

## UK COVID-19 INQUIRY

### EXHIBIT NR/1

#### CHRONOLOGY OF ADVOCACY CONDUCTED BY LONG COVID SUPPORT

Date	Event	Source
2 May 2020	The Covid-19 Support Group was set up on Facebook	
18 May 2020	Twitter campaign of patients holding placards with symptoms and duration of illness	
June 2020	The Facebook Group was renamed Long Covid Support Group	INQ000249045
June 2020	<p>Start of NIHR review: 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.</p> <p>On 19/08/2020 Long Covid Support received a message of thanks for their involvement in the focus groups.</p>	NIHR review - INQ000249019
16-17 June 2020	Two UK parliamentarians, Natalie Bennett and Steve McCabe, tabled written questions about Long Covid in the UK House of Commons, the latter in response to a letter written to Steve McCabe by a founding member of Long Covid Support who was his constituent	INQ000248889 INQ000249035
17 June 2020	Long Covid Support members met with Shadow Public Health Minister Alex Norris.	
19 June 2020	The COVID-19 Research involvement was set up on Facebook	
28 June 2020	The Long Covid.org website was launched	INQ000248856
August 2020	Long Covid Support met with Prof Sally Singh about Your Covid Recovery website	
5 August 2020	Long Covid Support gave oral evidence at the All-Parliamentary Group on Coronavirus. The report that followed concluded that the UK Government was not counting those with long lasting effects of Covid-19 as a measure of severity and impact of the pandemic	NR/15 - INQ000000 Report December 2020 - INQ000249062
6 August 2020	Long Covid Support members met with Greater Manchester Mayor Andy Burnham	

28 August 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	Letter from Long Covid Support: INQ000248900  Letter from Jeremy Hunt to Matt Hancock: INQ000249042
2 October 2020	Long Covid Support were asked by the NIHR to recruit volunteers for a film about Long Covid. The request stated: "We are working closely with the DHSC and Her Majesty's Government who are planning on doing a 'piece' next week on Long COVID: highlighting that COVID-19 isn't just a disease that either kills you in the short term or doesn't affect you, but that it can have long term health impacts (emphasising the importance of following rules on hands, face, space campaign)."	NR/19 - INQ0000000
13 October 2020	Long Covid Support spoke at the first Long Covid Ministerial Roundtable chaired by Lord Bethell. At these monthly meetings Long Covid Support raised concerns on behalf of their members.	INQ000238600
29 October 2020	First NHS Long Covid Task force meeting was held. Long Covid Support had a representative on the main Task Force and on each of the 8 subgroups that were added subsequently.	INQ000238600
11 November 2020	Members of Long Covid Support presented at the NIHR webinar 'Acting on the lived experience of Long Covid'.	NR/20 - INQ0000000
15 November 2020	Long Covid Support members participated in a panel discussion about Long Covid at the World Innovation Summit for Health	
16 November 2020	Long Covid Support attended the second Ministerial Roundtable on Long Covid, chaired by Lord Bethell.	INQ000238600
26 November 2020	Long Covid Support attended the second NHS Long Covid Task force meeting.	INQ000238600
09-10 Dec 2020	Long Covid Support organised the Long Covid Forum in collaboration with ISARIC and GLOPIDR opened by the WHO Director General.	INQ000249064
18 December 2020	NHSE announced Long COVID patients to get help at more than 60 clinics.	NR/21 - INQ0000000
18 December 2020	Members of Long Covid Support wrote an article for the Lancet, in which they raised concerns about the shortcomings of the NICE guideline.	INQ000249005
21 December 2020	Dr Tedros Ghebreyesus WHO wrote a letter to Long Covid Support about Long Covid.	INQ000249017
21 December 2020	Long Covid Support responded to consultation on NICE guidelines on Long Covid.	NR/22 - INQ0000000
6 January 2021	Announcement of Long Covid clinics experience survey by Long Covid Support	INQ000248949

7 January 2021	Long Covid Support attended the third NHS Long Covid Task force meeting	INQ000238600
9 January 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
29 January 2021	Long Covid Support attended the Ministerial Roundtable on Long Covid.	INQ000238600
2 February 2021	Long Covid Support and Patient Safety Learning issued a joint call for an urgent and significant increase in the scale and pace of the response, and a coordinated, multistakeholder approach.	INQ000249068
4 February 2021	Long Covid Support attended the NHS Long Covid Task force meeting and presented a Patient Experience survey.	INQ000248971
7 February 2021	Long Covid Support email to ONS, Department Health and Social Care and NHSE	INQ000249020
12 February 2021	Long Covid Support member Claire Hastie sent an email to the DHSC, NHSE and the Office for National Statistics (ONS)	INQ000248996
16 February 2021	Long Covid Support meets with the Office for National Statistics	
22 February 2021	Long Covid Support member Claire Hastie sent an email to ONS about phrasing of survey questions	INQ000249021
23 February 2021	Long Covid Support attended the Ministerial Roundtable chaired by Secretary of State for Health and Social Care Matt Hancock and Lord Bethell.	INQ000238600
23 February 2021	Email exchanges with <b>NR</b> , Head of Long Covid NHS Policy and Performance Group Department of Health and Social Care regarding patient and public voice participation and Long Covid Support	INQ000249048
March 2021	Long Covid Support spoke at the WHO "In the Wake of the Pandemic" policy briefing.	INQ000249018
March 2021	Long Covid Support's Employment Group provided evidence to the Health and Safety Executive Report on Return to Work after Long Covid	INQ000249009
10 March 2021	Long Covid Support's submitted evidence to the Welsh Health and Social Care and Sport Committee	
15 April 2021	Two members of Long Covid Support spoke with Fiona Glen of NICE and Gail Allsopp of Royal College of GPs. They called for the risk of post-exertional malaise (PEM) to be flagged in the clinical guideline.	INQ000249006
22 April 2021	Long Covid Support were invited to present at Long COVID - priorities for research and improving patient care, treatment and support	

29 April 2021	Members of Long Covid Support participated in the webinar: "(REACT-LC) COVID-19 Community Involvement: Let's Talk About... Long COVID Research"	NR/23 - INQ000000
21 May 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 Support joined Patient and Public Voice partners for NHS England between June 2021 and June 2022	
June 2021	Long Covid Support's Employment Working group submitted written evidence to Work and pensions Committee	INQ000249010
9 June 2021	Long Covid Support attended an NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600
13 June 2021	Long Covid Support responded to DHSC's call for evidence on 'Women's Health Strategy'	NR/24 - INQ000000
16 June 2021	Long Covid Support attended the Ministerial Roundtable on Long Covid chaired by Lord Bethell.  At this meeting Long Covid Support presented the findings of their survey into patient experiences of Long Covid assessment services and their concerns regarding the NHSE 5-point plan	Roundtable minutes: INQ000238600  LC Support presentation: INQ000249050
20 June 2021	Long Covid Support partnered with TUC regarding disability and Long Covid calling for Long Covid to be urgently recognised as a disability and Covid-19 as an occupational disease, to give workers access to legal protections and compensation.	INQ000249073
1 July 2021	Long Covid Support response following the NHSE PPV3 meeting	NR/25 - INQ000000
7 July 2021	Long Covid Support attended an NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600
8 July 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
1 September 2021	Long Covid Support attended an NHS Long Covid Taskforce Research subgroup meeting and an NHS Long Covid assessment clinics subgroup meeting	INQ000238600
2 September 2021	Long Covid Support received a letter of response from DHSC concerning a letter to Sajid Javid	INQ000249052
9 September 2021	Email sent from Long Covid Support 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	NR/7 - INQ000000

12 September 2021	Long Covid Support received a response from the NHSE Clinical Policy team concerning the appointment of National Specialty Advisor Graham Burns who had previously publicly stated that Long Covid was fuelled by insomnia and anxiety	NR/26 INQ000000	-
23 September 2021	Long Covid Support attended a Ministerial Roundtable on Long Covid chaired by Sajid Javid, Secretary of State for Health and Social Care	INQ000238600	
29 September 2021	Long Covid Support attended an NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600	
11 October 2021	Long Covid Support Employment Group have submitted a response to the Department for Work and Pensions, Shaping Future Support: The Health and Disability Green Paper consultation	INQ000249013	
17 November 2021	Long Covid Support attended the NHS Post Covid National Taskforce Subgroup Your Covid recovery rollout, development and Long Covid rehabilitation	INQ000238600	
24 November 2021	Long Covid Support attended an NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600	
29 November 2021	Long Covid Support meet with Jeremy Hunt	INQ000249053	
1 December 2021	Long Covid Support's Employment Group submitted a response to the BEIS Flexible Working Consultation	INQ000249014	
7 December 2021	<p>Long Covid Support attended the Ministerial Roundtable on Long Covid chaired by Maria Caulfield MP, Minister for Patient Safety and Primary Care</p> <p>Long Covid Support questioned Graham Burns (Long Covid Specialty Advisor) on his repeated assertion attributing the condition to 'anxiety at the thought of never recovering as well as associated insomnia' as first stated at the Westminster Health Forum.</p>	INQ000238600	
12 December 2021	Long Covid Support submitted a response to the Department of Business Energy and Industrial Strategy consultation on flexible work	INQ000249014	
15 December 2021	Long Covid Support attended an NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600	
February 2022	Long Covid Support's Employment Group submitted written evidence (HAB0126) regarding Employment	INQ000249011	
3 February 2022	Long Covid Support attended an NHS Long Covid Task force meeting	INQ000238600	
March 2022	Long Covid Support members gave evidence to the APPG Coronavirus report on Long Covid	NR/27 - INQ000000	
10 March 2022	Long Covid Support attended a Ministerial Roundtable on Long Covid, Chaired by Ed Scully	INQ000238600	

	Director of Primary Care and Community Health Services	
16 March 2022	Long Covid Support attended an NHS Post Covid Specialist Services subgroup meeting	INQ000238600
22 March 2022	Long Covid Support were invited to present at Long Covid - improving patient care and access to support, progress in service development, and priority areas for research	
24 March 2022	Long Covid Support members explored the most effective approach to protecting patients with Long Covid at the HSJ Patient Safety Congress 2021	Irrelevant & Sensitive
	Irrelevant & Sensitive	
20 April 2022	Long Covid Support attended an NHS Post Covid Specialist Services subgroup meeting	INQ000238600
6 September 2022	Letter to Prime Minister from Long Covid Support regarding adopting measures to prevent spread of Covid-19	INQ000249075