

UK COVID-19 INQUIRY

EXHIBIT LC/2

COLLABORATION BETWEEN THE LONG COVID CORE PARTICIPANT GROUP AND OTHER BODIES

World Health Organisation

Collaboration	Exhibit
<p>In July 2020 Long Covid SOS were contacted by Maria Van Kerkhove and invited to convene a meeting about Long Covid. The meeting took place on 21 August 2020 and was attended by WHO members including Director General Tedros Adhanom Ghebreyesus. Long Covid Kids also attended the meeting.</p> <p>Subsequently several meetings took place between Long Covid SOS and WHO to inform them on the development of clinical guidelines for Long Covid. Long Covid SOS co-ordinated reports on Long Covid from all WHO regions.</p> <p>Long Covid SOS have collaborated with the WHO on the development of webinars on Long Covid and have been members of committees set up to develop clinical guidelines.</p>	INQ000238544
<p>In December 2020, Long Covid Support organised the Long Covid Forum in collaboration with ISARIC and GLOPIDR, which was opened by the WHO Director General. Following this, the WHO Director General sent a letter of thanks.</p> <p>Long Covid Support member, Dr Clare Rayner attends Dr David Nabarro's fortnightly briefings</p> <p>Long Covid Kids have also worked with the World Health Organisation on their expert panels, on the nature of Covid-19 and impact on children. As part of this work LCK shared concerns and issues raised by members of their support groups, their surveys on symptoms and other issues relating to Long Covid in children and young people</p>	INQ000249017

National Institute for Health and Care Excellence

<p>Long Covid Kids and Long Covid Support were involved in the consultation process for the NICE Long Covid guidelines (published December 2020). Long Covid SOS and Long Covid Support raised several concerns during the consultation process.</p> <p>Long Covid Kids, Long COVID Physio and Long Covid SOS are stakeholders for NICE</p>	LC/26 - INQ000320251 INQ000238630
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<p>Members of Long Covid SOS were and continue to be part of the NICE Expert Panel on Long Covid</p> <p>On 15 April 2021 members of Long Covid Support had a phone call with Fiona Glen of NICE and Gail Allsopp of RCGP during which they called for the risk of post-exertional malaise (PEM) to be flagged in the clinical guidelines</p> <p>In November 2021 Long Covid Support contributed to the consultation review of the NICE Long Covid guidelines</p> <p>A member of Long Covid Support is on the Steering Committee for the NICE Voluntary and Community Service Forum from 2022 to present</p> <p>A member of Long Covid Support met with the Head of NICE Public Involvement Programme, and other small charities, to discuss improvements to the way NICE engages with small voluntary and community sector organisations</p>	
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NHS Long Covid Task Force

<p>Long Covid Kids, Long Covid SOS and Long Covid Support attended and participated in the NHSE Long Covid Taskforce from October 2020</p> <p><i>Long Covid: The NHS plan for 2021</i> was informed by the meetings between Long Covid SOS and the Clinical Policy Unit at NHSE, and subsequent discussions in taskforce meetings and subgroups.</p> <p><i>The NHS plan for improving Long Covid Services</i> was based on the findings in the Health and Social Care Select Committee report on the NHS Backlog. Long Covid SOS contributed heavily to the Long Covid element of the report</p> <p>Long Covid Support conducted patient experience surveys, which were fed back to the Long Covid Taskforce</p>	<p>LC/10 - INQ000272247</p>
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All-Party Parliamentary Groups

<p>In August 2020, Long Covid Support gave evidence to the APPG on Coronavirus. The report in December 2020 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.</p>	INQ000272258
<p>In January 2021, Long Covid Kids and Long Covid Support gave evidence to the APPG on Coronavirus report on Long Covid.</p>	LC/27 - INQ000320252

Health and Safety Executive

<p>Long Covid Support gave evidence for the report by HSE: <i>'Return to work after long COVID: Evidence at 8th March 2021'</i></p>	INQ000249009
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Trades Union Congress

<p>Long Covid Support partnered with TUC 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</p>	LC/57 - INQ000272240
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