 'post-covid syndrome', to understand their lived experience. This study was included in the first Living with Covid19 review and our members presented as part of the first review online webinar with policymakers.	LC/61 - INQ000058418
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	LC/20 - INQ000320245
17/06/2020	Long Covid Support members met with Shadow Public Health Minister Alex Norris.	
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	LC/21 - INQ000238582
06/08/2020	Long Covid Support members met with Greater Manchester Mayor Andy Burnham	
August 2020	Long Covid Support members met with Prof Sally Singh about Your Covid Recovery website	
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	LC/22 - INQ000248911
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	
01/09/2020	Long Covid SOS attend a meeting with Dr Sally Singh to discuss the development of the NHSE 'Your Covid Recovery' website	

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	
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	
02/10/2020	Long Covid Support were asked by the NIHR to recruit volunteers for a film about Long Covid.	
13/10/2020	Long Covid SOS and Long Covid Support attended the first Long Covid Ministerial Roundtable chaired by Lord Bethell	INQ000238600
13/10/2020	Long Covid SOS attended a meeting with the Clinical Policy team at NHS England to discuss Post-Covid clinics	
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	LC/32 - INQ000272223
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 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	INQ000238600
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	INQ000238600
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	INQ000238600
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	
16/12/2020	Long Covid SOS attends the Taskforce Subgroup on Long Covid assessment services rollout and feedback	INQ000238600
18/12/2020	Long Covid Support responded to consultation on NICE guidelines on Long Covid.	LC/26 - INQ000320251
23/12/2020	Long Covid Kids had an email exchange with Chris Loder MP about Commons debate on Long Covid in January 2021	LC/48 - INQ000320273
07/01/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended the fourth NHS Long Covid Task force meeting	INQ000238600
07/01/2021	Long Covid Kids sent an email to Layla Moran MP	LC/49 - INQ000272145
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	INQ000248900
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.	INQ000238622
15/01/2021	Long Covid SOS attends the Taskforce Subgroup on Long Covid assessment services rollout and feedback	INQ000238600
29/01/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended the Ministerial Roundtable on Long Covid	INQ000238600
04/02/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended the NHS Long Covid Task force meeting	INQ000238600
07/02/2021	Long Covid Support sent an email to ONS, DHSC and NHSE	LC/33 - INQ000249020
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	INQ000238600
12/02/2021	Long Covid Support member Claire Hastie sent an email to the DHSC, NHSE and ONS	LC/34- INQ000248996

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	INQ000249049
22/02/2021	Long Covid Support member Claire Hastie sent an email to ONS about phrasing of survey questions	LC/35 - INQ000249021
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.	INQ000238600
23/02/2021 – 24/02/2021	Long Covid Support had email exchanges with Emma Spencelayh, Head of Long Covid NHS Policy and Performance Group at DHSC re patient and public voice participation	
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	INQ000238601
04/03/2021	Long Covid Kids sent an email to Chris Loder MP with their Schools Pack	INQ000272185
04/03/2021	Long Covid SOS received a response from DHSC to 12 January 2021 letter to Boris Johnson	
29/03/2021	Long Covid SOS received response from Matt Hancock to 25 February 2021 letter	INQ000238602
12/04/2021	Long Covid Kids sent a joint letter (with Safe Ed for All) to Matt Hancock	INQ000272150
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>	
04/05/2021	Long Covid Kids sent a letter to Gavin Williamson, Secretary of State for Education	LC/51 - INQ000320276
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	INQ000238600
13/06/2021	Long Covid Support responds to DHSC's call for evidence on "Women's Health Strategy"	LC/66 - INQ000272255
16/06/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended the Ministerial Roundtable on Long Covid chaired by Lord Bethell	INQ000238600
18/06/2021	Long Covid SOS had a telephone call with the Therapeutics Policy and Engagement Lead at DHSC	
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	
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	INQ000272188

03/07/2021	Long Covid Kids sent a joint email with Safe Ed for All to Neil O'Brien MP	INQ000272189
07/07/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600
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	INQ000248931
09/07/2021	Long Covid Kids wrote letter to Sajid Javid raising concerns about long covid in children	INQ000272152
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	INQ000238584
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	INQ000238600
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	INQ000238600
02/09/2021	Letter of response from DHSC to Long Covid Support	INQ000249052
02/09/2021	Long Covid SOS, Long Covid Support and Long Covid Kids attended the NHS Long Covid National Taskforce Research subgroup	INQ000238600
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	INQ000249000
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.	INQ000238620
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	INQ000238600
06/10/2021	Long Covid SOS and Long Covid Support attended the NHS Long Covid National Taskforce Research subgroup	INQ000238600
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 to present on lived experience of those with Covid and risk of suicide.	INQ000238600
03/11/2021	Long Covid Support and Long Covid SOS attended the NHS Long Covid National Taskforce Research subgroup	INQ000238600
04/11/2021	Long Covid Support, Long Covid SOS and Long Covid Kids attend the NHS Long Covid Taskforce Meeting	INQ000238600
17/11/2021	Long Covid Kids, Long Covid SOS and Long Covid Support attended NHS Post Covid National Taskforce Subgroup	INQ000238600
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	INQ000238600
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	INQ000238600
07/12/2021	Long Covid SOS attended a roundtable with Maria Caulfield, Minister for Patient Safety and Primary Care	INQ000238600
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	INQ000272192
15/12/2021	Long Covid SOS and Long Covid Support attended NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600
03/02/2022	Long Covid Kids, Long Covid SOS and Long Covid Support attended NHS Long Covid Task force meeting	INQ000238600
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	INQ000238600
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	INQ000238600
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	INQ000238600
17/03/2022	Long Covid Kids sent an email to Damien Hinds MP about visit to Downing Street	INQ000272158

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	LC/52 - INQ000320277 INQ000272161
06/04/2022	Long Covid SOS and Long Covid Support attended the NHS Long Covid National Taskforce Research Subgroup	INQ000238600
07/04/2022	Long Covid SOS attended the NHS Long Covid National Taskforce Meeting	INQ000238600
20/04/2022	Long Covid SOS and Long Covid Support attended NHS Post Covid Specialist Services subgroup meeting	INQ000238600
23/04/2022	Long Covid Kids member [I & S] sent a letter to Boris Johnson	INQ000272161
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	INQ000272164
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	INQ000272165
01/08/2022	Long Covid SOS met with NHS England Director of Clinical Policy and Senior Programme Manager for Long Covid	
06/09/2022	Long Covid Support wrote a letter to the Prime Minister regarding adopting measures to prevent spread of Covid-19	INQ000249075
06/09/2022	Long Covid Kids received a letter from James Morris MP, DHSC on behalf of Prime Minister responding to Downing Street visit	INQ000272166
21/09/2022	Long Covid SOS wrote to the Secretary of State for Health and Social Care	INQ000238585
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	INQ000272194