



Recognition - Research - Rehabilitation

## Questionnaire

### UK COVID-19 Inquiry: Module 2 - Rule 9 Request to LC SOS

Reference: M2/R9R/LCSOS/TJS

Long Covid SOS (“LC SOS”) set out our responses to the Inquiry’s request for information below. We have prepared our responses without sight and substantial consideration of the relevant evidence or disclosure. However, in order to assist the Inquiry as much as possible, we have tried to respond to the Inquiry’s requests as comprehensively as we could at this early stage. This response is correct to the best of our knowledge given that the organisation was set up by patients who were extremely unwell at the time, many of whom continue to have ongoing health issues. It is provisional information provided without disclosure and to that end we reserve our right to amend or provide further information as necessary.

LC SOS would of course be willing, in due course, to provide a statement to the Inquiry on the issues raised in the Inquiry’s Rule 9 questionnaire.

**1. A brief overview of the history, legal status and aims of the organisation or body. Please explain whether the work of the organisation or body is UK wide, or is instead confined to England, Scotland, Wales or Northern Ireland only.**

LC SOS is a patient advocacy charity. It was established in June 2020 by survivors of Covid-19 who had not recovered. LC SOS is a registered charity in England and Wales (registered from May 2022, Charity Number 1199120), however LC SOS advocates for people UK wide. The charity was set up in order to advocate for recognition, research and rehabilitation for people impacted by Long Covid.

The charitable objectives include:

- raising awareness about Long Covid, its treatment, recovery and rehabilitation with health policy makers, healthcare providers and the general public;
- advocating on behalf of and making known to healthcare providers, health policy makers and other relevant policy makers the views and lived experience of those suffering from or affected by Long Covid;

- supporting or carrying out research into the causes, prevention, diagnosis and treatment of Long Covid and publishing the useful results of such research.

**2. A brief description of the group(s) which the organisation or body supports or represents.**

People living with Long Covid in the UK.

**3. A brief overview of the work of the organisation or body in supporting or representing the relevant group(s) between January 2020 and Spring 2022 as it relates to the response to Covid-19 of (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive.**

Appendix 1 is a chronology of the work of LC SOS between January 2020 to Spring 2022. This sets out in broad outline the work of the organisation in supporting and representing people living with Long Covid.

In summary, LC SOS advocated on behalf of people living with Long Covid in the UK by:

1. Establishing a relationship with WHO
2. Advocacy with Prime Minister and Government
3. Participating in NHS Task Force and expert panels relevant to Long Covid;
4. Submitting evidence to Select Committee Inquiries
5. Contributing to UK and international research
6. Peer reviewing and publishing original research

**(1) Relationship with WHO**

LC SOS was contacted by Maria van Kerkhove (technical lead for the COVID-19 response at the WHO) in July 2020 and set up a [meeting](#) about Long Covid with the WHO in August 2020 with a range of speakers and around 50 invitees. This was the first meeting about Long Covid at the WHO and is therefore significant. The meeting took place on 21 August 2020. LC SOS members chaired it and two of the co-founders, Frances Simpson and Lyth Hishmeh discussed their perspective of having Long Covid and of being a parent of children with Long Covid. At the meeting WHO Director General Dr Tedros Adhanom Ghebreyesus told the audience that



he had received the SOS and “*heard loud and clear that Long Covid needs recognition, guidelines, research and ongoing patient input and narratives, to shape the WHO response from here on*”.

The charity continues to work with the WHO in contributing to webinars and developing guidance on Long Covid. It has been members of the WHO Long Covid Webinars Steering Committee and their Long Covid Guidelines Development Group.<sup>1</sup> For example there was a [seminar](#) on 9 February 2021 titled “ [Expanding our understanding of Post COVID-19 condition](#)” and on 6 October 2021 titled “[Expanding our understanding of Post COVID-19 condition: Rehabilitation.](#)” LC SOS was a recognised partner in the seminars which were held “*under the auspices of WHO and in consultation with the International Severe Acute Respiratory and Emerging Infection Consortium (ISARIC), Global Research Collaboration for Infectious Disease Preparedness (GloPID-R), National Institutes of Health/National Institute of Allergy and Infectious Diseases (NIH/NIAID), LongCovidSOS and patient representatives.*”<sup>2</sup>

LC SOS is in the process of setting up a formal partnership with WHO. LC SOS is applying to formalise its partnership under WHO Framework of Engagement with non-State Actors (FENSA).

## **(2) Advocacy with UK Government**

As well as advocating and raising awareness internationally with its relationship with the WHO, LC SOS advocated at a national level with the UK government about Long Covid.

In 2020 and 2021, LC SOS wrote to the Prime Minister and Secretary of State for Health and Social Care (further details and references are set out in response to question 4) raising concerns about Long Covid.

The organisation also participated in and was represented at the monthly Long Covid Ministerial Roundtable Meetings chaired by Lord Bethel, Under Secretary of State for Health

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<sup>1</sup> For example: Webinar 9.2.21 [report](#) on Expanding Understanding of Post Covid Condition seminar

<sup>2</sup> [https://cdn.who.int/media/docs/default-source/searo/indonesia/covid19/external-situation-report-53\\_28-april-2021.pdf?sfvrsn=c2563ad9](https://cdn.who.int/media/docs/default-source/searo/indonesia/covid19/external-situation-report-53_28-april-2021.pdf?sfvrsn=c2563ad9)

and Social Care from October 2020 and twice chaired by the Secretary of State. At these meetings LC SOS highlighted the difficulties faced by people with Long Covid in obtaining treatment and rehabilitation, and the lack of research on Long Covid. The organisation also stressed the importance of keeping infections low in order to avoid more people developing a condition for which there was no treatment.

### **(3) Participating in NHS Task Force and expert panels relevant to Long Covid**

Members of the LC SOS team were, and continue to be, part of the NHS England Long Covid Taskforce, NICE Expert Panel on Long Covid, NIHR Expert Group on Long Covid and the organisation is a stakeholder for NICE. They represent the organisation's views in these forums.

LC SOS submitted evidence to the Health and Social Care Select Committee Inquiry into the NHS backlog caused by the pandemic and were quoted extensively in their final report in the sections on Long Covid (see response to question 4).

The charity has an ongoing relationship with NHS England since first meeting with Prof Powis, Medical Director of NHS England, in September 2020. LC SOS continues to regularly meet with the Director of Clinical Policy, Cathy Hassell, and her team. During these meetings LC SOS feeds back the experiences and views expressed by people with Long Covid who are trying to get care, interacting with their GPs, being referred to and attending the Long Covid Clinics. Potential treatments are also discussed as well as issues with the Your Covid Recovery website and problems with diagnostics and treatments

Three current and former members of LC SOS were Patient and Public Voice (PPV) partners for NHS England between June 2021 and June 2022.

In May 2022 LC SOS joined with others including Covid-19 Bereaved Families for Justice, Unison, Unite, UCU, ASLEF, the BMA and Independent Sage to launch the Covid Safety Pledge to encourage business to protect their workers, service users and customers from covid-19.

#### **(4) Submitting evidence to Select Committee Inquiry**

Members of LC SOS provided written and oral evidence to the Health and Social Care Committee Inquiry into Clearing the NHS Backlog. On 21 September 2021 Ondine Sherwood, co-founder of LC SOS, gave oral evidence to the Select Committee. She gave evidence that:

*“the aspect of not being believed is highly typical, certainly in the early days. Despite the fact that we knew from the first SARS epidemic that there were many people who did not recover in months or years, the whole system seemed to be completely unprepared for that possibility. Therefore, when people were not getting better, there was absolutely nothing. There were no resources for them. There was no information. I think that each individual felt alone. Certainly, that was my experience. I did not realise that there were other people in the same situation. I thought, “There’s something wrong with me. I can’t shake this off.” Everybody was unprepared. When they tried to speak to medical professionals, the medical professionals knew nothing. A lot of people said that they would go to A&E and be met with shrugs, because people did not know what to do for them.*

Her full evidence is available [here](#). LC SOS written evidence is [here](#).

The report published on 14 December 2021 referenced LC SOS evidence at [pages 20-21](#).

#### **(5) Contributing to research on Long Covid**

LC SOS has directly and indirectly informed UK and international research. For example, it was part of a consultation to inform and develop NIHR funding calls. Members of the team are involved in several NIHR-funded research projects as PPI and are on the steering committee of the UCL-led STIMULATE-ICP project.

In the STIMULATE-ICP project, it is represented in both the PPI group and the Trial Steering Committee. Trustee Prof Amitava Banerjee is Chief Investigator of STIMULATE-ICP. In this

role he leads and works with several national and international collaborations regarding direct, indirect and long-term effects of Long Covid

Peer reviewed and published original [research](#) carried out by LC SOS on the impact of Covid-19 vaccines on Long Covid symptoms has been cited by the [UKHSA](#), [NICE](#), [ONS](#) and [SAGE](#) (referenced under the authors Strain WD, Sherwood O, Banerjee A, Toghiani VVD, Hishmeh L, Rossman J). The group also carried out surveys for NHS England on patients' experiences with GPs and on the Long Covid clinics, which can be found [here](#).

LC SOS is a partner in the Uni of Birmingham TLC study which is researching a targeted intervention for Long Covid via an app which will include symptom management and validation of interventions.

A member of LCSOS is part of the Expert Advisory Group for the WILCO study at Imperial College London examining the immunology of Long Covid with a view to determining the mechanisms of disease and the development of diagnostics and treatments.

LCSOS also provides PPI for the 'Understanding experiences of Long Covid in families' project which is based at the University of Oxford

The group has worked with the Royal College of General Practitioners to co-produce a series of educational webinars on Long Covid.

LC SOS has been quoted extensively in the media – print, broadcast, TV and online. See Appendix 3 List of Media.

**4. A list of any articles or reports the organisation or body has published or contributed to, and/or evidence it has given (for example to Parliamentary Select Committees) regarding the impact on the group(s) which the organisation or body supports or represents of the response to Covid-19 by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please include links to those documents where possible.**

Please see Appendix 1: Overview Chronology and Appendix 2: List of Articles, Evidence and Publications LC SOS has contributed to and Appendix 3: List of Media LC SOS has contributed to.

In particular, LC SOS would highlight the following letters, evidence and papers which they have contributed to:

**Open letters sent to members of UK government:**

1. 3 July 2020: [open letter](#) to Prime Minister Boris Johnson “on behalf of thousands of forgotten victims of Covid-19” sent to the Prime Minister by email and hard copy, and copied to health policy makers and all sitting MPs
2. 12 January 2021: [letter published in the BMJ](#) to Boris Johnson on “The risk of Long Covid must be a primary consideration in policy decisions” (also sent by email to the Prime Minister)
3. 15 July 2021: [open letter](#) to Sajid Javid, published in the BMJ “We must take long covid into account when easing covid restrictions” also sent to Mr Javid by email
4. 21 September 2022: [open letter](#) to Therese Coffey, Secretary of State for Health and Social Care published in the BMJ asking her to prioritise the needs of people with Long Covid

**Health and Social Care Select Committee Inquiry into the NHS backlog**

September 2021: [written evidence](#) submitted

21 September 2021; [Oral evidence](#) provided in person and via video link

14 December 2021: [report](#) published. LC SOS quoted/referenced on pp 20, 21. The report incorporating the evidence we provided was used as the basis for the NHS England [Long Covid Plan 2022/23](#)

**Published paper:**

LC SOS also published research on the basis of a survey conducted by LC SOS: The Impact of COVID Vaccination on Symptoms of Long COVID: An International Survey of People with Lived Experience of Long COVID – peer reviewed and published in [Vaccines](#)

See also [preprint](#) and [lay report](#)



**5. The view of the organisation or body as to whether the group(s) it supports or represents was adequately considered when decisions about the response to Covid-19 were made by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please also explain the reasons for the view expressed by the organisation or body in this respect.**

We provide these comments to assist the Inquiry with our views which are formed on the basis of our experience and knowledge of events to date. However, they are only preliminary comments provided without sight of disclosure or evidence. It is our view that the impact of Long Covid was not adequately considered when making decisions about the response to Covid-19 by the UK Government. This applies equally to those who were already suffering from the condition and those who would potentially be infected in the future. We have come to this view taking into account the following non-exhaustive factors:

- i. The Covid-19 ‘dashboard’ does not refer to morbidity or continuing symptoms and has not done so since its inception. This did not change even after estimates had begun to be provided by the Office for National Statistics (ONS).
- ii. Public health and government messaging throughout this period (and to date) very rarely referenced the relatively high proportion of people infected with Covid-19 who did not recover, only using deaths and hospitalisation as metrics to measure the impact of the pandemic. This incorrectly gave the impression that all others recovered without any ongoing health issues.
- iii. Government briefings on TV and social media rarely if ever mentioned Long Covid except as a footnote or brief comment.
- iv. There has only been as far as LC SOS is aware one Government campaign in October 2020 about the long-term risks of COVID-19 ([here](#)). To the best of our knowledge there was no other campaign by the Government (the NHS did refer to the risk of Long Covid in relation to encouraging young people to vaccinate) but compared to the amount of public messaging in general about Covid-19 especially during lockdowns and periods where restrictions were in force, this is very minor. Long Covid was rarely (if at all) mentioned by the government. In our view the effect of this is to leave health bodies unsupported and the general public in ignorance of the facts (for example in August 2022 the British Medical Association called for [guidance and support](#)).

- v. After the lifting of restrictions, government sponsored material on avoiding Covid-19 has focussed on vaccination as the sole preventative measure with very little guidance on avoiding infection through better ventilation or the wearing of masks in crowded indoor places. Although vaccination reduces the incidence of Long Covid it only does so by 15-50% (depending on the research)<sup>3</sup>. A 50% reduction, if correct, is significant, however the numbers of people who have been infected in the Omicron waves is far higher than in previous variants
- vi. The ‘roadmap out of [lockdown](#)’ published 22 February 2021 contained a single descriptive paragraph which referred to ‘prolonged symptoms’:

*“While for many people COVID-19 is a mild illness, for some, regardless of age, the effects can linger into the long-term. The NHS and partner organisations are already implementing initiatives to support people with prolonged symptoms following COVID-19 infection. In addition, the National Institute for Health Research (NIHR) and UK Research and Innovation (UKRI) have announced funding for a number of ambitious studies that will help the Government learn more about the long-term effects of the virus, including among people who have not been hospitalised”*

It is our concern that the potential for many people to develop Long Covid may not have been seriously or adequately considered when preparing the ‘roadmap’ and forming policy around easing restrictions.

- vii. The long-term health, public health and economic impact of Long Covid appears not to have been part emergency preparedness or implementation. This has left those with Long Covid and those at risk of Long Covid massively exposed to risk and harm.

**6. Whether the organisation or body raised any concerns about the consideration being given to the group(s) which it supports or represents with (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive, when the Government(s) and/or Executive were making decisions about their response to Covid-19. Please provide a list of any such correspondence or meetings with the UK Government, Scottish Government, Welsh Government and/or the Northern Ireland Executive, including the dates on which the body or organisation wrote or such**

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<sup>3</sup> For example <https://www.gov.uk/government/news/ukhsa-review-shows-vaccinated-less-likely-to-have-long-covid-than-unvaccinated>

**meetings were held, to whom the correspondence was addressed or with whom the meeting was held, and any response received from the UK Government, Scottish Government, Welsh Government and/or Northern Ireland Executive addressing such concerns.**

See answers below and summary as set out in Appendices.

LC SOS first wrote to the Prime Minister in July 2020. In this [open letter](#) dated 3 July 2020 to Prime Minister Boris Johnson sent to the Prime Minister by post and email and copied to health policy makers they wrote:

*“There appears to be very little focus on the part of government on the ongoing very poor health of potentially hundreds of thousands of people. It is imperative that the needs of this group are addressed, and sufferers given the support they need. Not only is this a calamity for each individual, it is a serious matter for an economy which is already facing an existential struggle: large numbers on long-term sick leave will significantly impact the workforce as it emerges from furlough.”*

These concerns were raised regularly during the monthly DHSC Long Covid roundtable meetings chaired by Lord Bethel and on one occasion with Rt Hon Matt Hancock and on another with Rt Hon Sajid Javid<sup>4</sup>. These meetings took place between October 2020 and March 2022.

At the first meeting on 13 October 2020, LC SOS co-founder Ondine Sherwood was asked to present. Below are extracts from her speech:

*“In order to examine the evolution of Long Covid it is imperative that funding is provided for research on community patients and that longitudinal studies are carried out.*

*“Demographic research is also urgently needed: we must now establish how many people have Long Covid in the UK and what proportion suffer for weeks, months or longer - something that we assume the ONS could provide. If we have hundreds rather*

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<sup>4</sup> Minutes of meetings

*than tens of thousands of sufferers then the potential impact on service provision is huge and the £10M investment will be inadequate.*

*“A cohort this size of previously active contributors to the economy cannot be ignored. An unpublished survey of 1570 long haulers across a wide age band found that only 7% have been able to return to full time work without compromising their recovery. A third cannot work at all. Given recent infection rates we risk continued disruption to the workforce with a significant economic impact. Provisions need to be made for long-term sick leave and benefits: we have heard from people who have lost their jobs or are being forced back into work and risking further ill health.*

*“Activism in the UK and this positive response from government and the NHS has presented an opportunity for the UK to be world leaders in the management of Long Covid and if these plans are followed through it may be a response to the pandemic that we can be truly proud of.”*

In a letter dated 12 January 2021 to Boris Johnson, which was published in the BMJ and was also sent to the Prime Minister by email, LC SOS wrote:

*..... if all or most restrictions are eliminated during this period, we run the risk of the virus circulating freely among younger people. We will then likely see a huge rise in the number of those going on to develop long covid.*

*“We appreciate that decisions on relaxing restrictions are not easy ones for any government to make. However, we urge you not to base these decisions on deaths and hospital admissions alone. It would be very short-sighted indeed to ignore the potential for a huge increase in people with long-term ill-health on top of those already suffering.*

*We are asking you to please make long covid a primary consideration in your policy decision making for lifting restrictions. The potential for covid-19 to cause significant morbidity is now recognised, and both NICE and NHS England are making provision for assessing, diagnosing, and treating those affected. The availability of a vaccine does not mean that we can relax containment measures – we must continue to test, trace and isolate sufferers, take steps to make schools safe and most importantly ensure that*

*the public is appraised of their ongoing risk so that as individuals they continue to be mindful of the consequences of infection.*

During the 23 February 2021 Ministerial meeting, LC SOS directly appealed to Secretary of State for Health and Social Care Matt Hancock to provide funding for research into treatments. This was followed up on 25 February 2021 by a [letter to Matt Hancock](#) requesting funding for research into treatment for Long Covid:

*“We believe that there is a requirement for rapid, robust clinical trials of therapeutics now – in truth, we needed them 6 months ago.*

*“As things stand there are no approved treatments for Long Covid patients. We hope that something along the lines of the RECOVERY trial can be set up – a multi-centre, multi-armed adaptive rapid assessment of therapeutics.*

*“The importance of these proposals cannot be understated; the economic, social, and healthcare burden of this cohort is likely to be enormous – many have decades of potentially disrupted life ahead of them which early treatment may help mitigate.”*

On 29 March 2021 LC SOS received this [response](#) from Matt Hancock which included the following:

*“Thank you for your letter dated 25 February 2021 and the valuable contributions you made during the roundtable meeting on 23 February 2021. I was very pleased to have been able to chair the roundtable session and listen directly to the feedback raised by you and other attendees.*

*“I agreed with the important points you made regarding the need for research into treatment options and I have been working with my officials to make additional funding available for research on Long COVID. I wanted to reply once I was in a position to confirm that this had been achieved.*

...

*“I again want to thank you and your colleagues in LongCovidSOS for your ongoing engagement and insight. I am incredibly grateful to you and other patient representatives for the contributions you have provided through the roundtables hosted by my colleague Lord Bethell.”*

In July 2021 in an [open letter](#) to Sajid Javid, Secretary of State for Health and Social Care LC SOS wrote:



*“Long Covid has not only been ignored in policy making decisions, and barely mentioned in the roadmap out of lockdown - it has been almost completely absent from the government’s public messaging. The population are now being asked to take responsibility for their own safety and ‘[exercise good judgement](#)’, but due to this communications failure many do not realise the extent of the risk they are taking when exposing themselves to this virus.*

*“It was the [position](#) of your predecessor that “the first responsibility of any government is to protect its citizens”: you must agree that this is an essential part of your job. There is no healthy economy without a healthy population.”*

This letter was covered in a [news story](#) in the Independent.

In June 2021 LC SOS co-founder presented at the roundtable on the results of the Vaccine survey. She was subsequently contacted by the Head of Policy and Engagement at the DHSC Therapeutics Taskforce, wanting to “*to seek your thoughts and reflections on long COVID – its possible causes, the classes of therapeutics for the condition, and the relationships between disease severity and the likelihood / intensity of developing long COVID*”

Sajid Javid chaired the Long Covid roundtable on 23/09/2021. During the meeting LC SOS co-founder Ondine Sherwood said:

*“We wrote to you back in July to ask you to consider Long Covid when making policy decisions. I hope what you have heard today will convince you that we face a real problem with this ‘pandemic within the pandemic’ and you can see how much effort is being put in to trying to deal with the fallout. The only way we have so far to prevent people getting Long Covid is to prevent them from getting infected in the first place and so we must do everything possible to lower the infections rate”*

After the meeting, Sajid Javid [tweeted](#):

*“Great to meet patient representatives yesterday with @NHSEngland & @ONS to discuss their experience & work on Long COVID. We’re committed to helping those living with the condition – investing £50m in research & opening over 80 Long COVID clinics across England.”*

On 7 December 2021 LC SOS attended the Ministerial Roundtable on Long Covid chaired by **NR** Minister for Patient Safety and Primary Care. At this meeting Ondine Sherwood asked:

*“It’s really troubling that the risk of long-term morbidity due to Covid-19 has never been part of health policy planning... It’s likely that at least half a million people infected since that date will be already suffering or will go on to experience Long covid. Because morbidity isn’t considered, the UK didn’t put in place any mitigations to bring infections down to the very low levels until quite recently seen in other countries in Europe.”*

*“have highly infectious variant which we are told will predominate in the UK within weeks causing a high level breakthrough infections which know can result in Long Covid... How can we tolerate this burden of ill health and disability? When will considerations around morbidity inform health policy? How will the NHS cope with this and is anyone researching the cost to society and the economy?”<sup>5</sup>*

On 21 October 2021 LC SOS Ondine Sherwood presented to the National Suicide Prevention Strategy Advisory Group, on Long Covid and suicide risk. The presentation contained this information from a [published paper](#):

*“There is a high probability that symptoms of psychiatric, neurological and physical illnesses, as well as inflammatory damage to the brain in individuals with post-COVID syndrome increase suicidal ideation and behaviour in this patient population. COVID-19 survivors without post-COVID syndrome may also be at elevated suicide risk.”*

The trauma suffered through not being believed by medical practitioners was highlighted, and the point made that this was the most cited reason for feeling hopeless in people with ME (who have been [found](#) to have a 7x increase in suicide compared to the general population) along with poor treatment by the healthcare system.

In response to the announcement in February 2022 that remaining restrictions would be phased out LC SOS issued a [statement](#) to the press on 10/02/2022 which contained the following:

*“If Covid is to be allowed to spread through the community in a completely uncontrolled way, with no precautionary measures in place, then we risk condemning hundreds of thousands more previously healthy and economically active people to a debilitating long term illness for which there are currently no effective treatments. This*

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<sup>5</sup> Notes from Ondine Sherwood dated 7 December 2021

*policy decision also fails to take into account those many clinically vulnerable people who will not be able to safely participate in society.”*

In response to a further announcement later on that month that all measures to control the spread of Covid-19 would be scrapped, LC SOS issued a further [statement](#) jointly with Long Covid Kids:

*“Long Covid has never formed part of policy making decisions during this pandemic, despite repeated [requests](#) on our part both in writing and in person to ministers. People with Long Covid need to protect themselves from reinfection, which can seriously exacerbate symptoms. They and the millions of clinically vulnerable will effectively be forced to shield and become prisoners in their own homes. Since we do not know who will get Long Covid, or how long those living with Long Covid will remain sick, all members of society remain vulnerable.”*

On 10 March 2022 at a Ministerial Roundtable on Long Covid chaired by Ed Scully, LCSOS raised recent publications which together demonstrate the disease burden of long COVID. These included ONS findings on large increases in disability, and the impact this then has on workforce attendance and job loss. LCSOS noted one particular study showing an association between COVID-19 and changes in brain structure. Although it is not known how such changes might impact on children’s ability to learn, this is a concern, given the number of children with long COVID. LCSOS emphasised the need for research and policies to prevent uncontrolled transmission of COVID-19, and attention to morbidity in messaging.

**7. A brief summary of the views of the organisation or body as to any lessons, if any, that can be learned from any consideration which was given to the group(s) that the organisation or body supports or represents by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive when they were making decisions about their response to Covid-19.**

We provide these comments to assist the Inquiry to focus its investigations however they are only preliminary comments provided without sight of disclosure or evidence. We will only be in a position to provide detailed submissions on lessons to be learned after receiving disclosure and hearing evidence adduced during the Inquiry.

Our preliminary views include that as an organisation we believe that it is essential when considering the health impacts of any infectious disease that resulting morbidity is given sufficient weight in decision making. During the ongoing Covid-19 pandemic this appears not to have been the case and the problems continue in the present.

For example, we are concerned that there was no public health messaging about the risk of a long term or chronic illness/disability from Covid-19 and the risk to the public of developing Long Covid appears not to have been adequately considered. (See LCSOS letter dated 12 January 2021 to Boris Johnson; LCSOS letter dated 15 July 2021 to Sajid Javid requesting that the risk of Long Covid be taken into account in policy decisions; and LCSOS representations at Ministerial Roundtables.

Our experience from the people we support is that people who did not recover and experienced ongoing symptoms and ill health were dismissed by doctors and other healthcare professionals. There were few measures place to provide care for people who were developing a chronic illness as a result of SARS-CoV-2 infection. They felt ignored and abandoned by the government and health system. Clear messaging from the Government on the risks and impact of Long Covid at an early stage in the pandemic and during 2020 to 2021 would have significantly improved people with Long Covid's experience with healthcare professionals.

We believe that the potential for a significant number of people to suffer considerable poor health for months or years was not adequately taken into account during policy planning, resulting in:

- An acceptance of very high levels of infections in the community without taking heed of the consequences that 5-15% of those infected would develop long term illness and/or disability.
- A lack of awareness among the public as to their risk of ongoing ill health if infected. This is exacerbated by a lack of public messaging and an emphasis on vaccinations having 'broken the link between infections and hospitalisations/deaths' while ignoring morbidity.
- A growing cohort of people of working age unable to return to their previous levels of employment leading to measurable impacts on the workforce and economy.
- An increasing burden on the NHS.

The population should be protected from disease, and chronic illness can have a major impact on quality of life and a person's ability to earn a living, support their families and care for others. During this pandemic the emphasis was placed on protecting the NHS so that it would not be overwhelmed during the acute phase of infection. The impact of long-term illness on a significant cohort of the population also has an impact on healthcare services as well as other social support services for an indefinite period into the future. It is important that any future planning for a pandemic takes into account the long-term costs and consequences of infections on individuals who do not recover within a short period of time as well as the short-term consequences of high levels of acute infections.

**15.12.22**





Recognition - Research – Rehabilitation

## Long Covid SOS

### Appendix 1: Overview Chronology of the work of Long Covid SOS

#### January 2020 to Spring 2022

Date	Event	Source
June 2020	Long Covid SOS was established by a group of survivors with Covid-19 who had not recovered.	<a href="https://www.longcovidsos.org">https://www.longcovidsos.org</a>
July 2020	“Message in Bottle” social media campaign was launched. <i>“Thousands and thousands of us have been struggling for weeks and months with ongoing symptoms of Covid-19.”</i>	LCSOS Website <a href="https://www.longcovidsos.org/film">https://www.longcovidsos.org/film</a>
3/07/2020	LC 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.	<a href="#">Letter dated 3 July 2020</a>
10/07/2020	LCSOS contributed to British Medical Journal publication <i>“Patients’ experiences of ‘long covid’ are missing from the NHS Narrative.”</i>	<a href="#">Patients’ experiences of ‘long covid’ are missing from the NHS Narrative BMJ 10.07.2020</a>
3/08/2020	LCSOS along with Professor Gardner, Professor of Infectious Disease at Liverpool University contributed to Financial Times report into Long Covid.	<a href="#">“Fatigue Plagues thousands suffering post coronavirus symptoms.”</a> Financial Times 3/08/2020
21/08/2020	LCSOS were invited by the World Health Organisation to convene a meeting about Long Covid. The meeting was attended by Maria Van Kerkhove, (WHO Covid Technical Lead) and Janet Diaz (WHO Head of Clinical Care) from the central WHO team. At the meeting,	See summary of meeting on <a href="#">website.</a>

September 2020	In September 2020 LCSOS met with Professor Stephen Powis Medical Director of NHS England and his team.	
October 2020	LCSOS 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	Email of [16/10/2020] (a data set on Long Covid was published in December 2020 but monthly prevalence of Long Covid was not published by ONS until April 2021)
13/10/2020	LCSOS attended the first Long Covid Ministerial Roundtable chaired by Lord Bethell was held.	Online Sherwood speech; Email dated 15.10.20 from DH Lords Diary @DHSC
29/10/2020	First NHS Long Covid Task force meeting was held. LCSOS and LC Support attended.	
16/11/2020	LCSOS attended the second Ministerial Roundtable on Long Covid, chaired by Lord Bethell.	
26/11/2020	Second NHS Long Covid Task force meeting LCSOS and LC Support attended .	
07.01.2021	NHS Long Covid Task force meeting	
12/01/2021	LCSOS 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.	<a href="#">Letter</a> to Boris Johnson dated 12 January 2021 and <a href="#">here</a>
29/01/2021	LCSOS attended the Ministerial Roundtable on Long Covid.	
February 2021	LCSOS partnered in the NIHR funded University of Birmingham TLC Long Covid research project	
04/02/2021	NHS Long Covid Task force meeting	
23/02/2021	LCSOS attended the Ministerial Roundtable led by Secretary of State for Health and Social Care Matt Hancock and Lord Bethell.	Minutes dated 23.02.21

	LCSOS asked him about funding more research into Long Covid, funding clinical trials.	
25/02/2021	LCSOS sent a letter to Secretary of State for Health and Social Care Matt Hancock regarding lack of research, funding for clinical trials and raising concerns that <i>“We find it troubling that there is no funded research currently being carried out within the NHSE assessment clinics themselves, given that this is where so many patients are being seen.”</i>	Letter dated 25/02/2021 to Matt Hancock, see <a href="#">here</a>
04/03/2021	Email from <b>NR</b> on behalf of the Department of Health and Social Care, to LCSOS in response to 12 January 2021 Letter to Boris Johnson.	See link to response <a href="#">here</a>
29/03/2021	Letter from Matt Hancock to Long Covid SOS regarding Ministerial Roundtable and letter dated 25 February 2021.	See response from Matt Hancock <a href="#">here</a> .
18/05/2021	LCSOS published the result of the survey into the impact of vaccination on Long Covid Symptoms.	See <a href="#">website</a> and publication in <a href="#">Vaccines</a> Journal “Impact of COVID vaccination on Symptoms of Long Covid: An international survey of people with lived experience of Long COVID” Vaccines, 2022 10(5) 653. See also <a href="#">preprint</a> and <a href="#">lay report</a>
June 2021	Members of LCSOS joined Patient and Public Voice partners for NHS England between June 2021 and June 2022.	
09.06.2021	NHS Long Covid Specialist assessment service subgroup meeting	
16/06/2021	LCSOS attended the Ministerial Roundtable on Long Covid chaired by Lord Bethell. Ondine Sherwood of Long Covid SOS presentation on vaccine survey findings (see above publication in Vaccines Journal). She was subsequently contacted by the Head of Policy and Engagement at the DHSC Therapeutics Taskforce, wanting to <i>“to seek your thoughts and reflections on long COVID – its possible causes, the classes of therapeutics for the condition, and the relationships between</i>	Minutes from meeting dated 16/06/2021 Slides to Impact of Vaccine and Long Covid

	<i>disease severity and the likelihood / intensity of developing long COVID”</i>	
07.07.2021	NHS Long Covid Specialist assessment service subgroup meeting	
15/07/2021	LCSOS wrote to Sajid Javid, Secretary of State for Health and Social Care asking that Long Covid be taken into account when easing restrictions as <i>“Thousands of predominantly young, active people are being condemned to prolonged ill-health and disability every day...The country has now arrived at this juncture: the coronavirus is circulating freely among young adults and children; cases are rising exponentially, but government policy is focused only on hospitalisations and deaths. However, in January, it was not anticipated that we would be facing a more transmissible and possibly more virulent variant which renders vaccines less effective....the population are now being asked to take responsibility for their own safety and “exercise good judgement“, but due to this communications failure many do not realise the extent of the risk they are taking when exposing themselves to this virus. We note with concern that your fellow cabinet member Rishi Sunak has announced his intention to stop wearing a mask as soon as possible, despite the strong recommendation from the World Health Organization (WHO) that even those double vaccinated should continue to wear masks to protect themselves and, importantly, others from the Delta variant.”</i>	<a href="#">Letter</a> to Sajid Javid dated 15 July 2021
01.09.2021	NHS Long Covid Taskforce Research subgroup meeting NHS Long Covid assessment clinics subgroup meeting	
21/09/2021	LCSOS 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.	See oral evidence transcripts <a href="#">here</a> and <a href="#">written evidence report</a> submitted. <a href="#">report</a> published in December 2021. Long Covid SOS quoted/referenced on pp 20, 21. The report incorporating the evidence we provided was used as the basis for

		the NHS England <a href="#">Long Covid Plan 2022/23</a>
23/09/2021	Ministerial Roundtable on Long Covid chaired by Sajid Javid, Secretary of State for Health and Social Care. LCSOS raised concerns as set out in July 2021 letter that Long Covid should be included in policy decisions about infection rates.	Ondine Sherwood note dated 23/09/21
29.09.2021	NHS Long Covid Specialist assessment service subgroup meeting	
21/10/2021	LCSOS attended the National Suicide Prevention Strategy Advisory Group- Covid-19 Sub Group Chaired by Fiona Walsh Department of Health and Social Care , Emma Spencelayh, Head of Long COVID, DHS.  LCSOS gave presentation on lived experience of those with Covid and risk of suicide.	Agenda dated 21/10/21
24.11.2021	NHS Long Covid Specialist assessment service sub group meeting	
17.11.2021	NHS Post Covid National Taskforce sub-group Your Covid recovery rollout, development and Long Covid rehabilitation	
24.11.2021	NHS Long Covid Specialist assessment service sub group meeting	
07/12/2021	LCSOS attended the Ministerial Roundtable on Long Covid chaired by <span style="border: 1px dashed black; padding: 2px;">NR</span> Minister for Patient Safety and Primary Care	Two Notes from OS dated 7 December 2021
15.12.2021	NHS Long Covid Specialist assessment service subgroup meeting	
03.02.2022	NHS Long Covid Task force meeting	
10/02/22	LCSOS issued a press statement. <i>“If Covid is to be allowed to spread through the community in a completely uncontrolled way, with no precautionary measures in place, then we risk condemning hundreds of thousands more previously healthy and economically</i>	Press <a href="#">statement</a> dated 10/02/2022



	<i>active people to a debilitating long term illness for which there are currently no effective treatments. This policy decision also fails to take into account those many clinically vulnerable people who will not be able to safely participate in society.”</i>	
16.03.2022	NHS Post covid Specialist Services subgroup meeting	
21/02/2022	Joint press statement with LCKids <i>“Long Covid has never formed part of policy making decisions during this pandemic, despite repeated <a href="#">requests</a> on our part both in writing and in person to ministers. People with Long Covid need to protect themselves from reinfection, which can seriously exacerbate symptoms. They and the millions of clinically vulnerable will effectively be forced to shield and become prisoners in their own homes. Since we do not know who will get Long Covid, or how long those living with Long Covid will remain sick, all members of society remain vulnerable.”</i>	Joint press <a href="#">statement</a>
10/03/2022	LCSOS attended a Ministerial Roundtable on Long Covid, Chaired by <span style="border: 1px dashed black; padding: 0 2px;">NR</span> Director of Primary Care and Community Health Services	Minutes of Meeting
20.04.2022	NHS Post Covid Specialist Services subgroup meeting	
May 2022	LCSOS joined with others including Covid-19 Bereaved Families for Justice, Unison, Unite, UCU, ASLEF, the BMA and Independent Sage to launch the <a href="#">Covid Safety Pledge</a> to encourage business to protect their workers, service users and customers from covid-19.	<a href="#">Covid Safety Pledge</a>
21/09/2022	LCSOS wrote to the Secretary of State for Health and Social care raising concerns that <i>“The covid-19 pandemic continues to have an impact on the nation’s health. It is encouraging that deaths are now at a comparatively low level, but sadly morbidity as a result of SARS-CoV-2 affects a large number of people, many of whom are effectively disabled and unable to work and live a normal life. We urge you to prioritise the needs of this group of people, many of whom are essential workers, carers,</i>	Letter to Teresa Coffey Secretary of State for Health and Social Care published <a href="#">here</a> .

	<i>parents, and children. Long covid is the “pandemic after the pandemic” and cannot be ignored....</i>	
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**LONG COVID SOS – Appendix 2 List of Articles, Publications and Evidence that Long Covid SOS has contributed to January 2020 to Spring 2022**

<b>Date</b>	<b>Publication</b>	<b>Title</b>	<b>URL</b>	<b>Quote/comments</b>
03/07/2022	Open letter	Urgent SOS from Long Covid Sufferers	<a href="https://www.longcovidsos.org/files/ugd/8bd4fe_e3779d8fa84c4c32bbd8ed43d70cd3cf.pdf?index=true">https://www.longcovidsos.org/files/ugd/8bd4fe_e3779d8fa84c4c32bbd8ed43d70cd3cf.pdf?index=true</a>	“Throughout this period the general public have been assured by government and public health sources that most ‘mild’ or ‘moderate’ cases, not requiring hospital admission, resolve within two weeks. However, it is becoming increasingly clear that for many this is far from the case”
10/07/20	British Medical Journal	Patients experience of long covid are missing from NHS narrative.	<a href="https://blogs.bmj.com/bmj/2020/07/10/patients-experiences-of-longcovid-are-missing-from-the-nhs-narrative/">https://blogs.bmj.com/bmj/2020/07/10/patients-experiences-of-longcovid-are-missing-from-the-nhs-narrative/</a>	LCSOS contribute to British Medical Journal publication “ <i>Patients’ experiences of ‘long covid’ are missing from the NHS Narrative.</i> ”
12/01/2021	British Medical Journal	The risk of Long Covid must be a primary consideration	<a href="https://blogs.bmj.com/bmj/2021/01/12/the-risk-of-long-covid-must-be-a-primary-consideration-in-policy-decisions/">https://blogs.bmj.com/bmj/2021/01/12/the-risk-of-long-covid-must-be-a-primary-consideration-in-policy-decisions/</a>	“We have no doubt that the population is desperate to return to previous freedoms, to be able to return to work, socialise and spend time in close proximity to friends and family members. However, we and many of those still suffering from long covid after managing acute covid-19 in the community in the early months of 2020 are extremely concerned at the potential consequences of such a decision”.

		in policy decisions		
18/05/2021	Survey	Publication of LCSOS Survey into impact of vaccinations	See <a href="#">website</a> and publication in <a href="#">Vaccines Journal</a>	“Impact of COVID vaccination on Symptoms of Long Covid: An international survey of people with lived experience of Long COVID” <i>Vaccines</i> , 2022 10(5) 653
15/07/2021	British Medical Journal	We must take Long Covid into account when easing restrictions	<a href="https://blogs.bmj.com/bmj/2021/07/06/we-must-take-long-covid-into-account-when-easing-covid-restrictions/">https://blogs.bmj.com/bmj/2021/07/06/we-must-take-long-covid-into-account-when-easing-covid-restrictions/</a>	“Long covid has not only been ignored in policy making decisions, and barely mentioned in the roadmap out of lockdown—it has been almost completely absent from the government’s public messaging. The population are now being asked to take responsibility for their own safety and “ <a href="#">exercise good judgement</a> “, but due to this communications failure many do not realise the extent of the risk they are taking when exposing themselves to this virus. “
21/09/2021	Health and Social Care Committee into clearing the backlog	Oral evidence to Select Committee	See oral evidence transcripts <a href="#">here</a> and <a href="#">written evidence</a> submitted. <a href="#">report</a> published in December 2021.	LCSOS 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. <i>Evidence: Despite the fact that we knew from the first SARS epidemic that there were many people who did not recover in months or years, the whole system seemed to be completely unprepared for that possibility. Therefore, when people were not getting better, there was absolutely nothing. There were no resources for them. There was no information. I think that each individual felt alone</i>
10/02/2022	Press release	Statement from LC SOS on the further easing of restrictions	<a href="https://www.longcovidsos.org/post/statement-from-longcovidsos-about-further-easing-of-restrictions-announced-by-boris-johnson-09-02-22">https://www.longcovidsos.org/post/statement-from-longcovidsos-about-further-easing-of-restrictions-announced-by-boris-johnson-09-02-22</a>	“If Covid is to be allowed to spread through the community in a completely uncontrolled way, with no precautionary measures in place, then we risk condemning hundreds of thousands more previously healthy and economically active people to a debilitating long term illness for which there are currently no effective treatments. This policy decision also fails to take into account those many clinically vulnerable people who will not be able to safely participate in society.”

21/02/2022	Press release	Joint Statement from Long Covid SOS and Long Covid Kids in response to the Prime Minister's announcement on 21/02/2022 removing all Covid measures	<a href="https://www.longcovidsos.org/post/statement-in-response-to-the-prime-minister-s-announcement-on-21-02-2022-removing-all-covid-measures">https://www.longcovidsos.org/post/statement-in-response-to-the-prime-minister-s-announcement-on-21-02-2022-removing-all-covid-measures</a>	<i>“Long Covid has never formed part of policy making decisions during this pandemic, despite repeated <u>requests</u> on our part both in writing and in person to ministers. People with Long Covid need to protect themselves from reinfection, which can seriously exacerbate symptoms. They and the millions of clinically vulnerable will effectively be forced to shield and become prisoners in their own homes. Since we do not know who will get Long Covid, or how long those living with Long Covid will remain sick, all members of society remain vulnerable.”</i>
21/09/2021	British Medical Journal	The needs of patients with long covid must not be ignored	<a href="https://www.bmj.com/content/378/bmj.o2287">https://www.bmj.com/content/378/bmj.o2287</a>	“The covid-19 pandemic continues to have an impact on the nation’s health. It is encouraging that deaths are now at a comparatively low level, but sadly morbidity as a result of SARS-CoV-2 affects a large number of people, many of whom are effectively disabled and unable to work and live a normal life.”





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### Long Covid SOS Appendix 3 List of Media Long Covid SOS has contributed to January 2020 to Spring 2022

Date	Publication	Title	URL	Quote/comments
08/07/2020	Huffington Post	'Waiting To Be Well': What It's Like To Suffer From 'Long Covid'	<a href="https://www.huffingtonpost.co.uk/entry/long-term-coronavirus-symptoms-what-it-is-like_uk_5f04570cc5b61c37e055af24">https://www.huffingtonpost.co.uk/entry/long-term-coronavirus-symptoms-what-it-is-like_uk_5f04570cc5b61c37e055af24</a>	Ondine Sherwood, a spokesperson for the group, says there is a need for clinics where patients can be assessed, diagnosed and properly cared for. "GPs must be given the right information so they can respond appropriately," she says. "And the government should now focus on the economic implications: sufferers need financial support and employers must be made fully aware of this growing impact on the workforce."
03/08/2020	Financial Times	Fatigue plagues thousands suffering post-coronavirus symptoms	<a href="https://www.ft.com/content/8a8c9630-7cce-417a-8732-f0589009be14">https://www.ft.com/content/8a8c9630-7cce-417a-8732-f0589009be14</a>	Mr Hishmeh (ex volunteer/cofounder) is one among many of these patients. He said he has felt completely unsupported by doctors throughout his illness, with several saying he was suffering from mental health problems and prescribing him anti-anxiety medication. "The government has to wake up and realise we might be dealing with a really big problem here, affecting hundreds of thousands," said Ondine Sherwood
21/7/2020	ITV News	'It completely reframes your life': The people who have had coronavirus but are suffering long lasting effects	<a href="https://www.itv.com/news/2020-07-21/it-completely-reframes-your-life-covid-19-survivors-grapple-with-long-term-effects">https://www.itv.com/news/2020-07-21/it-completely-reframes-your-life-covid-19-survivors-grapple-with-long-term-effects</a>	Video broadcast and LCSOS referenced
12/08/2020	ITV News	The impact of Long Covid	<a href="https://www.youtube.com/watch?v=pTYsmXbUV9s">https://www.youtube.com/watch?v=pTYsmXbUV9s</a>	Features 2 members of LCSOS Research at Uni of Leicester/PHOSP COVID

21/07/2020	CNN	Covid-19 survivors grapple with lingering effects	<a href="https://edition.cnn.com/videos/world/2020/07/21/italy-uk-coronavirus-covid-19-long-term-effects-soares-pkg-intl-hnk-vpx.cnn">https://edition.cnn.com/videos/world/2020/07/21/italy-uk-coronavirus-covid-19-long-term-effects-soares-pkg-intl-hnk-vpx.cnn</a>	Features the LCSOS film although described as a facebook support group
09/08/2020	LBC	Phone in	<a href="https://www.youtube.com/watch?v=xEvaboVLpJQ">https://www.youtube.com/watch?v=xEvaboVLpJQ</a>	LCSOS co-founder (Liz) talking about the 100s of thousands of people still suffering weeks after getting Covid. Campaign set up to bring this to govt's notice. People suffering at home practically ignored. Film, open letter. Asked employers to understand issues faced by employees. This is not an epidemic of mass hysteria
19/08/2020	The Atlantic	Long Haulers are Redefining Covid-19	<a href="https://www.theatlantic.com/health/archive/2020/08/long-haulers-covid-19-recognition-support-groups-symptoms/615382/">https://www.theatlantic.com/health/archive/2020/08/long-haulers-covid-19-recognition-support-groups-symptoms/615382/</a>	A British group—LongCovidSOS—launched a campaign to push the government for recognition, research, and support.
21/08/2020	Buzzfeed	COVID Is Making Younger, Healthy People Debilitatingly Sick For Months. Now They're Fighting For Recognition.	<a href="https://www.buzzfeednews.com/article/briannasacks/covid-long-haulers-who-coronavirus">https://www.buzzfeednews.com/article/briannasacks/covid-long-haulers-who-coronavirus</a>	Covered LCSOS WHO meeting On Friday, led by LongCovidSOS, a patient-led advocacy group in the UK, Davis and about 60 other long-haulers had a closed, invite-only meeting with top officials from the World Health Organization in the biggest recognition yet that the medical world is starting to pay attention and figure out solutions. The long-haulers called in to the WHO meeting from places around the world — the US, the UK, India, Italy, Spain, France, Finland, Senegal, and South Africa — but they all shared largely the same story: I was young and active before this, and now I cannot seem to get better. I haven't been able to get my doctor to believe me because I do not have a positive test result, and I need a lot of care that does not exist where I live.
21/08/2020	WHO	Virtual Press conference	<a href="https://www.who.int/docs/default-source/coronaviruse/transcripts/covid-19-virtual-press-">https://www.who.int/docs/default-source/coronaviruse/transcripts/covid-19-virtual-press-</a>	WHO Director-General Dr Tedros: “Last month my colleague, Dr Maria Van Kerkhove, contacted a group called Long COVID SOS representing patients with long-term effects from COVID-19 infection. This afternoon I had the privilege of speaking with them. They told us about their experience and the ongoing

			<a href="#">conference---21-august.pdf?sfvrsn=ada7ae85_0</a>	challenges they face. These patients want three things; recognition, rehabilitation and research; recognition of their disease, appropriate rehabilitation services and more research to be done into the long-term effects of this illness.
03/09/2020	Reuters	Fear and dread haunt COVID-19 'long-haulers'	<a href="https://www.reuters.com/article/us-health-coronavirus-long-fear-feature/fear-and-dread-haunt-covid-19-long-haulers-idUSKBN25U0ET">https://www.reuters.com/article/us-health-coronavirus-long-fear-feature/fear-and-dread-haunt-covid-19-long-haulers-idUSKBN25U0ET</a>	<p>“That’s been the pattern - relapse and remit - for so many of us,” said Sandra Edwards, a 46-year-old Briton who now helps run a newly-formed patient advocacy group called LongCovidSOS.</p> <p>“We’re in no man’s land. We don’t know if this is chronic or if it will come to a point where we’ll make a full recovery,” she told Reuters. “You wake up in the morning and don’t know how you’re going to feel - not just day by day, but sometimes hour by hour. It slowly chips away at you.”</p> <p>According to LongCovidSOS, data from a symptom tracker app devised by King’s College London scientists shows that 10% of COVID-19 patients are still unwell after three weeks, and up to 5% may continue to be sick for months.</p>
09/09/2020	ABC News	Doctors working to crack the mystery of 'long haul' COVID-19 sufferers	<a href="https://abcnews.go.com/Health/doctors-working-crack-mystery-long-haul-covid-19/story?id=72862670">https://abcnews.go.com/Health/doctors-working-crack-mystery-long-haul-covid-19/story?id=72862670</a>	<p>Referenced LCSOS WHO meeting</p> <p>Last month, LongCovidSOS, a patient advocacy group composed of long-haulers in the UK, had an invitation-only meeting with top officials from the World Health Organization (WHO</p>
11/09/2020	Wired	They never officially had Covid-19. Months later they’re living in hell)	<a href="https://www.wired.co.uk/article/coronavirus-long-haulers-negative-tests-covid-19">https://www.wired.co.uk/article/coronavirus-long-haulers-negative-tests-covid-19</a>	The UK-based group <a href="#">LongCovidSOS</a> orchestrated a campaign to send a letter to the government urging it to commission research into Covid-19 and develop better care for patients. Since then, the group has worked with the NHS, WHO and universities to increase understanding of the condition. The message seems to be getting through. On September 8, health secretary Matt Hancock mentioned long-term Covid-19 as a reason for young people to take the virus more seriously.



				<p>“We’ve seen younger people make the argument that they are less likely to die of this disease, but young people can have debilitating long-term consequences from [it],” he told parliament.</p>
07/09/2020	UK Parliament Post	Short and long term health effects of COVID-19	<a href="https://post.parliament.uk/short-and-long-term-health-effects-of-covid-19/">https://post.parliament.uk/short-and-long-term-health-effects-of-covid-19/</a>	<p>Patient-led initiatives, such as the Patient-Led Research Team or Long COVID SOS, are conducting research and campaigns to support the recognition of the debilitating effects of ‘long COVID’.</p>
02/09/2020	Undark	When Children’s Covid-19 Symptoms Won’t Go Away	<a href="https://undark.org/2020/09/02/kids-covid-19-long-haulers/">https://undark.org/2020/09/02/kids-covid-19-long-haulers/</a>	<p>Quotes from co-founder Fran Simpson.          “We could have a catastrophic level of chronic illness among our children that may impact them forever,”          “He just didn’t want to hear about Covid,” Simpson recalled of her children’s pediatrician. “He said, ‘It’s probably nothing’” and that          ““everyone thinks they’ve got Covid right now.”” But, Simpson said, “I knew for myself and for them, this is just the same thing, and every day we wake up in this same nightmare.”</p>
13/09/2020	The Observer	I was infected with coronavirus in March, six months on I’m still unwell	<a href="https://www.theguardian.com/world/2020/sep/13/i-was-infected-with-coronavirus-in-march-six-months-on-im-still-unwell">https://www.theguardian.com/world/2020/sep/13/i-was-infected-with-coronavirus-in-march-six-months-on-im-still-unwell</a>	<p>Long Covid SOS and other groups say that their members receive little help and there is little recognition of the condition. They want the government to formally recognise the long -term impact of the virus, provide financial support for those unable to work because of long Covid and establish multidisciplinary clinics to help assess and treat patients.</p>
20/09/2020	One News NZ – video and press	Long-term fatigue dubbed the ‘hidden toll’ of Covid-19	<a href="https://www.1news.co.nz/2020/09/20/long-term-fatigue-dubbed-the-hidden-toll-of-covid-19/">https://www.1news.co.nz/2020/09/20/long-term-fatigue-dubbed-the-hidden-toll-of-covid-19/</a>	<p>LCSOS film features in the video          A campaign dubbed the ‘Long Covid SOS’ has been established in Britain, claiming thousands of patients have been experiencing symptoms like exhaustion, brain fog, fever, insomnia, headaches, muscle pain, memory loss, nausea, palpitations, dizziness and an ongoing cough.</p> <p>Organiser and Covid survivor Lere Fisher says he is still exhausted, despite being diagnosed some six months ago.</p>

				<p>“With Covid, and the long haul symptoms that we have, it’s literally hour to hour, which means you can’t plan anything,” he says.</p> <p>“You might be fine in the morning but by 12pm you’re knocked out, so every day is a different day. You could arguably say it’s a bit like a cocktail, you just don’t know what it’s going to be on a daily basis.”</p>
18/09/2020	Sky News	Coronavirus: More than half of COVID-19 patients experience ongoing fatigue, study finds	<p><a href="https://news.sky.com/story/coronavirus-more-than-half-of-covid-19-patients-experience-ongoing-fatigue-study-finds-12074119">https://news.sky.com/story/coronavirus-more-than-half-of-covid-19-patients-experience-ongoing-fatigue-study-finds-12074119</a></p> <p>Video available here but not public: <a href="https://youtu.be/FKHxKuCPoBg">https://youtu.be/FKHxKuCPoBg</a></p>	<p>Campaigner Ondine Sherwood, one of the founders of Long-COVID SOS, said: The discourse has been about this two-week illness, about underlying conditions and older people, and that is not the reality.</p> <p>"What we need is a dedicated service for people with COVID symptoms... a rehabilitation service which includes proper diagnostics.</p> <p>"People need more sophisticated tests that show what's going on with their hearts, their vascular system and their neurological systems. Also includes footage of Tom Stayte who joined us as a volunteer</p>
15/09/2020	Radio NZ	Sick and tired of Covid-19: The 'recovered' patients who aren't getting better	<a href="https://www.rnz.co.nz/news/on-the-inside/426123/sick-and-tired-of-covid-19-the-recovered-patients-who-aren-t-getting-better">https://www.rnz.co.nz/news/on-the-inside/426123/sick-and-tired-of-covid-19-the-recovered-patients-who-aren-t-getting-better</a>	<p>James has shared his story on the Long Covid SOS website, a group advocating for people experiencing prolonged recoveries: "My life has essentially stopped. I wake up every day feeling just as ill as I was in the early weeks. I'm constantly worried my condition will get worse like it has done before - only this time something terrible will happen."</p> <p>"A few months ago, I was the average 19-year-old who never really had to think about his health but now I live in fear wondering what my future holds."</p>
07/10/2020	NHS England	NHS to offer 'long covid' sufferers help at specialist centres	<a href="https://www.england.nhs.uk/2020/10/nhs-to-offer-long-covid-help/">https://www.england.nhs.uk/2020/10/nhs-to-offer-long-covid-help/</a>	In response to the announcement, Ondine Sherwood of LongCovidSOS, said: “LongCovidSOS welcome this announcement from NHS England. We believe that multi-disciplinary clinics are essential for the assessment, treatment and rehabilitation of the huge numbers of people still suffering the effects of COVID-19. We hope that clinical guidance from NICE will ensure that necessary referral pathways are in place and



				that general practitioners are empowered to treat patients with long covid appropriately.”
08/10/2020	The Times	Long Covid patients to be offered care in special NHS clinics	<a href="https://www.thetimes.co.uk/article/long-covid-patients-to-be-offered-care-in-special-nhs-clinics-8dbjzdgbb">https://www.thetimes.co.uk/article/long-covid-patients-to-be-offered-care-in-special-nhs-clinics-8dbjzdgbb</a>	Ondine Sherwood, from the campaigning patient group Long Covid SOS, said: “Long Covid SOS welcome this announcement from NHS England. We believe that multi-disciplinary clinics are essential for the assessment, treatment and rehabilitation of the huge numbers of people still suffering the effects of Covid-19.”
08/10/2020	The Sun	TOUGH WINTER Coronavirus spike is ‘disturbing’ but with new drugs and more knowledge NHS is better placed for 2nd wave, says chief	<a href="https://www.thesun.co.uk/news/12875930/coronavirus-spike-disturbing-nhs-braced-second-wave-winter/">https://www.thesun.co.uk/news/12875930/coronavirus-spike-disturbing-nhs-braced-second-wave-winter/</a>	Sir Simon Stevens: “The clinics will offer support for the tens of thousands, probably hundreds of thousands, of patients who have got long Covid.” The first Long Covid clinic at University College London has treated over 900 people since it opened in mid-May.learning more about Covid with every passing week. “It is now clear that Long Covid can have a major impact on the lives of a significant minority of patients weeks or months after they have contracted the virus. “So just as the NHS quickly put in place specialist hospital care for acutely ill Covid patients at the start of the pandemic, now we must respond sensitively and effectively to these new patient needs. Ondine Sherwood, from patient group Long Covid SOS, described the multidisciplinary clinics as “essential”.
09/10/2020	Politico	Health systems stumble on ‘Long COVID’ as crisis grows	<a href="https://www.politico.eu/article/health-systems-stumble-on-long-covid-as-crisis-grows/">https://www.politico.eu/article/health-systems-stumble-on-long-covid-as-crisis-grows/</a>	"Things are moving in the right direction, but it is very slow," said Sherwood. "The problem is that when they say to us it's early days ... it doesn't feel like it's early for us."But it’s the work of people like Gorna, Sherwood, Macniven and Oustric that has been the major catalyst for recent action. These small groups of organizers have managed to create supportive online communities for tens of thousands of people. Sherwood is now focused on helping this to happen elsewhere beyond the U.K. "We need to try and influence other countries so that they recognize the condition and don't send patients off to psychiatrists or ignore them" — Ondine Sherwood, an organizer with LongCovidSOS
19/10/2020	Evening Standard	Long Covid curse: More	<a href="https://www.standard.co.uk/news/health/long-covid-curse-1-">https://www.standard.co.uk/news/health/long-covid-curse-1-</a>	He used to spend his holidays jumping off rocks. But after a moderate bout of Covid-19, Lyth Hishmeh hit rock bottom.

		than 1,000 struck down in London as under-50s unable to shake off syndrome	<a href="https://www.bbc.com/news/health-5572101">000-london-struck-down-a4572101.html</a>	He went off sick from work as a computer software engineer and lost seven to eight kilograms in weight. Through participation in the Coverscan clinical trial, which scans six key organs, he discovered he had a swollen left kidney and a mildly impaired cardiac pumping function. “For someone my age, that was staggering,” he said. Mr Hishmeh, from Camberley, is part of the long Covid SOS group. He is working with the NHS to get the condition medically classified. “It’s younger, more athletic people who are suffering,” he said. “There are loads in their thirties and forties. None of them had pre-existing conditions.”
21/10/2020	BBC News	Feature on Long Covid for News at 10	<a href="https://youtu.be/vw-GPlcQSmg">https://youtu.be/vw-GPlcQSmg</a>	“We really do need research into why people are getting this condition, what can be done to stop them suffering long term. What are the best therapies, what tests need to be carried out”
23/10/2020	BBC Radio 4 Women’s Hour	Women and Long Covid	<a href="https://www.bbc.co.uk/sounds/play/m000nm5p">https://www.bbc.co.uk/sounds/play/m000nm5p</a>	Highlighted employment issue at around 40 mins in. with people, many young, not being able to return to their jobs – “there’s going to be a big hole in the economy”
30/10/2020	WHO	Covid-19 Press briefing (48,612 views to date)	<a href="https://youtu.be/sXsPHgdt3so">https://youtu.be/sXsPHgdt3so</a>	Co-founder Layth speaks from 11:08 “There is no system in my body that hasn’t been affected... I looked at the statistics and I thought it would be flu-like, mild, two weeks and I’ll be fine but it has not been the case. I want my mental abilities back” Dr Tedros: “It also reinforces to me just how morally unconscionable and unfeasible the so-called ‘natural herd immunity’ strategy is. Not only would it lead to millions more unnecessary deaths it would also lead to a significant number of people facing a long road to full recovery”
05/11/2020	Pharmaceutical Journal	‘I could barely function’ – the devastating	<a href="https://pharmaceutical-journal.com/article/feature/i-could-barely-function-the-devastating-effects-of-long-covid">https://pharmaceutical-journal.com/article/feature/i-could-barely-function-the-devastating-effects-of-long-covid</a>	However, for those already experiencing long COVID, the prospect of waiting months, or even years, for answers is too much. In an “urgent SOS” to government, members of LongCovidSOS said they were unable to access the right care and felt “abandoned”. “It is imperative that the needs of this group are addressed, and sufferers given the support they need,” they wrote.

		effects of long COVID		<p>[Re new clinics:]</p> <p>The announcement has been welcomed by LongCovidSOS. “We believe that multidisciplinary clinics are essential for the assessment, treatment and rehabilitation of the huge numbers of people still suffering the effects of COVID-19,” says LongCovidSOS member Onidine Sherwood.</p> <p>“We feel strongly that the clinics should be truly multidisciplinary, based on a ‘one-stop shop’ format,” she adds. “We want to avoid a situation where people are referred to specialists but then find themselves at the back of long ‘non-urgent’ waiting lists.”</p>
06/11/2020	Personnel Today	Could ‘long Covid’ become the biggest return-to-work challenge yet for OH?	<a href="https://www.personneltoday.com/hr/could-long-covid-become-the-biggest-return-to-work-challenge-yet-for-oh/">https://www.personneltoday.com/hr/could-long-covid-become-the-biggest-return-to-work-challenge-yet-for-oh/</a>	<p>Equally, a “long Covid ‘SOS’” campaign group has been set up to raise awareness of the condition among the general public and with employers. It is also working to put pressure on the government to do more to recognise the needs of those suffering long-term after-effects from the virus.</p> <p>It has called for a working group to be set up to address the needs of all long-term Covid-19 sufferers and for more research to be carried out as a matter of urgency.</p> <p>It has argued that healthcare providers need to be better educated and “empowered” to treat patients with the condition properly and for multidisciplinary clinics to be set up to properly assess, test, diagnose and care for long Covid patients.</p> <p>It has also said there needs to be a focus on the economic implications of long Covid, including the provision of long-term sick leave, financial support and take steps to ensure employers are made fully aware of the condition. Its website can be found at: <a href="https://www.longcovidsos.org/">https://www.longcovidsos.org/</a></p>
01/12/2020	Agence France Presse	The Covid ‘longhauleders’ behind a global patient movement	<a href="https://uk.news.yahoo.com/covid-longhauleders-behind-global-patient-040355384.html">https://uk.news.yahoo.com/covid-longhauleders-behind-global-patient-040355384.html</a>	<p>In London, Ondine Sherwood was suffering fatigue, post-exertional malaise and gastrointestinal problems when she discovered the Body Politic group and was "astonished" to see so many people with similar -- or worse -- symptoms.</p>



				<p>She was among a group of British members who decided to form their own organisation, Long Covid SOS, to send a message to the government.</p> <p>But how?</p> <p>"We thought we might march on parliament, which of course would have been impossible because most of us wouldn't have had the strength or the ability to march, so we thought maybe we would go in wheelchairs, but it was lockdown," said Sherwood, a systems developer. In the end they made a film montage of "long-hauler" stories called "Message in a Bottle" and shared it online, hoping to raise the profile of long Covid.</p> <p>It worked: The film caught the eye of the WHO and the group was tasked with gathering patients for an August meeting that saw Davis present the Body Politic study and included stories of long-haul children and testimony from doctors with persistent symptoms.</p> <p>The WHO has since said more research is needed into why symptoms persist and called on governments to recognise the condition.</p>
01/12/2020	Bristol Cable	'Bone numbingly tired': The exhausting reality of Long-Covid	<a href="https://thebristolcable.org/2020/12/bristol-covid-19-bone-numbingly-tired-exhausting-reality-long-covid/">https://thebristolcable.org/2020/12/bristol-covid-19-bone-numbingly-tired-exhausting-reality-long-covid/</a>	<p>Long Covid SOS, a volunteer campaign group set up to lobby the government into providing more support and recognition for Long-Covid sufferers, has been putting pressure on the government to commission research into the condition, raise awareness among practitioners and employers so sufferers are not discriminated against, and recognise the economic impact on sufferers.</p> <p>Fran Simpson, a Long-Covid sufferer since she contracted the virus in March, is a founding member of the group. She couldn't find any reference to Long-Covid at first. "It felt like we didn't exist – medical gaslighting, being told it was just anxiety. No treatment or diagnosis." She says that having the condition recognised is "validating".</p> <p>The campaign group hopes that the pressure they're putting on the government will lead to more research into what it is, how it works and how we can treat it, with sufferers having an opportunity to be seen at a clinic and get the financial support needed when unable to work.</p>

18/12/2020	Sky News	COVID-19: New clinics to offer help for people with long-term symptoms in England	<a href="https://www.youtube.com/watch?v=xSys92cnh4A">https://www.youtube.com/watch?v=xSys92cnh4A</a>	Video featuring Helen: “It very hard to live happily in the moment with no hope. Because at the moment I don’t have any hope” OS: “We hope that this will now spell the end of people being dismissed by their doctors, being told they are suffering anxiety, and being unable to get the treatment they need” LCSOS film featured
19/02/2021	British Safety Council	Long covid: can work lift the burden?	<a href="https://www.britsafe.org/publications/safety-management-magazine/safety-management-magazine/2020/long-covid-can-work-lift-the-burden/">https://www.britsafe.org/publications/safety-management-magazine/safety-management-magazine/2020/long-covid-can-work-lift-the-burden/</a>	A shocking lack of attention has been paid to this significant group of people of all ages, and many sufferers feel badly let down,” says the Long Covid SOS support group, which has nearly 25,000 members.  It says that “countless sufferers are forced to return to work, risking serious consequences for their recovery.” In the open letter to the prime minister, the group calls for government to take steps to ensure employers are fully aware of the situation, including making provision for long-term sick leave.
20/02/2021	The Observer	Long Covid: ‘It’s a year since I’ve felt like myself’	<a href="https://www.theguardian.com/society/2021/feb/20/long-covid-still-suffering-effects-virus-months-nhs-clinics">https://www.theguardian.com/society/2021/feb/20/long-covid-still-suffering-effects-virus-months-nhs-clinics</a>	Support groups such as LongCovidSOS have been fighting hard for the condition to be recognised and taken seriously – sufferers say they feel disbelieved, and doctors initially had little information, support or even funding.
22/02/2021	The Star (Sheffield)	Sheffield marathon runner battling long Covid issues warning over lockdown easing	<a href="https://www.thestar.co.uk/health/coronavirus/sheffield-marathon-runner-battling-long-covid-issues-warning-over-lockdown-easing-3142117">https://www.thestar.co.uk/health/coronavirus/sheffield-marathon-runner-battling-long-covid-issues-warning-over-lockdown-easing-3142117</a>	Feature on LCSOS Tom Stayte warning we must be cautious about easing restrictions “If we open up again very quickly and people don’t know about long Covid, my worry is that lots more people will get the virus and while there may be fewer deaths a lot of them will suffer terribly for a long time to come,” "It doesn’t exist in the public consciousness in the way it should, and I think it’s really important that people understand what the risks are to them.”
27/02/2021	The Spectator	The mysteries of ‘Long Covid’	<a href="https://www.spectator.co.uk/article/the-mysteries-of-long-Covid/">https://www.spectator.co.uk/article/the-mysteries-of-long-Covid/</a>	There are financial burdens to consider, too. A letter published last month in the BMJ, from patient campaign group Long Covid SOS,



				warns of a ‘concerning number’ of previously healthy people who are now on sick pay and benefits.
02/03/2021	The Independent	Scientists and campaigners call for more research into long Covid in children	<a href="https://www.independent.co.uk/news/health/long-covid-children-cases-latest-uk-b1810658.html">https://www.independent.co.uk/news/health/long-covid-children-cases-latest-uk-b1810658.html</a>	Long Covid SOS, an adult campaign group, said it was time to challenge the “general narrative around children: that they don’t get infected as frequently as adults, don’t suffer so badly, and don’t spread it. The very real issue of long Covid in children must be taken seriously”.
24/04/2021	Sunday Times	The race to cure long Covid, the world’s next health crisis	<a href="https://www.thetimes.co.uk/article/the-race-to-cure-long-covid-the-worlds-next-health-crisis-36d7vgr8x">https://www.thetimes.co.uk/article/the-race-to-cure-long-covid-the-worlds-next-health-crisis-36d7vgr8x</a>	Describes how LSCOC was originally set up. WHO Janet Diaz, in charge of global response to Long Covid: Ironically it was an email that landed in her inbox from LongCovid SOS — “A tremendous patient advocacy group,” she says — that helped convince Diaz that “more action” was needed. She and Ghebreyesus met patients with long Covid, and their “powerful” stories have since influenced WHO policy.
11/04/2021	CNN	For many sufferers of long Covid, proving they are sick is a big part of the battle	<a href="https://edition.cnn.com/2021/04/11/health/coronavirus-long-covid-intl/index.html">https://edition.cnn.com/2021/04/11/health/coronavirus-long-covid-intl/index.html</a>	Features co-founder Layth Hishmeh
19/05/2021	Covid Calls podcast	Long Haul Covid	<a href="https://youtu.be/zxT6joC5s7c">https://youtu.be/zxT6joC5s7c</a>	Interview with OS and Vicky van der Togt. Discussion about how Long Covid is not being mentioned in public messaging and still being ignored from around 54:00
02/06/2021	ITV	Campaigners call for more consistent Long Covid treatment (+video)	<a href="https://www.itv.com/news/calendar/2021-06-02/campaigners-call-for-more-consistent-long-covid-treatment">https://www.itv.com/news/calendar/2021-06-02/campaigners-call-for-more-consistent-long-covid-treatment</a>	Ondine Sherwood, from Long Covid SOS, said: "We feel that the government has paid lip service to long covid but it is rarely mentioned in public messaging. "It is not emphasised enough to educate the public, to avoid infection." (1.35)

02/04/2021	Lived Health	How are patient advocacy groups helping Long covid recognition and research?	<a href="https://youtu.be/wxyDzalDQ_s">https://youtu.be/wxyDzalDQ_s</a>	Highlighted the fact that there are a million people needing treatment. Suggest people write to their MP – to lobby the govt to do more about Long covid, needs to be part of policy. Not in roadmap out of lockdown “There is no evidence that any policy is being informed by the fact that there is this enormous morbidity in survivors of covid-19. Young healthy people can get this illness and they can be ill for months and months, it’s not shown in the figures, it’s not part of policy”
18/05/2021	The Guardian	Long Covid symptoms ease after vaccination, survey finds	<a href="https://www.theguardian.com/society/2021/may/18/long-covid-symptoms-ease-after-vaccination-survey-finds">https://www.theguardian.com/society/2021/may/18/long-covid-symptoms-ease-after-vaccination-survey-finds</a>	Story about the results of the LCSOS vaccination survey
02/07/2021	Talk Radio	Interview with Julia Hartley Brewer	<a href="https://youtu.be/S5u6CO8uQvg">https://youtu.be/S5u6CO8uQvg</a>	Long Covid SOS co-founder Ondine Sherwood says "We should be concerned" as almost 400,000 suffer long Covid symptoms for over a year. "It's affecting young people. It is a big problem. This is going to be a massive impact on the NHS and the economy."
06/07/2021	The Independent	Long Covid campaigners urge Sajid Javid to ‘reconsider’ timing of restriction lifting	<a href="https://www.independent.co.uk/news/health/long-covid-sajid-javid-lockdown-b1878939.html">https://www.independent.co.uk/news/health/long-covid-sajid-javid-lockdown-b1878939.html</a>	LongCovidSOS, an advocacy group that campaigns on behalf of survivors of Covid-19 who suffer from long-term after-effects, said the decision to allow the virus to rip through communities would condemn “thousands of predominantly young, active people ... to prolonged ill-health and disability every day”. The group added: “As well as putting considerable pressure on the NHS, [victims’] reduced capacity to work will further contribute to the impact long Covid is already having on society and the economy through reduced output and tax revenues, and increased sick pay and benefits claims. “Long Covid has not only been ignored in policy-making decisions, and barely mentioned in the roadmap out of lockdown – it has been almost completely absent from the government’s public messaging. “We have been an afterthought in the government’s response.” LCSOS letter to Boris Johnson urging him to include LC in the public inquiry also mentioned

07/07/2021	Newsnight	Feature on Long Covid in the context of 'Freedom day'	<a href="https://youtu.be/PQWWFuivYPo">https://youtu.be/PQWWFuivYPo</a>	Emily Maitliss queries whether the risk of Long Covid should be factored into the Govt's plans for easing restrictions Includes Chris Whitty stating: "I regret to say that I think we will get a significant amount more Long Covid particularly in the younger ages where the vaccination rates are much lower" OS: "People can't back to where they were before" Pointed out that we don't know whether vaccination will actually reduce the rate of Long Covid as it still causes mild disease
08/07/2021	Express	Long Covid sufferer says 'lives are radically changed' by persistent symptoms	<a href="https://www.express.co.uk/news/uk/1459887/long-covid-long-term-symptoms-Condona-Sherwood-Long-Covid-SOS-David-Strain-ont">https://www.express.co.uk/news/uk/1459887/long-covid-long-term-symptoms-Condona-Sherwood-Long-Covid-SOS-David-Strain-ont</a>	Story following Newsnight appearance Ondine Sherwood, co-founder of Long Covid SOS, spoke out during the BBC 2 Newsnight programme. "People's lives have been radically changed and they just cannot get back to where they were before," she said. She spoke as scientists and medical experts warned the Government about possible severe repercussions from the July 19 easing. David Strain, a senior clinical lecturer and Covid researcher at Exeter University, shared his concerns about long Covid to the Financial Times. "Many of us have been urging the new health secretary Sajid Javid to consider long Covid when evaluating the easing of lockdown," he said. "But he does not seem to have taken it into account at all, even though long Covid is probably going to have more impact on the economy than any other aspect of the pandemic."
21/07/2021	Dr John Campbell – YouTube	Important Long Covid information	<a href="https://youtu.be/rRTKIIS7egI">https://youtu.be/rRTKIIS7egI</a>	464,109 views OS interviewed along with Vicky van der Togt "After a year we're still working on recognition"
06/08/2021	Talk TV	Interview with Julia Hartley Brewer	<a href="https://youtu.be/gyhdQr4WBb8">https://youtu.be/gyhdQr4WBb8</a>	"Almost 1% of the UK population has Long Covid that impact their daily activities...Long covid is not trivial. For many people it is significantly disrupting their lives"
17/09/2021	Talk TV	Interview with Julia	<a href="https://youtu.be/uPMxCmJaKKE">https://youtu.be/uPMxCmJaKKE</a>	Discussion about latest ONS figures

		Hartley Brewer		
21/09/2021	Health and Social Care Committee into clearing the backlog	Oral evidence to Select Committee	LCSOS 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. <i>Evidence: Despite the fact that we knew from the first SARS epidemic that there were many people who did not recover in months or years, the whole system seemed to be completely unprepared for that possibility. Therefore, when people were not getting better, there was absolutely nothing. There were no resources for them. There was no information. I think that each individual felt alone</i>	See oral evidence transcripts <a href="#">here</a> and <a href="#">written evidence</a> submitted. <a href="#">report</a> published in December 2021.
21/09/2021	Evening Standard	'My life is unrecognisable' – long Covid patients describe struggle to get care	<a href="https://www.standard.co.uk/news/uk/people-mps-gps-nhs-england-b956503.html">https://www.standard.co.uk/news/uk/people-mps-gps-nhs-england-b956503.html</a>	Published after LCSOS provided evidence to the HSC Inquiry into the backlog Ondine Sherwood, co-founder of support group LongCovidSOS, said that people not being believed is “typical” of a lot of patient stories. She told MPs: “I think that each individual felt alone, and certainly that was my experience. “A lot of people said they’d go to A&E and they would be met with shrugs because people didn’t know what to do for them.”



				<p>On current long Covid care, she added: “Unfortunately we do still hear about people, really, really struggling to get referred and some doctors still don’t seem to be fully informed about the condition.</p> <p>“A huge number of people who were ill in March 2020 in the first wave, many of them still haven’t been able to be assessed.”</p> <p>Ms Sherwood added: “Not every long Covid patient needs to be seen in an assessment centre, but a lot of people are waiting for way too long.”</p>
04/11/2021	South China Morning Post	The growing problem of Covid-19’s ‘long-haulers’ a global challenge	<a href="https://www.scmp.com/news/china/science/article/3154738/growing-problem-covid-19s-long-haulers-global-challenge">https://www.scmp.com/news/china/science/article/3154738/growing-problem-covid-19s-long-haulers-global-challenge</a>	<p>Campaigners like Sherwood from LongCovidSOS warn there will be disparities between affluent and low-income areas in their support for the Covid-19 long haulers. “We call it the postcode lottery because it depends on where you live. You might get better care if you live near a good hospital or a teaching hospital. The social aspects of health have always been the case,” she said.</p>
06/01/2022	Mail+	‘Like being hit by a bus’: Long Covid sufferers say ministers abandoned them	<a href="https://www.mailplus.co.uk/edition/news/coronavirus/141921/long-covid-sufferers-accuse-ministers-of-abandoning-them">https://www.mailplus.co.uk/edition/news/coronavirus/141921/long-covid-sufferers-accuse-ministers-of-abandoning-them</a>	<p>Ondine Sherwood, co-founder of LongCovidSoS, a campaign group for sufferers, accused the Government of ‘merely paying lip service to the issue’.</p> <p>Ms Sherwood, who has held meetings with ministers and advised the Health and Social Care Select Committee, said: ‘We have meetings with ministers who listen to sufferers and call them heart-rending.</p> <p>‘They even tweet about how heartbreaking these stories are, but they still don’t take it up to the top of policymaking and they don’t want to talk about it publicly.’</p> <p>She said the lack of publicity given to long Covid had led the public to be unaware of the true dangers posed by the virus.</p> <p>Ms Sherwood added: ‘Chronic illness is often ignored and long Covid sufferers have even told me that they are often not believed or even not treated, because there’s not enough research on this issue.</p> <p>‘At the end of the day, it’s got to the point where it’s just easier for the Government not to concern themselves with the 1.3 million people in chronic pain.’</p>



14/02/2022	The Big Issue	Changemakers 2022: Health and sport	<a href="https://www.bigissue.com/life/health/changemakers-2022-health-and-sport/">https://www.bigissue.com/life/health/changemakers-2022-health-and-sport/</a>	<p>Listed as a ‘Changemaker’ – campaigning to help create positive change.</p> <p>This group of long-term sufferers of Covid are campaigning the government for a working group to be set up and for health policy to properly support people affected. In 2021, the campaign wrote to Health Secretary Sajid Javid saying: “Long Covid has not only been ignored in policymaking decisions, it has been almost completely absent from the government’s messaging.”</p> <p>In September the group submitted evidence to the Health and Social Care Select Committee’s inquiry. Watch this group continue to be part of the conversation in 2022.</p>
10/02/2022	Mail	Scientists accuse PM of lifting Covid restrictions early as ‘distraction	<a href="https://www.mailplus.co.uk/edition/news/coronavirus/153288/scientists-accuse-pm-of-lifting-covid-restrictions-early-as-distraction">https://www.mailplus.co.uk/edition/news/coronavirus/153288/scientists-accuse-pm-of-lifting-covid-restrictions-early-as-distraction</a>	<p>The campaign and advocacy group LongCovidSOS also criticised the move, writing that the decision was ‘condemning’ large swathes of the population to ‘a debilitating long term illness’, as well as ignoring the clinically vulnerable.</p> <p>‘If Covid is to be allowed to spread through the community in a completely uncontrolled way, with no precautionary measures in place, then we risk condemning hundreds of thousands more previously healthy and economically active people to a debilitating long term illness for which there are currently no effective treatments,’ they wrote. ‘This policy decision also fails to take into account those many clinically vulnerable people who will not be able to safely participate in society.’</p>
13/02/2022	iNews	Long Covid will hit hundreds of thousands more people if all restrictions axed,	<a href="https://inews.co.uk/news/covid-restrictions-lifted-long-covid-hundreds-of-thousands-more-people-1456164">https://inews.co.uk/news/covid-restrictions-lifted-long-covid-hundreds-of-thousands-more-people-1456164</a>	<p>LongCovidSoS said the Prime Minister’s intention to end all coronavirus laws in two weeks’ time would allow the virus to spread “uncontrolled” and lead to hundreds of thousands more people, who were previously healthy and economically active, being unable to work for long periods.</p> <p>Ondine Sherwood, co-founder of LongCovidSOS, said: “We have twice written to the government to urge it to take long Covid into account when making policy decisions around protecting the population from Covid-19.</p>

		campaigners say		<p>“Evidence is now starting to emerge showing how long Covid is impacting the workforce – this is inevitable when 1.3 million people in the UK are living with this condition, and many cannot return to their jobs.</p> <p>“If Covid is to be allowed to spread through the community in a completely uncontrolled way, with no precautionary measures in place, then we risk condemning hundreds of thousands more previously healthy and economically active people to a debilitating long-term illness for which there are currently no effective treatments.”</p>
14/02/2022	iNews	NHS long Covid mobile testing units could be rolled out in areas worst hit by pandemic.	<a href="https://inews.co.uk/news/long-covid-mobile-testing-units-rollout-across-england-nhs-1456231">https://inews.co.uk/news/long-covid-mobile-testing-units-rollout-across-england-nhs-1456231</a>	<p>The campaign group LongCovidSOS welcomed the move, but claimed it would have a limited impact on the true health costs of the virus. A spokeswoman for LongCovidSOS said: “We support this initiative because clearly spirometry testing can pick up a range of lung conditions, and we understand that these vans will reach underserved communities, which is excellent news.</p> <p>“However, long Covid is not a typical respiratory condition. Often, people who do suffer from breathlessness report that all their lung tests are normal. It is only very recently that research is starting to find answers as to why some with long Covid may have shortness of breath, and quite sophisticated diagnostics are needed to identify pathology. In addition, many with long Covid won’t present with breathlessness at all but with any of a huge range of other symptoms.”</p> <p>She added that the mobile testing will identify “only a small percentage of people with long Covid via the spirometry test”.</p> <p>“We hope however that those working in these mobile clinics will be trained to recognise other symptoms of this condition and so will be able to help refer people to appropriate care,” she said.</p>
05/03/2022	The Observer	Covid pandemic sparks steep rise in number of people in UK	<a href="https://www.theguardian.com/society/2022/mar/05/covid-pandemic-sparks-steep-rise-in-number-of-people-in-uk-with-long-term-illness">https://www.theguardian.com/society/2022/mar/05/covid-pandemic-sparks-steep-rise-in-number-of-people-in-uk-with-long-term-illness</a>	<p>Ondine Sherwood, co-founder of Long Covid SoS, said: “We don’t yet have data on how many infected during the huge Omicron wave will go on to experience prolonged symptoms, so [numbers] will almost certainly grow. Many, if not most of those with long Covid, are of working age and were previously fit and healthy – there is surely going to be a major effect on the workforce.”</p>

		with long-term illness		She pointed to a study published in Nature last month, which shows that even a mild infection can increase the risk of heart disease for a year after diagnosis. “Given the huge numbers affected, both in the UK and worldwide, there is a real danger that the ‘average’ level of health people enjoy could already be lower and will deteriorate further.”
18/05/2022	Huck Magazine	The fight for Long Covid to be recognised as a disability	<a href="https://www.huckmag.com/perspectives/the-fight-for-long-covid-to-be-recognised-as-a-disability/">https://www.huckmag.com/perspectives/the-fight-for-long-covid-to-be-recognised-as-a-disability/</a>	<p>“There are many who are severely disabled by [long Covid] and who’ll need the most support,” Ondine Sherwood, a founding member of the group, says. “People have lost their jobs, their livelihoods and in some cases, their accommodation.”</p> <p>Ondine raises the Personal Independence Payment (PIP) benefit as a scheme that can help. Under PIP, those with a long-term illness, mental health condition or disability can claim financial support to mitigate living costs. According to the Department for Work and Pensions, there are 2.9 million claimants across the UK. Yet, only 850 have long Covid listed as their main disabling condition. “If long Covid was [more] recognised as a disability, that will help with the [claiming of] benefits,” she says.</p> <p>“Once you start working with institutions like the NHS, you begin to realise and understand why it’s not so easy to just wave a magic wand and make everything work,” she says. But considering that people’s lives – physically, mentally, financially and more – are at stake, the urgency stands. “There’s a lot more money that needs to be spent on this because at the moment, there simply isn’t the funding available to help people.”</p>
01/06/2022	Express	Two MILLION people in UK living with Long Covid – Half for at least a year	<a href="https://www.express.co.uk/life-style/health/1619532/coronavirus-long-covid-uk-symptoms-fatigue-muscle-ache-office-for-national-statistics">https://www.express.co.uk/life-style/health/1619532/coronavirus-long-covid-uk-symptoms-fatigue-muscle-ache-office-for-national-statistics</a>	Ondine Sherwood, of the Long Covid SOS campaign, said: “There are now no measures in place to prevent infection. Anyone who gets Covid is vulnerable to developing long Covid, irrespective of their age or health.”



20/06/2022	Independent	Desperate couple with long Covid planned suicide as 'neglected' sufferers struggle	<a href="https://www.independent.co.uk/news/health/long-covid-depression-suicide-treatment-b2104764.html">https://www.independent.co.uk/news/health/long-covid-depression-suicide-treatment-b2104764.html</a>	Ondine Sherwood, a spokesperson for the charity Long Covid SOS, said the subset of patients who "cause the most concern" are the 398,000 individuals who are effectively disabled and unable to undertake everyday activities. "There's not enough investment, and there's too much variability in the centres," Ms Sherwood said. "It's been said over and over again, but unless we get the money to better research and treat long Covid, this health crisis is going to grow and grow – to the detriment of people's mental health."
30/06/2022	Express	Covid experts issue warning over new wave of infections 'Not gone away!'	<a href="https://www.express.co.uk/life-style/health/1633607/Covid-latest-new-wave-coronavirus-variants">https://www.express.co.uk/life-style/health/1633607/Covid-latest-new-wave-coronavirus-variants</a>	Ondine Sherwood, of the Long Covid SOS campaign, said the Government seemed to be focused on urging the public to get back to normal rather than encouraging simple precautions. She said: "I think most people in this country are very happy to put it behind them and think the pandemic is over. "I can understand why - I've had long Covid and even I get lulled into a false sense of security. Everyone's had enough of the pandemic. "However, I don't see what's wrong with taking some precautions. Mask wearing is still mandated in some countries in Europe, why not protect yourself?"
21/07/2022	Independent	Bereaved families demand 'core' role in UK Covid inquiry as 'investigative' phase begins	<a href="https://www.independent.co.uk/news/health/uk-covid-inquiry-bereaved-families-latest-b2126575.html">https://www.independent.co.uk/news/health/uk-covid-inquiry-bereaved-families-latest-b2126575.html</a>	Ondine Sherwood, a spokesperson for Long Covid SOS, said the group's engagement with the inquiry so far had been "positive" but added that "it's our concern we won't play a big part". She added: "We want to make sure long Covid has the emphasis it deserves. The government will be represented by lawyers and will have money to throw at their defence. "We're a small group, we don't have the money or resources, and we're worried we'll be outgunned by their legal team. We need to have the right to challenge the government."
06/10/2022	The Guardian	More than 1m people report Long Covid a year	<a href="https://www.theguardian.com/society/2022/oct/06/more-than-1m-people-report-long-covid-in-uk-a-year-after-infection">https://www.theguardian.com/society/2022/oct/06/more-than-1m-people-report-long-covid-in-uk-a-year-after-infection</a>	Ondine Sherwood, a co-founder of the advocacy group and charity Long Covid SOS, says the number of people now reporting long Covid – 342,000 of whose lives are "severely impacted" as result – illustrates that this is "not just a personal tragedy but a societal, health and workforce problem".



		after infection		
18/10/2022	iNews	'Anyone can get sick': Will long Covid finally solve the mystery of chronic illnesses like ME?	<a href="https://inews.co.uk/inews-lifestyle/mc-chronic-fatigue-long-covid-research-treatments-1911812">https://inews.co.uk/inews-lifestyle/mc-chronic-fatigue-long-covid-research-treatments-1911812</a>	"There's a lot of gaslighting, which is born from the inability of doctors to provide answers, and a tendency to fall back on blaming the patient" + more
27/10/2022	The Guardian	Long Covid: 'fraction' of sufferers getting NHS help in England	<a href="https://www.theguardian.com/society/2022/oct/27/long-covid-fraction-of-sufferers-getting-nhs-help-in-england">https://www.theguardian.com/society/2022/oct/27/long-covid-fraction-of-sufferers-getting-nhs-help-in-england</a>	Ondine Sherwood, a co-founder of the advocacy charity Long Covid SOS, said many people with long Covid "are struggling to get any healthcare. Many are not getting any treatment at all." She said public misconceptions around long Covid made it harder for sufferers to ask for and get help. "There was a lack of preparedness for the potential long-term morbidity which was not conveyed to healthcare professionals and this has contributed to the lack of care for long Covid." Sherwood said long Covid sufferers' voices needed to be heard as part of the forthcoming coronavirus inquiry. "It's a pattern we've seen all the way through the pandemic that people with long Covid were the poor relation, were never counted officially, were never mentioned in the government briefings. When they sought help many were told they were imagining it."
10/11/2022	House of Lords Library	Long Covid: What are the short- and long-term challenges?	<a href="https://lordslibrary.parliament.uk/long-covid-what-are-the-short-and-long-term-challenges/">https://lordslibrary.parliament.uk/long-covid-what-are-the-short-and-long-term-challenges/</a>	Quotes from Guardian piece: Criticising the total number of people with long Covid that had been seen by an NHS specialist service, Ondine Sherwood, the co-founder of the charity Long Covid SOS, said that "there was a lack of preparedness for the potential long-term morbidity which was not conveyed to healthcare professionals". She argued that this had "contributed to the lack of care for long Covid".