

Questionnaire

UK COVID-19 Inquiry: Module 2 - Rule 9 Request to Long Covid Support

Reference: M2/R9R/LONG COVID SUPPORT/TJS

We 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 and 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.

We would of course be willing to provide a statement to the Inquiry on the issues raised in the Inquiry's Rule 9 questionnaire in more detail.

Please provide the following information¹:

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.

The chronology of the organisational history of Long Covid Support is as follows:

- i) 2nd May 2020 - the COVID-19 Support Group was set up on Facebook (June 2020 - the Facebook Group was renamed the Long Covid Support Group)
- ii) 19th June 2020 - the COVID-19 Research Involvement Group was set up on Facebook
- iii) 28th June 2020 - the [LongCovid.org](https://www.longcovid.org) website was launched
- iv) 26th May 2021 - Long Covid Support incorporated as a CLG.
- v) 12th May 2022 - Long Covid Support registered as a charity with the Charity Commission England and Wales.

The Long Covid Support Facebook group was established to provide a space for patients who went online seeking support and information about their ongoing health issues during the early days of the pandemic. At the time there was a void in policy and medical information about the chronic illness resulting from SARS-CoV-2 infection. Individuals began to work together to form a coalition of volunteers under the umbrella of Long Covid Support. Members of this coalition connected with other individual advocates and patient groups that came together internationally. Some individuals from the Long Covid Support Facebook Group went on to form separate groups that focused on specific issues such as [Long Covid Kids](#) and [Long Covid Physio](#). Others formed groups that advocated on the specific government and health policy of

¹ Please note where documents are publicly available links are provided. Other documents are specified and can be provided.

the devolved nations - Long Covid Wales and [Long Covid Scotland](#), International members of the group went on to set up organisations in their own countries.

Long Covid Support went on to register as a [charity](#) in England and Wales. The organisation hosts an active programme of online social and wellbeing activities including our Long Covid Choir, weekly zoom chats, chair yoga, opera breathing, and other areas of potential help or interest to our members. Together with others, Long Covid Support was instrumental in establishing the term [Long Covid](#) and bringing the condition to the attention of the medical profession, policy-makers and the wider public.

Long Covid Support facilitates a [peer support group via Facebook](#) offering international support. Strictly for people with Long Covid or their direct carers, this online group is one of the largest of its type in the world, with members in over 100 countries and territories. It presently has over 56,000 members, 41% of whom are from the UK. The group has grown continuously since its creation and continues to grow, membership having increased by 25% over the past year.

Long Covid Support advocates for UK policy changes regarding NPIs, NHSE healthcare provision, employment, welfare and research funding. Long Covid Support has a dedicated team focused on employment and benefits, comprising people with professional as well as lived experience. Some members of the group also run [Long Covid Work](#), a multidisciplinary consultancy of associate vocational rehabilitation professionals. Our work focuses on supporting workers and employers with return to work, and we have co-developed materials with bodies including the UK's Society of Occupational Medicine (SOM) and Chartered Institute of Personnel and Development (CIPD). The group have also worked extensively with Unions and have collaborated with the TUC to run surveys into the impact of the condition on employment status and quality of life.

Long Covid Support has been instrumental in facilitating patient involvement in research in the UK. The charity runs the [COVID-19 Research Involvement Group](#), a thriving forum in which researchers, investigators and academics interact with each other and patients. We work extensively with researchers, including as co-investigators, members of advisory groups and co-authors of numerous papers published in respected journals. We have provided training in Patient and Public Involvement in Research to members of the Long Covid community in the UK. We worked closely with the NIHR to recruit people with Long Covid to be trained as lay reviewers for the Community Long Covid commissioned calls for research in Autumn 2020 and Spring 2021.

Long Covid Support is a member of [Long Covid Europe](#), which has partnered with the World Health Organization Europe and seeks to influence EU wide policy on Long Covid to ensure that there is an agreed definition for Long Covid and shared learning with regards to research, innovation and healthcare policy around the condition.

Internationally, Long Covid Support has worked with the World Health Organization, the International Severe Acute Respiratory and Emerging Infection Consortium (ISARIC) and The Global Research Collaboration for Infectious Disease Preparedness (GloPID-R). Together, we organised the [Long Covid Forum](#) in December 2020, the first international research conference on the condition, which was opened by the WHO Director General. In February 2021, the WHO held the first of three [webinars](#) on Post Covid Condition at which Long Covid Support presented.

Our aim as a charity is to improve the futures of people with Long Covid by ensuring equitable access to high quality healthcare, employment rights and welfare services.

The objects of the charity as set out in its governing document are:

4.1.1 to promote and protect the good health of the public and to relieve the needs of people with Long Covid and their families and carers in particular but not exclusively by:

- *Providing support, advocacy, information and guidance to those affected by Long Covid as well as information to the wider public about Long Covid*
- *Supporting research into Long Covid, its diagnosis, treatment, and rehabilitation from it and the dissemination of useful results of such research for the public benefit;*

4.1.2 for the public benefit, to advance the education of medical and other professions and sectors, sufferers and their families and carers, and the public in all aspects of Long Covid.

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

Long Covid Support undertakes targeted awareness raising in order to achieve the following:

- Prevent more people being affected by Long Covid by not catching SARS-CoV-2.
- Reduce the likelihood of those who have caught SARS-CoV-2 going on to develop Long Covid.
- Support for those already living with Long Covid, whilst they await further research developments into treatments.

In that sense we are supporting individuals and their carers who are already living with the condition and representing those already affected and those who stand to be affected in the future.

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

Long Covid Support is a registered charity in England and Wales (1198938)
Registered Company Number (England and Wales) 13422248
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response to COVID-19 of (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive.

We have set out at Appendix 1 a chronology of the work of Long Covid Support 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, Long Covid Support advocated on behalf of people living with Long Covid in the UK by:

1. Writing to the Prime Minister and relevant Government Ministers
2. Meeting with Government Ministers
3. Participating in relevant Task Forces and expert panels relevant to Long Covid
4. Submitting evidence to APPG and Select Committee Inquiries
5. Collaborating with other relevant partners
6. Contributing to UK and international research
7. Conducting surveys into patient experience, peer reviewing and publishing original research
8. Undertaking wider advocacy

On May 18th 2020, two founding members of Long Covid Support started a placard campaign on Twitter listing symptoms and the number of days of being ill, a concept that was later used in films made by patients in France (June 8th), Spain (June 15th), and the UK (July 8th).

Since May 2020, Long Covid Support has been instrumental in providing lived-experience expertise to the Long Covid response. The organisation has consistently advocated for better policy and practise with all relevant stakeholders:

1. Writing to the Prime Minister and relevant Government Ministers

Long Covid Support has advocated at the highest level of government including from the very early days of the pandemic as we were a cohort that was not recovering from Covid-19.

16th-17th June 2020

Two UK parliamentarians, Natalie Bennett and Steve McCabe, tabled [written questions](#) about Long Covid in the UK House of Commons, the latter in response to a letter written to Steve McCabe by Claire Hastie, a [founding member](#) of Long Covid Support, who was his constituent.

28th August 2020

Long Covid Support and partners sent [a letter to Jeremy Hunt](#), chair of the Health & Social Care Committee, to ask for the UK Government to assemble a multi-disciplinary Long Covid taskforce to address the urgent needs of people living with persistent on-going symptoms of COVID-19. We asked the Department of Health and Social Care to:

1. Develop and disseminate information on treatment, management of symptoms and rehabilitation
2. Fund more and better research
3. Provide quality psychosocial and mental health services
4. Implement better public health programmes
5. Help NHS and social care workers to return to work safely (many had been infected on the frontline of the pandemic response)
6. Provide funding for patient-led support groups.

9th January 2021

Long Covid Support founding member Claire Hastie sent a letter by email to all MPs² urging them to participate in the Commons debate on Long Covid, scheduled for 14th January, as well as the APPG on Coronavirus oral hearing about Long Covid among health professionals on 12th January. The letter raised the following key points:

1. Long Covid affects vast numbers of people and has a significant impact on people's lives and ability to work.
2. More needs to be done to prevent more people getting Long Covid including preventative public health measures to raise awareness and early treatment interventions for those infected by SARS-CoV-2.
3. More needs to be done to support people affected by Long Covid including better and more consistent access to Long Covid services, greater investment in research and support with returning to work.
4. For support groups to be funded to continue the valuable work that they do.

8th July 2021

Long Covid Support [wrote to Sajid Javid](#) urging that, when evaluating policy, he takes account of the devastating and prolonged impact that Long Covid can have on people of all ages. We urged him to:

1. Support those living with Long Covid by providing inclusive and equitable access to appropriate care
2. Provide appropriate support for NHS staff returning to work
3. Prevent further people being affected by Long Covid by implementing measures to reduce the risk of SARS-CoV-2 infection

2. Meeting with Government Ministers - DHSC Ministerial round tables

² Email letter dated 9 January 2021 from Claire Hastie, Long Covid Support

Members of Long Covid Support attended the Long Covid roundtables, initially chaired by Lord Bethell. The first of these was held on October 13th, 2020, at which Claire Hastie, a founding member of Long Covid Support, was invited to speak. In June 2021, Long Covid Support presented the [findings](#) of their [survey into patient experiences](#) of Long Covid assessment services and their concerns regarding the [NHSE 5-point plan](#). In December 2021, at the first roundtable chaired by Maria Caulfield MP, Long Covid Support questioned Graham Burns (Long Covid Speciality Advisor) on his repeated assertion attributing the condition to ‘anxiety at the thought of never recovering as well as associated insomnia’. He first stated these views at the Westminster Health Forum in Spring 2021.

3. Participating in NHSE Task Force and expert panels relating to Long Covid

Long Covid Support has worked with NHSEI including in stakeholder meetings and being Patient and Public Voice members. Long Covid Support had called for the establishment of a Task Force and Long Covid Minister. Long Covid Support were members of the NHSEI Task Force on Long Covid since the first meeting on 29th October 2020.

NHS England

August 2020

Claire Hastie, one of the founding members of Long Covid Support, and Professor Nisreen Alwan spoke with Professor Sally Singh (Head of Pulmonary and Cardiac Rehabilitation at University Hospitals of Leicester NHS Trust and the University of Leicester) [about plans for the Your Covid Recovery website](#), initially targeted at post-hospitalised patients. It was emphasised that it should include short videos for people with cognitive difficulties, making clear that exercise and other exertion can lead to PEM/PESE (post-exertional malaise/post-exertional symptom exacerbation), and that vast numbers of people who had not been hospitalised were experiencing debilitating symptoms.

29th October 2020

First monthly NHS England Long Covid Task Force meeting, attended by members of Long Covid Support and other individual patients and patient groups. Long Covid Support had a representative on the main Task Force and on each of the 8 subgroups.

18th December 2020

NHSE announced ‘Long COVID patients to get help at more than 60 clinics’. Until June 2021 these were only assessment services that were not funded to provide treatment. Patient organisations repeatedly raised concerns that there was a lack of information about where services were available, how patients could access them and how clinicians should refer. Some of the listed services were not operational due to delays in resourcing the provision e.g., due to the emergence of the Kent variant of SARS-CoV-2. To date, from what we have been told via

our ongoing survey into patient experience and our peer support group, there has not been a consistently satisfactory level of service.

4th February 2021

Long Covid Support presented the findings of their [survey](#) into patient experiences of Long Covid assessment services to the NHSE Long Covid Task Force. We raised concerns that:

- These are currently only in England, there are large geographical gaps even in England, a lack of consistency in the service offered, significant barriers to access (being believed, identifying operational clinics, waiting times, proximity, etc.), and clinicians don't know how to help.
- Patients were and still are being given unsafe advice around exercise when research indicates that a high proportion of people with Long Covid experience post-exertional malaise (PEM) / post-exertional symptom exacerbation (PESE) and have detectable organ damage, although many may not have had this diagnosed on account of lack of appropriate investigations.

Further presentations were given in [March](#), [April](#) and [May](#)³ 2021 highlighting both improvements and where issues remained with Long Covid services.

7th February 2021

Long Covid Support member Claire Hastie sent an email to ONS about the limited list of symptoms included in the ONS Covid Infection Survey *“the poor communication of the breadth of symptoms (even today, Googling “NHS covid symptoms” results in a page that lists only cough, fever and loss of taste or smell - with all the risks of unwitting spread that brings). Any question that presupposes the respondent knowing they have had Long Covid may underestimate prevalence as people are likely to skip that question.”*

12th February 2021

Long Covid Support member Claire Hastie sent an email⁴ to the DHSC, NHSE and the Office for National Statistics (ONS) raising concerns that NHS Budget modelling significantly underestimated the burden of disease; that the NHSE list of 3 symptoms for acute illness was resulting in many not realising that they had COVID-19; that community cases of Long Covid were significantly greater in number than those who were hospitalised, and that community cases were taking significantly longer to recover than hospitalised cases, likely due to lack of treatment.

24th February 2021

³ 11.04.22 NHSE Lived Experience Partners Recruitment; 26.05.22 NHSE Recruitment of Lived experience partners for 2022_23; March 21 LCS report on Long Covid Assessment Services - Patient Feedback; April 21 LCS report on Long Covid Assessment Services - Patient Feedback; May 21 LCS report on Long Covid Assessment Services - Patient Feedback

⁴ Email dated 12 February 2021 from Claire Hastie, Long Covid Support.

The 8 members of Long Covid Support who had been on the NHSE Task Force received an email⁵ thanking them for their extensive contributions to date and explaining how they would be reimbursed. The email went on to explain that going forward 5 PPV4 members would be appointed (reimbursed) and others would be appointed to PPV3 roles as a patient advisory group (not reimbursed). Communications around the application process were poor, the application form was complex, people were not notified if they had been unsuccessful. No members of Long Covid Support were appointed to PPV4 roles and we had to challenge NHSE to get a seat at the table as a patient organisation.

1st July 2021

Patients were invited to attend a Patient and Public Voice Network induction webinar, although it did not focus specifically on Long Covid nor did it take into consideration the considerable expertise that had already been shared by patient partners up until this point. Long Covid Support raised concerns about the running of the Patient and Public Voice Network and the next meeting did not take place until December 2021. It was then decided that PPV3 partners would meet monthly with members of the NHSE Task Force as a Long Covid Advisory Forum commencing in February 2022.

9th September 2021

Long Covid Support founding member Claire Hastie, wrote to Cathy Hassell (NHSEI Director, Clinical Policy, Quality and Operations⁶ and Kiren Collison (NHSEI Deputy Medical Director for Primary Care and Head of the Task Force)⁷ following the announcement of the National Specialty Advisers on Long Covid. She expressed dismay that both are respiratory consultants (yet there has been compelling evidence since early in the pandemic that Long Covid is a vascular condition; see for example The Lancet May 2 2020 [“Endothelial cell Infection and Endotheliitis in COVID-19”](#)⁸ and one has repeatedly and publicly made assertions that are not backed by evidence and that minimise Long Covid, attributing the condition to anxiety at the thought of never recovering as well as associated insomnia.

7th January 2022

Our Chair of Trustees met with NR Head of the Task Force and Cathy Hassell, Director of Clinical Policy. At this meeting we were advised that there could be 1 representative of the charity on the Task Force going forwards. The organisation successfully argued that it should also continue to have representation in each of the Task Force subgroups. However, these have now all ceased to operate.

11th April 2022

⁵ Email dated 24 February 2021 from NHSE Long Covid Patient and Public Voice arrangements

⁶ 14.09.21 email exchange C Hassell and C Hastie

⁷ 09.09.21 C Hastie email to K Collison and 12.09.21 K Collinson email to C Hastie

⁸ See also National Library of Medicine, [“COVID-19 is, in the end, an endothelial disease”](#) September 2020.

NHSE announced that they were again restructuring patient involvement in the Long Covid Task Force. A series of emails⁹ were sent out detailing very strict criteria under which patients could apply. This meant that many existing representatives of the Task Force were suddenly excluded.

From February 2022 NHSE began working collaboratively with lived experience partners on the NHS plan for improving long COVID services in 2022. Through this partnership, Long Covid Support raised concerns with NHSE that budget modelling significantly underestimated the burden of Long Covid.

NICE

Long Covid Support was invited to participate in the consultation process for the NICE COVID-19 rapid guideline: ‘managing the long-term effects of COVID-19’, published on the December 18th, 2020. Long Covid Support welcomed its holistic approach but were disappointed that several concerns raised during the consultation process were not addressed, including:

- insufficient guidance on the range of physical symptoms leading to problems of diagnosis, coding, referral and treatment.
- the rather arbitrary three phases, risking barriers to investigations and care, as evidenced in the NHS guidance for clinics, which at that time specified that referral to services could take place from 12 weeks post-infection rather than 4 weeks outlined in the NICE/SIGN/RCGP clinical guideline.
- the name, leading to problems with applying codes (post-acute Covid rather than Long Covid in EMIS).

Members of Long Covid Support wrote an [article for the Lancet](#), in which they raised concerns about the shortcomings of the NICE guideline. Notably that:

1. It did not cover the full range and severity of symptoms as noted by patients.
2. It did not acknowledge the relapsing remitting nature of the disease, which may lead to premature dismissal of patients
3. There was an over-focus on self-management, psychological support, and rehabilitation, resulting in the potential for “watered-down” versions of NHS long COVID clinics that do not provide thorough physical assessment of patients.
4. There is no mention of the three proposed mechanistic theories - persistent virus in immune-privileged sites, aberrant immune response, or autoimmunity.

⁹ Email dated 11.04.22 NHSE Lived Experience Partners Recruitment and email dated 26.05.22 NHSE Recruitment of Lived experience partners for 2022/23

5. The use of arbitrary phases (ongoing symptomatic COVID-19 from 4 to 12 weeks and post-COVID-19 syndrome - 12 weeks or more) with the risk of damaging patient care by creating barriers to services and investigations.

On April 15th, 2021, members of Long Covid Support had a phone call with Fiona Glen of NICE and Gail Allsopp of RCGP in which they called for the risk of post-exertional malaise (PEM) to be flagged in the clinical guideline¹⁰.

November 2021

Long Covid Support contributed to the consultation review of the NICE COVID-19 rapid guideline: managing the long-term effects of COVID-19. Concerns were raised by the organisation that insufficient time was allocated for people with Long Covid to review the documentation.

Long Covid Support are now represented on the NICE Voluntary and Community Forum Steering Group, and on the Voluntary and Community Forum itself. Our members have been involved in the therapeutic appraisal process for Covid therapies.

Westminster Health Forum

Members of Long Covid Support presented at the Westminster Health Forum ‘Long COVID - priorities for research and improving patient care, treatment and support’ in Spring 2021. Concerns were raised from our speaker and others about the presentation¹¹ from Dr Graham Burns in which he stated that the cure for Long Covid was getting a good night's sleep and for patients to get over their anxiety. Members also spoke at the ‘Long Covid - improving patient care and access to support, progress in service development, and priority areas for research’ in Spring 2022.

4. Submitting evidence to APPG and Select Committee Inquiries

Long Covid Support has submitted relevant evidence to the APPG on Coronavirus and select committees (we have also included this evidence in Appendix 2 being the List of Articles, Publications and Evidence Long Covid Support has contributed to):

August 2020

On August 5th, 2020, members of Long Covid Support gave evidence to MPs and members of the House of Lords at the second hearing of the UK's newly formed All Party Parliamentary Group on Coronavirus, which was covered in all major media outlets, including on the front page of The Telegraph and on Channel 4 News. Members of Long Covid Support went on to

¹⁰ Written list of questions LC Support Phone call with Fiona Glen of NICE and Gail Allsopp of RCGP

¹¹ Slide from Graham Burns Presentation - Westminster Forum Spring 2021

give further evidence to several All-Party Parliamentary Group ([APPG](#)) hearings on Long Covid.

August 2020

Long Covid Support gave oral evidence at the All Parliamentary Group on Coronavirus hearing on Long Covid. The report that followed stated that: “*The UK government is not counting the number of individuals who are left with long-lasting effects of COVID-19 as a measure of the severity and impact of the pandemic; As a medical condition, Long Covid has not yet received full recognition, sufficient research funding or adequate rehabilitation support. There are very few guidelines for employers or for GPs on recognising and managing Long Covid.*”

March 2021

The Long Covid Support Employment Group provided evidence to the Health and Safety Executive report on [Return to work after long COVID](#).

June 2021

The Long Covid Support Employment Group submitted written evidence to the Work and Pensions Committee DES008 regarding employment support¹².

October 2021

The Long Covid Support Employment Group submitted written evidence to the Work and Pensions Committee HAB0126 - Health assessments for benefits (published May 2022).¹³

11th October 2021

The Long Covid Support Employment Group submitted a response to the Department for Work and Pensions, Shaping Future Support: The Health and Disability Green Paper consultation. Much of our evidence focused on DWP support and possible solutions for people with LC who receive benefits (ESA/ UC).¹⁴

1st December 2021

The Long Covid Support Employment Group submitted a response to the Department for Business Energy and Industrial Strategy consultation on Flexible working¹⁵.

February 2022

The Long Covid Support Employment Group submitted evidence to the Parliamentary Inquiry on Health Benefits.

¹² June 21 LCS Employment Group Response to DES0008

¹³ Oct 21 LCS Employment Group Response to HAB0126

¹⁴ Oct 21 LCS Employment Group Response to Health & Disability Green Paper.

¹⁵ 01.12.21 LCS Employment Group Response to BEIS Consultation on Flexible Working

March 2022

Members of Long Covid Support gave evidence to the APPG on Coronavirus report on [Long Covid](#). Recommendations by the APPG in the report include:

- *Long Covid is having a significant impact on the UK workforce and, as the UK response transitions from pandemic to endemic, then learning to live with Covid means living with Long Covid too.*
- *The APPG recommends that the UK Government add Long Covid to the existing list of considerations when making public health policy.*

5. Collaboration with other relevant national and international partners

Long Covid Support has members internationally and has consistently worked collaboratively across borders. Since the early days of the pandemic, members of Long Covid Support have connected through platforms such as Twitter with other individuals and patient groups in multiple countries. As an organisation we have continued to work to strengthen these connections.

UK Sepsis Trust

In July 2020, Long Covid Support collaborated with the UK Sepsis Trust on a ‘Just think: could it be Covid’ social media advertisement in order to raise awareness that the symptoms of acute COVID-19 were much broader than the three symptoms publicised by the government and NHS England and that symptoms could last for weeks/months¹⁶.

World Health Organization

Since collaborating on the Long Covid Forum in December 2020, Long Covid Support continues to work with the WHO. Long Covid Support gathered video testimonies from people around the world to be played in the breaks of the Long Covid Forum. On 21 December 2020 Dr Tedros Ghebreyesus replied to our letter thanking him for opening the Long Covid Forum. In his letter he stated “*I agree wholeheartedly that greater action is needed to provide for people living with the complications caused by COVID-19...we are committed to working side by side with you to ensure that the needs of people suffering from the lasting impacts of COVID-19 are understood clearly...*”

Long Covid Support member, Richard Roels spoke at the press briefing of the WHO Europe publication “In the Wake of the Pandemic: Preparing for Long COVID” at which he made the following points:

¹⁶ Sepsis Trust Long Covid Ad, June 2020

- People have extremely varied symptoms.
- We should focus more on the impact on people's lives, rather than the symptoms.
- Living with Long COVID, everything becomes a burden.
- It was a trauma at the beginning as no one knew what it meant when COVID symptoms returned – you had to confront and navigate this illness alone.
- Long-COVID is now on the radar of health professionals (in the UK) but Long COVID denial is still widespread among the public.
- We are still “at sea” regarding diagnosis.

Long Covid Support member, Dr Clare Rayner attends Dr David Nabarro's (WHO) fortnightly briefings.

World Innovation Summit for Health

Members of Long Covid Support were invited to be on the panel at the WISH conference in November 2020.

6 Contributing to UK and International research

Long Covid Support members have since June 2020 contributed to UK and international research on Long Covid.

NIHR

In June 2020 members of Long Covid Support were interviewed by Dr Elaine Maxwell as part of her work at NIHR on the evidence base for ‘post-covid syndrome’, to understand their lived experience. This study was included in the first Living with Covid19 review published on 15th October 2021. Our members presented as part of the first review online webinar.

Long Covid Support members helped to design the survey that informed the Living with Covid 19 second review, including details of access to healthcare service and impact on work, social and family life. This review was published in March 2021. One of our members was on the science advisory committee and therefore a co-author.

Members of Long Covid Support reviewed applications for the Commissioned calls for research into Community Long Covid in November 2020 and March 2021. After the first funding round, Long Covid Support expressed concerns that the chosen projects focused too heavily on prevalence and symptoms, rather than intervention and treatment, counter to the feedback provided by lived experience participants during the review process.

After the first funding round, Long Covid Support expressed concerns that recommendations of lived experience reviewers had not been given sufficient consideration in the review process, since research projects prioritised by patient reviewers had not been funded, and the funded

projects focused too heavily on prevalence and symptoms, rather than intervention and treatment, counter to the feedback provided by lived experience participants.

Long Covid Support went on to work with the PPIE lead and the manager of the relevant NIHR funding stream to implement improvements to the patient involvement process. Improvements were put in place by the time of the second call in Spring 2021.

Long Covid Support worked with the NIHR Centre for Engagement and Dissemination to explore our experiences to stimulate changes to their processes. We co-created and presented at an event as part of the NIHR Necessary Conversations series in May 2022. The purpose of the event was to consider what has worked well in patient involvement in research, but also to identify areas for improvement to determine where the NIHR and other funders and institutions need to address effort to ensure that good quality, meaningful involvement happens throughout the research process.

ONS Coronavirus Infection Survey (CIS)

Principal Scientists leading the ONS CIS regularly attended NHSE Long Covid Taskforce research subgroup and National Task Force meetings to present their findings. Members of Long Covid Support gave feedback and commentary on the CIS in relation to its measurement of Long Covid, and held several follow up meetings at various points with Daniel Ayoubkhani and others from the ONS to discuss patient involvement in the survey, and to discuss particular questions:

7th February 2021

Long Covid Support emailed the ONS¹⁷ to express concerns that the ONS survey questions on Long Covid were too limited to capture the potentially high numbers of people unaware that their symptoms may be due to Long Covid.

16th February 2021

Members of Long Covid Support met with the ONS to discuss the Long Covid questions. LCS emphasised that people who had been asymptomatic or had a ‘mild’ disease at the acute stage of infection could go on to develop Long Covid and that survey questions needed to take account of the relapsing remitting nature of the disease.

22nd February 2021

Long Covid Support emailed the ONS¹⁸ with a summary list of concerns about the existing survey questions and suggestions to improve.

¹⁷ 07.02.21 LCS email to ONS

¹⁸ 22.02.21 LCS email to ONS

8th June 2022

Long Covid Support met with senior scientists from the ONS CIS to share the results of its survey on reinfections in people with Long Covid, with the intention of informing planned questions on reinfection in the CIS.

7. Conducting surveys into patient experience, peer reviewing and publishing original research

Since the introduction of Long Covid Assessment Services in England, Long Covid Support have been running surveys into patient experiences, which they have fed back to both the Department of Health and the NHS England Long Covid Taskforce. A series of reports based on this survey are available on our [website](#).

In November 2021, Long Covid Support published an [information leaflet](#) in collaboration with Long Covid Kids, to educate the public on the symptoms of Long Covid, signpost to our support group and to seek medical help where necessary. The leaflet was produced by people with lived experience of Long Covid, including GPs, and reviewed by the Patient Information Forum. Long Covid can be difficult to diagnose, and some people might not realise their symptoms could be linked to prior COVID-19 infection.

8. Wider advocacy

Members and trustees of Long Covid Support have also contributed extensively to Independent SAGE sessions on Long Covid. Here are examples of Long Covid Support member Claire Hastie raising concerns and asking questions at session in [Sept 2020](#), [Jan 2021](#) and [July 2021](#). Members of Long Covid Support and Nisreen Alwan (Long Covid Support advisory board members contributed to an [Independent Sage film](#).

Our members have spoken at medical conferences for GPs, nurses and pharmacists, some of which have carried CPD accreditation. The Long Covid Support Employment Group has worked closely with bodies such as the Royal College of Nursing, Society of Occupational Medicine, Chartered Institute of Personnel and Development and TUC on the wider issues affecting people with Long Covid such as employment and benefits.

17th June 2020

Long Covid Support members met with Shadow Public Health Minister Alex Norris.

6th August 2020

Long Covid Support members met with Greater Manchester Mayor Andy Burnham.

March 2021

The Long Covid Support Employment Group collaborated with the Society of Occupational Medicine to produce guidance for [Employers](#) and [Employees](#) on Returning to Work with Long Covid.

21st May 2021

Members of Long Covid Support met with Dean Russell MP, member of the Health & Social Care Select Committee

Feb 2022

The Long Covid Support Employment Group collaborated with CIPD to produce [Working with long COVID: research evidence to inform support](#)

March 2022

The Long Covid Support Employment Group collaborated with CIPD to produce [Working with Long Covid-Guidance to provide support](#)

June 2022

The Long Covid Support Employment Group together with Long Covid Occupational Therapists produced a guide on [Claiming Personal Independence Payment \(PIP\) for people living with Long Covid](#).

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, Publications and Evidence to committees.

In particular, Long Covid Support would highlight the following letters, evidence and papers which they have contributed to:

- i. The first questions to the Department of Health and Social Care on 16th and 17 June 2020
- ii. Evidence provided to the All-Parliamentary Group on Coronavirus on 5 August 2020 raising many concerns about Long Covid and those that had not recovered from Covid-19. The report concluded *“The UK government is not counting the number of individuals who are left with long-lasting effects of COVID-19 as a measure of the severity and impact of the pandemic; As a medical condition, Long Covid has not yet received full recognition, sufficient research funding or adequate rehabilitation support. There are very few guidelines for employers or for GPs on recognising and managing Long Covid,”*

- iii. Letter to Jeremy Hunt dated 28 August 2020 asking for the UK Government to assemble a multi-disciplinary Long Covid task force
- iv. Long Covid Support's response to the NICE guidance in December 2020 in particular for example it did not cover the full range and severity of symptoms as noted by patients. It did not acknowledge the relapsing remitting nature of the disease, which may lead to premature dismissal of patient
- v. Long Covid Support's evidence about its patient experience surveys
- vi. Long Covid Support's emails concerning the poor communication about the breadth of symptoms of Covid-19 in February 2021
- vii. Long Covid Support's concerns raised in the WHO press briefing: Preparing for Long Covid dated March 2021
- viii. Long Covid Support's letter to Sajid Javid, then Secretary of State for Health and Social Care dated 8 July 2021 stating that it was urgent that when evaluating policy, he takes account of the impact of Long Covid on people.
- ix. Long Covid Support's meeting with Jeremy Hunt, the Secretary of State for Health and Social Care dated 29 November 2021

Further, members of Long Covid Support have co-authored more than 35 publications in medical journals such as BMJ, Lancet, and Nature. Publications which relate to the work of the NIHR, and NIHR funded research studies are shown in Appendix 2:

Our members have also given frequent interviews to local, national and international media - print/online, radio and television. A non-exhaustive list of these is provided in Annex 2 . Further a list of educational podcasts and videos produced by members of Long Covid Support is provided in Annex 3.

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 and remains 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 issues:

- i. The primary focus within government policy on hospitalisations and deaths created a blind spot with regard to those who survived COVID-19 yet remain unrecovered.

- ii. Long Covid Support raised concerns in summer and autumn 2022 that whilst there were some encouraging steps in 2020 - such as the launch of the NHS 'Your Covid Recovery' website and the £8.4 million investment in the PHOSP-COVID study - these were focused on people who were previously admitted to hospital. There was in our view a lack of attention to those experiencing persistent, often debilitating, symptoms in the community. The vast majority of people with Long Covid were never hospitalised and - for those who fell ill in the first wave of the pandemic and at some times since then - never tested (due to lack of available tests). We are aware from our members that many non-hospitalised patients made multiple trips to A&E and were not recovering quickly. We know from our members that during the first lockdown patients were often advised by NHS111 staff to shelter at home and/or were turned away from A&E leaving them to deal with serious symptoms at home. Often little or no follow-up care was put in place for these people.
- iii. Long Covid Support sought to draw attention to the fact that many caught COVID-19 in frontline and essential services, and subsequently went on to develop Long Covid. These were people in occupations such as health, social care, education, transport, factories and logistics who remained in work whilst the country locked down, often - and this remains the case - without access to appropriate PPE. A significant number are either unable to work at all or to their previous capacity, or are working, unsustainably, while still ill.
- iv. We also raised concerns that insufficient consideration was being given to the disproportionate impact of Long Covid, and the various associated disease outcomes, on socially and economically marginalised communities. Hence further widening the health and social care inequalities gap.

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 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.

Please see Appendix 1 Overview Chronology.

Long Covid Support has advocated and raised concerns to the UK Government and others arising from our experiences as sufferers of Long Covid and on behalf of our members since the early days of the pandemic.

16th-17th June 2020

Two UK parliamentarians, Natalie Bennett and Steve McCabe, tabled written questions about Long Covid in the UK House of Commons, the latter in response to a letter written to Steve McCabe by a founding member of Long Covid Support, who was his constituent. The written questions are [here](#) and [here](#). The questions to the Government were (i) *to ask the Secretary of State for Health and Social Care, whether he plans to commission research into the long term effects of covid-19 on people whose symptoms last longer than three weeks* and (ii) *to ask Her Majesty's Government what plans they have to support those suffering long-term effects from COVID-19.*

5th July 2020

Health Secretary Matt Hancock acknowledged publicly the existence of Long Covid during a speech to mark the NHS' 72nd birthday, mentioning plans to establish support for patients.

28th August 2020

Long Covid Support and partners sent [a letter to Jeremy Hunt](#), chair of the Health & Social Care Committee, to ask for the UK Government to assemble a multi-disciplinary Long Covid taskforce to address the urgent needs of people living with persistent on-going symptoms of COVID-19. We asked the Department of Health and Social Care to:

- Develop and disseminate information on treatment, management of symptoms and rehabilitation
- Fund more and better research
- Quality psychosocial and mental health services
- Better public health programmes
- Help for NHS and social care workers to return to work safely (many had been infected on the frontline of the pandemic response)
- Funding for patient-led support groups.

7th September 2020

The UK government acknowledged long term effects in the UK Parliament "Rapid response" on '[Short- and long-term health effects of COVID-19](#)' in which the advocacy work of Long Covid Support is referenced. The report states: "*There is emerging evidence that COVID-19 affects many systems of the body, with patients reporting a wide range of symptoms. 'Long-haulers' are patients who experience ongoing COVID-19 symptoms for several months after infection.*" It is noted that "*As described on the NHS website, the main symptoms of SARS-CoV-2 infection are: 1) a high temperature, 2) a new, continuous cough, and 3) a loss or change of smell or taste. However, there is emerging evidence supporting a more complex*

range of clinical features of SARS-CoV-2 infection.” It then goes on to note that there is a much broader range of symptoms listed in Guidance from Public Health England. Despite our repeated requests for the NHS symptom list to be updated this did not happen until 1st April 2022. This directly impacted on test eligibility, public awareness that their symptoms were due to COVID-19 and hence transmission of SARS-CoV-2 and ability to seek help for ongoing symptoms of Long Covid.

8th September 2020

Health Secretary Matt Hancock publicly acknowledged receipt of the letter (forwarded to him by Jeremy Hunt) at the Health & Social Care committee, and also discussed his understanding of Long Covid in detail, showing he had taken on board points raised. He stated: *“There is no doubt about the impact and severity of Long Covid... the long-term impacts are not strongly correlated with the severity of the illness ...it doesn’t matter how serious your infection was, the impact of long covid can be really debilitating...it is an incredibly important area to me.”*

7th October 2020

NHS England announced a [Five Point Plan](#) to support people with Long Covid.

12th October 2020

[Jeremy Hunt wrote](#) to Matt Hancock on the specific issues that we raised that had not been covered in the September dialogue:

1. The establishment of a multi-disciplinary Long Covid taskforce
2. Improvements to continuing professional education
3. Better public health programmes
4. Help for NHS and social care workers to return to work safely
5. Funding for patient-led support groups.

13th October 2020

A founding member of Long Covid Support spoke at the DHSC Round Table on Long Covid.

9th January 2021

Long Covid Support founding member Claire Hastie sent a letter to all MPs urging them to participate in the Commons debate on Long Covid, scheduled for 14th January, as well as the APPG on Coronavirus oral hearing about Long Covid among health professionals on 12th January¹⁹. The letter raised the following key points:

1. Long Covid affects vast numbers of people and has a significant impact on people's lives and ability to work.

¹⁹ Email letter 9.1.21 from LCS

2. More needs to be done to prevent more people getting Long Covid inc. preventative public health measures to raise awareness and early treatment interventions for those infected by SARS-CoV-2.
3. More needs to be done to support people affected by Long Covid, including better and more consistent access to Long Covid services, greater investment in research and support with returning to work.
4. For support groups to be funded to continue the valuable work that they do.

The organisation received very few responses and those that we did receive were generic statements regarding the NHSE Long Covid Plan and did not address the points raised.

14th January 2021

The first [debate](#) on Long Covid was held in the UK parliament.

2nd February 2021

Long Covid Support and Patient Safety Learning wrote a [Joint Call to Action](#) calling for an urgent and significant increase in the scale and pace of the response, and a coordinated, multi-stakeholder approach.

8th February 2021

Long Covid Support sent an email to Lord Bethell²⁰ raising the following concerns:

1. The voice of lived experience reviewers had not been adequately considered in the NIHR Long Covid funding bid.
2. The need for trials into early treatment with antiviral combinations should be prioritised as an urgent complement to the vaccine programme.

11th February 2021

Long Covid Support received an email from [NR] Head of Long COVID, DHSC wanting to discuss the February presentation of our survey results to the NHSE Long Covid Task Force.

19th February 2021

Members of Long Covid Support met with [NR] We had forwarded²² the following points for discussion ahead of the meeting along with a copy of the presentation:

1. The need for a dedicated Long Covid Minister with responsibility, accountability and a cross-departmental remit
2. Patient panels to review and approve any initiative: 'nothing about us, without us'

²⁰ Email dated 8.7.21 LCS email to Lord Bethell

²¹ E Spencelayh email to LCS following meeting of the 19.02.22

²² Email dated 24.02.21 LCS email to E Spencelayh

3. Accurate data on prevalence to inform policy and funding needs
4. Funding for research and interventions into 2 key strands of need:
 - Prevention of Long Covid (and severe acute Covid)
 - Treatment and support for those living with Long Covid

Long Covid Support wrote up minutes of the meeting²³ and shared them with DHSC. In summary, we were advised that our best route to raise clinical concerns was through the NHSEI Long Covid Task Force and that it was not necessary to establish a minister for Long Covid as Lord Bethell fulfilled this role. Concerns were shared around the scope and scale of research and that funding so far had been more focused on Long Covid prevalence and symptoms, not intervention and treatment.

June 2021

Long Covid Support presented the findings of their ongoing [survey](#) into patient experiences of Long Covid assessment services and their concerns regarding the NHSE 5-point plan to the DHSC Round Table on Long Covid. We raised the concern that there seems to be a disconnect between the stated purpose of assessment services and patient experience. We asked:

1. Who has oversight and responsibility for patient care?
2. What is the intended purpose of Long Covid assessment services?
3. What are the criteria for a patient to be referred and for the referral to be accepted?
4. To what extent do services meet the requirements of the NHS Commissioning Guidelines (April 26th update)?

8th July 2021

Long Covid Support [wrote to](#) Sajid Javid urging that, when evaluating policy, he takes account of the devastating and prolonged impact that Long Covid can have on people of all ages. We urged him to:

1. Support those living with Long Covid by providing inclusive and equitable access to appropriate care
2. Provide appropriate support for NHS staff returning to work
3. Prevent further people being affected by Long Covid by implementing measures to reduce the risk of SARS-CoV-2 infection

2nd September 2021

Long Covid Support received a response from the DHSC²⁴ The response explained the NHSE 5 and subsequent 10-point plan, the Your Covid Recovery website and the NIHR funded research calls. It focused on rehabilitation and goal setting and did not address any of our

²³ LCS Support Minutes of meeting 19.2.21

²⁴ Email dated 02.09.21 DHSC email to LCS in response to S Javid letter

specific concerns regarding serious pathology, unsafe rehabilitation advice and inconsistencies in provision of services.

1st December 2021

Long Covid Support, Long Covid SOS and Long Covid Kids met with Jeremy Hunt²⁵. Key concerns raised were:

Support NHS staff returning to work. Providing greater access to effective measures such as extended phased returns, occupational health and vocational rehabilitation support, which would cost less than the significantly greater economic burden of chronic ill health, unemployment and the loss of skilled workforce.

Require the use of appropriate PPE for all health and care staff working with patients with confirmed or suspected Covid-19. Surgical masks provide inadequate protection.

Reinstate the advice for face coverings to be worn in schools, given the rapid increase in infection rates of the Delta variant and the disproportionate rise in cases among school-aged children.

Offer vaccination to children, with the aim of reducing individual risk, as well as that of communities and wider society, and educational disruption.

Provide grants for equipment to improve ventilation and air quality in schools, healthcare settings, public transport, workplaces, and arts/leisure venues.

Expand service provision to enable inclusive and equitable access to assessment, treatment and rehabilitation at the earliest opportunity to maximise chances of recovery and resuming work, education and/or caring responsibilities.

Count Long Covid to better plan health and social care support by establishing a patient registry that would also serve to follow up any potential longer-term consequences of Covid-19.

Communicate an updated list of acute symptoms of Covid-19 in both adults and children to allow people to apply for PCR tests and to prevent unwitting spread, including taking account of the differing presentations of the Delta and new variants.

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:

²⁵ LCS notes dated 29.11.21

1. As an organisation, we are concerned that the Government did not give sufficient consideration to morbidity in its pandemic planning; that this continued not to be given sufficient weight throughout the Government's ongoing response and that this problem persists into the present. It is important that consideration is given to why post acute viral sequelae were apparently not given sufficient attention in terms either of public health messaging or as a metric to measure the impact of the pandemic.
2. Our experience from the people with Long Covid that we support is that they have been overlooked and their concerns dismissed; as a result of this they have struggled to access healthcare and experienced significant denial and stigma. In our view this arose from the government's mischaracterisation of Covid-19 from the outset. It is essential that relevant bodies listen and act on the lived experience of patients. Early acknowledgement would have significantly improved the experience of healthcare for people with Long Covid.
3. The way to avoid Long Covid is to avoid Covid. This message was absent in public health messaging, despite being known since the summer of 2020. This, along with poor communication about the breadth of Covid symptoms, may have led to behaviours that led a significant number of people to contract Covid-19, assuming a brief illness with a full recovery, who now maintain episodic or full-time disability as a consequence of infection. In our view, as they were not informed of the risks of developing long term illness, there has been a mass disabling of previously fit and healthy people. Clear messaging from the Government regarding the impact of Long Covid on quality of life, ability to earn a living and care for others would have enabled people to make more informed choices about their personal risk.
4. The growing numbers of people being affected by Long Covid have been further exacerbated by an over reliance on vaccines over other measures to limit the spread of SARS-CoV-2. Vaccines do not provide lasting immunity against SARS-CoV-2 leaving people open to reinfection which exacerbate existing Long Covid and can cause a recurrence in those who had recovered. Whereas vaccines confer a high-risk reduction against acute Covid-19, they only offer a weak risk reduction and/or mitigation for Long Covid. In our opinion, the long-term disabling impact of Long Covid should have been factored into decisions about public health that allow high levels of community infection.
5. We are concerned that the Government has failed to fund sufficient capacity within Long Covid services to meet the needs of all those who require medical support. The NHSE Plan for Long Covid published in June 2021 assumed that only 68,000 people would need specialist Long Covid clinics (LCS has repeatedly raised concerns about the numbers of persons with Long Covid see for example letter to Jeremy Hunt dated 28 August 2020, Jeremy Hunt letter to Matt Hancock dated 12 October 2020, LC Support in email to MPs dated 9 January 2021) ²⁶. Further 2.2m people (3.4 % of the

²⁶ See also: Lord Bethell stated in the recent HoL debate 17.11.2022 (12.56) "[The Osays that there are 1.5 million sufferers, yet the long Covid clinics can see only 60,000 patients per year.](#)" See also comments by Baroness Thornton Baroness Thornton (12.32)"*Despite the investment*

UK population) now have Long Covid (ONS, 9 December 2022). According to the NHS plan for improving long COVID services July 2022²⁷ 19% of these are likely to need care at a specialist Long Covid service. The plan also states, “Since July 2021 over 60,000 people have received specialist assessment in these services.” Given the present number of people already affected by Long Covid, the trajectory of SARS-CoV-2 infections and hence potential additional Long Covid, it would be prudent to plan for increases some way beyond current estimates given that the current funding does not meet today’s Long Covid population.

6. An increasing number of people of working age are being left unable to work at all or to their previous capacity as a result of their Long Covid. This is impacting on key public services, including the NHS, whilst simultaneously adding to the pressure on NHS services. The fall in labour market participation is already having a measurable impact on the economy. Future modelling and policy decisions need to recognise that this is an ongoing problem; the number of people with Long Covid is likely to stabilise at its current very high levels or increase as community transmission rates remain high. People can get Long Covid even if they have recovered unremarkably from previous infections. As far as Long Covid is concerned there will always be people who are vulnerable; we presently have no means of identifying who those people are.

In summary our view the Government response to both the prevention of Long Covid and the care for those with Long Covid appears to have been inadequate and arose from the Government’s ongoing failure to respond to the evidence and to factor in the risks of Long Covid throughout its pandemic management and decision making (see for example our letter to Sajid Javid, evidence to APPG in August 2020). Whilst it is only natural for the immediate focus to be on acute illness and ensuring services are not overwhelmed, chronic illness and disability must be considered as an important part of pandemic preparedness. Long-term ill-health issues such as Long Covid and other serious health-related outcomes have the potential to burden health care, social care and the wider economy for years to come.

15 December 2022

into research for treatments for long Covid, much of the research is in its early stages, resulting in a lack of evidence on effective treatments. In terms of resources, of the million or more who are reporting with long Covid, only 60,000 patients can access treatment. This means that hundreds of thousands of people with long Covid are feeling isolated and frustrated in their search for treatment, and as a result sometimes live in poverty and despair. I would like to commend the patient groups that have been doing a great job in mutual support and campaigning.” Baroness Donaghy also stated (12.45) “NHS England data suggested that, up to August 2022, only 60,000 people suffering from long Covid had been assessed by an NHS specialist. If the 600,000 figure is correct, the gap is concerning.”

²⁷ https://www.england.nhs.uk/wp-content/uploads/2022/07/C1607_The-NHS-plan-for-improving-long-COVID-services_July-2022.pdf

Long Covid Support

Appendix 1:

Overview Chronology of the work of Long Covid Support regarding Module 2

January 2020 to Spring 2022

Date	Event	Source
02/05/2020	The Covid-19 Support Group was set up on Facebook	
18/05/2020	Twitter campaign of patients holding placards with symptoms and duration of illness	
June 2020	The Facebook Group was renamed Long Covid Support Group	
June 2020	Start of NIHR review: Members of Long Covid Support were interviewed by Dr Elaine Maxwell as part of her work at NIHR on the evidence base for 'post-covid syndrome', in order to understand their lived experience	NIHR review On 19/08/2020 Long Covid Support received a message of thanks for their involvement in the focus groups.
16-17 June 2020	Two UK parliamentarians, Natalie Bennett and Steve McCabe, tabled written questions about Long Covid in the UK House of Commons, the latter in response to a letter written to Steve McCabe by a founding member of Long Covid Support who was his constituent	Hansard: Question for Department of Health and Social Care UNI60680 https://questions-statements.parliament.uk/written-questions/detail/2020-06-17/60680 HL 5748 https://questions-statements.parliament.uk/written-questions/detail/2020-06-16/hl5748
17/06/2020	Long Covid Support members met with Shadow Public Health Minister NR	
19/06/2020	The COVID-19 Research involvement was set up on Facebook	
28/06/2020	The Long Covid.org website was launched	Website https://www.longcovid.org/
06/08/2020	Long Covid Support members met with Greater Manchester Mayor Andy Burnham	
August 2020	Meeting with Prof Sally Singh about Your Covid Recovery website	
05/08/2020	Long Covid Support gave oral evidence at the All-Parliamentary Group on Coronavirus. The report that followed concluded that the UK Government was not counting those with long lasting effects of Covid-19 as a measure of severity and impact of the pandemic	Oral evidence session August 2020 Report December 2020 p.41-42

28/08/2020	Long Covid Support and partners sent a letter to Jeremy Hunt, chair of the Health & Social Care Committee, to call for the UK Government to assemble a multi-disciplinary Long Covid task force. This letter was forwarded by Mr Hunt to Matt Hancock, then Secretary of State for Health and Social Care	Letter dated 28 August 2020 See Jeremy Hunt letter to Matt Hancock dated 12 October 2020
02/10/2020	Long Covid Support were asked by the NIHR to recruit volunteers for a film about Long Covid. The request stated: “We are working closely with the DHSC and Her Majesty’s Government who are planning on doing a ‘piece’ next week on Long COVID: highlighting that COVID-19 isn’t just a disease that either kills you in the short term or doesn’t affect you, but that it can have long term health impacts (emphasising the importance of following rules on hands, face, space campaign).”	
09-10 Dec 2020	Long Covid Support organised the Long Covid Forum in collaboration with ISARIC and GLOPIDR opened by the WHO Director General.	https://isaric.org/event/long-covid-joint-research-forum-virtual-events-9-10-december-2020/
13/10/2020	Long Covid Support spoke at the first Long Covid Ministerial Roundtable chaired by Lord Bethell. At these monthly meetings Long Covid Support raised concerns on behalf of their members.	
29/10/2020	First NHS Long Covid Task force meeting was held. Long Covid Support had a representative on the main Task Force and on each of the 8 subgroups.	
11/11/2020	Members of Long Covid Support presented at the NIHR webinar ‘Acting on the lived experience of Long Covid’.	https://www.youtube.com/watch?v=wZ_ipmf0s-Q
15/11/2020	Long Covid Support members participated in a panel discussion about Long Covid at the World Innovation Summit for Health	
16/11/2020	Long Covid Support attended the second Ministerial Roundtable on Long Covid, chaired by Lord Bethell.	
26/11/2020	Second NHS Long Covid Task force meeting Long C Support attended.	
18/12/2020	NHSE announced ‘Long COVID patients to get help at more than 60 clinics’	

21/12/2020	Dr Tedros Ghebreyesus WHO letter to Long Covid Support about Long Covid.	Letter from Dr Ghebreyesus World Health Organisation dated 21 December 2020
21/12/2020	Long Covid Support responded to consultation on NICE guidelines on Long Covid.	Long Covid Guidelines need to reflect lived experience
06/01/2020	Announcement of Long Covid clinics experience survey by Long Covid Support	See here
07/01/2021	Third NHS Long Covid Task force meeting	
09/01/2021	Long Covid Support founder Claire Hastie sent a letter to all MPs urging them to participate in the Commons debate on Long Covid scheduled for 14 January 2021.	Letter dated 9/01/2021
29/01/2021	Long Covid Support attended the Ministerial Roundtable on Long Covid.	
03/02/2021	Long Covid Support and Patient Safety Learning issued a joint call for an urgent and significant increase in the scale and pace of the response, and a coordinated, multi-stakeholder approach.	See call to action here
04/02/2021	NHS Long Covid Task force meeting Long Covid Support presented Patient Experience survey.	See here
07/02/2021	Long Covid Support email to ONS, Department Health and Social Care and NHSE	Email dated 7/02/21
12/02/2021	Long Covid Support member Claire Hastie sent an email to the DHSC, NHSE and the Office for National Statistics (ONS)	Email dated 12/02/21
22/02/2021	Long Covid Support member Claire Hastie sent an email to ONS about phrasing of survey questions	Email to ONS dated 22/02/21
23/02/2021	Long Covid Support attended the Ministerial Roundtable chaired by Secretary of State for Health and Social Care Matt Hancock and Lord Bethell.	
23/02/2021	Email exchanges with Emma Spence Layh Head of Long Covid NHS Policy and Performance Group Department of Health and Social Care re patient and public voice participation and Long Covid Support	Emails dated 23/02/21-24/02/21
March 2021	Long Covid Patient Experience assessment survey published by Long Covid Support	https://www.longcovid.org/impact/long-covid-survey-updated-analysis
March 2021	Long Covid Support spoke at the WHO “In the Wake of the Pandemic” policy briefing	See WHO Policy Briefing: Preparing for Long Covid
15/04/2021	Two members of Long Covid Support spoke with Fiona Glen of NICE and Gail Allsopp of	Questions from call

	Royal College of GPs. They called for the risk of post-exertional malaise (PEM) to be flagged in the clinical guideline	
22/04/21	Long Covid support were invited to present at Long COVID - priorities for research and improving patient care, treatment and support	Westminster Health Forum
29/04/2021	Members of Long Covid Support participated in the webinar: "(REACT-LC) COVID-19 Community Involvement: Let's Talk About... Long COVID Research"	REACT-LC (one of the first NIHR commissioned Long Covid research projects)
21/05/2021	Members of Long Covid Support met with Dean Russell MP, member of the Health & Social Care Select Committee	
June 2021	Members of Long Covid Support 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	LC Support attended the Ministerial Roundtable on Long Covid chaired by Lord Bethell. At this meeting Long Covid Support presented the findings of their survey into patient experiences of Long Covid assessment services and their concerns regarding the NHSE 5-point plan	Minutes from meeting dated 16/06/2021
07/07/2021	NHS Long Covid Specialist assessment service subgroup meeting	
08/07/2021	Long Covid Support wrote to Sajid Javid urgently requesting that when evaluating policy, he takes account of the impact of Long Covid on people	Letter to Sajid Javid, then Secretary of State for Health and Social Care, dated 8 July 2021
01/09/2021	NHS Long Covid Taskforce Research subgroup meeting NHS Long Covid assessment clinics subgroup meeting	
02/09/2021	Letter of response from DHSC to Sajid Javid letter	Letter dated 2/09/21 from Juanita Rowan, Ministerial Correspondence and Public Enquiries Refers to NHS funding for Long Covid clinics but does not respond to questions re infection rates, updated symptoms etc.
09/09/2021	Email to Clinical Policy NHSE raising concerns about the appointment of National	Response dated 12/09/2021

	Specialty Advisor Graham Burns who had previously publicly stated that Long Covid was fueled by insomnia and anxiety	
23/09/2021	Ministerial Roundtable on Long Covid chaired by Sajid Javid, Secretary of State for Health and Social Care	
29/09/2021	NHS Long Covid Specialist assessment service subgroup meeting	
14/10/2021	Long Covid Support partnered with TUC regarding disability and Long Covid calling for Long Covid to be urgently recognised as a disability and Covid-19 as an occupational disease, to give workers access to legal protections and compensation	https://www.tuc.org.uk/news/tuc-calls-long-covid-be-urgently-recognised-disability-prevent-massive-discrimination
17/11/2021	NHS Post Covid National Taskforce Subgroup Your Covid recovery rollout, development and Long Covid rehabilitation	
24/11/2021	NHS Long Covid Specialist assessment service sub group meeting	
29/11/2021	Long Covid Support meet with Jeremy Hunt	Questions from Long Covid Support in advance of meeting
07/12/2021	Long Covid Support attended the Ministerial Roundtable on Long Covid chaired by NR Minister for Patient Safety and Primary Care	Long Covid Support questioned Graham Burns (Long Covid Specialty Advisor) on his repeated assertion attributing the condition to 'anxiety at the thought of never recovering as well as associated insomnia' as first stated at the Westminster Health Forum.
15/12/2021	NHS Long Covid Specialist assessment service subgroup meeting	
03/02/2022	NHS Long Covid Task force meeting	
March 2022	LC Support members gave evidence to the APPG Coronavirus report on Long Covid	Report March 2022
10/03/2022	Long Covid Support attended a Ministerial Roundtable on Long Covid, Chaired by Ed Scully Director of Primary Care and Community Health Services	Minutes of Meeting
16/03/2022	NHS Post Covid Specialist Services subgroup meeting	
22/03/2022	Long Covid Support were invited to present at Long Covid - improving patient care and	Westminster Health Forum

	access to support, progress in service development, and priority areas for research	
20/04/2022	NHS Post Covid Specialist Services subgroup meeting	
06/09/2022	Letter to Prime Minister from Long Covid Support regarding adopting measures to prevent spread of Covid-19	Letter dated 6/09/2022

Long Covid Support

Appendix 2:

List of Articles, Publications and Evidence to Committees that Long Covid Support has contributed to

January 2020 to Spring 2022

Date	Publication	Title	Quote/comments
5/05/20	BMJ Global Health	COVID-19: maintaining essential rehabilitation services across the care continuum May 2020	“Rehabilitation services, which optimise physical and cognitive functioning to reduce disability, are a core component of high-value care”
July 20	Physical Therapy and Rehabilitation Journal	Six Lessons for COVID-19 Rehabilitation from HIV Rehabilitation	“Rehabilitation is a fundamental health service within universal health coverage and enables greater participation in education, employment, and community life, with far-reaching health, social, and economic benefits”
05/08/20	Oral evidence to the APPG on Coronavirus. which helped to inform the Dec Interim Report	APPG Interim report on Coronavirus	Chapter 4 “The UK government is not counting the number of individuals who are left with long-lasting effects of <i>COVID-19</i> as a measure of the severity and impact of the pandemic; As a medical condition, Long Covid has not yet received full recognition, sufficient research funding or adequate rehabilitation support. There are very few guidelines for employers or for GPs on recognising and managing Long Covid”
September 20	BMJ Letters	From doctors as patients: a manifesto for tackling persisting symptoms of COVID-19	“Many patients who may, under normal circumstances, have been admitted to hospital instead managed their extremely difficult symptoms at home during this crisis. We should not assume that pathology is different between patients who were admitted to hospital and those who were not”
October 20	NIHR Review Living with Long Covid	NIHR Themed Review 1 - Living with Long Covid	“There is a widespread perception that people either die, get admitted to hospital or recover after two weeks. It is increasingly

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			clear that for some people there is a distinct pathway of ongoing effects. There is an urgent need to better understand the symptom journey and the clinical risks that underlie that. People, their families and healthcare professionals need realistic expectations about what to expect.”
December 20	BMJ Global Health	Characterising long-term COVID-19: a rapid living systematic review	“A significant number of people continue to describe ongoing symptoms long after the acute phase of COVID-19, often referred to as long COVID”
December 20	NICE	Covid 19 rapid guideline: Vitamin D- NICE Guideline (NG187) -	evidence from published literature on vitamin D supplementation for preventing or treating COVID-19
December 20	Lancet	COVID-19 rapid guideline: managing the long-term effects of COVID-19	“This guideline covers identifying, assessing and managing the long-term effects of COVID-19, often described as ‘long COVID’”
21/12/20	Lancet	https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)32705-7/fulltext	“Long Covid guidelines need to reflect lived experience throughout 2020 we also experienced other symptoms and conditions, never experienced before our acute illnesses (panel). All of these conditions began during, or shortly after, acute COVID-19. We each are experiencing different patterns and varied severity of symptoms; we all share difficulties accessing adequate health-care services; some of us have received misguided assessment and treatment in some of the UK's recently established long COVID clinics and encountered dismissive behaviour from some health professionals. ⁶ We share these experiences with thousands of people we engage with in rapidly growing online support groups.”
January 21	medrxiv	From SARS and MERS to COVID-19: a review of the quality and responsiveness of clinical management guidelines in outbreak settings	“To assess the responsiveness and quality of clinical management guidelines (CMGs) in SARS, MERS and COVID-19 and determine whether this has improved over time”

February 21	Website	https://www.longcovid.org/images/Documents/Long_Covid_is_policy_reaching_patients.pdf	People with Long Covid are desperate. Desperate to be seen, desperate to be listened to, desperate to be helped. There has been some progress to put in place support in parts of the UK, but this is not yet reaching large numbers of people, many of whom have lived with debilitating symptoms for a year and have seen their ability to work, study or care for others significantly impaired. This is the case even for the vast majority of people who were not admitted to hospital during the early weeks of their illness.
February 21	The Lancet Infectious Diseases	Long COVID: tackling a multifaceted condition requires a multidisciplinary approach - The Lancet Infectious Diseases	“Highlight the persistent, heterogeneous, and recurring symptoms of long COVID. A <i>Lancet</i> Editorial asks for better research and care to avoid years of struggle for individuals with long COVID.”
February 21	BMJ Leader	Leadership through crisis: fighting the fatigue pandemic in healthcare during COVID-19	“COVID-19 presents many challenges to healthcare systems internationally, none more so than the significant reporting among healthcare workers (HCWs) of occupational fatigue and burnout or Long COVID related symptoms.”
February 21	Journal of Orthopaedic and Sports Physical Therapy	Physical Therapists Living With Long COVID, Part 1: Defining the Indefinable	“Physical therapists have been vital to the international health care response to acute COVID-19 ³¹ and to managing the long-term sequelae of COVID-19, also known as "long COVID.”
February 21	Journal of Orthopaedic and Sports Physical Therapy	Physical Therapists Living With Long COVID, Part 2: When "Keep Pushing" Isn't the Answer	“Current guidance cautions against graded exercise therapy for people living with long COVID, following reports of adverse effects from exercise in people living with myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS).”
March 21	NIHR Themed Review 2	NIHR Themed Review 2 - Living with Long Covid	Whilst there is a growing list of symptoms associated with Long Covid, we know little about different clusters and patterns of symptoms (sometimes described as phenotypes, syndromes or clusters). There is increasing evidence of organ impairment in both people who were admitted to hospital and those who stayed at home. The limited evidence of correlation between past history and current pathology would suggest a need to

			investigate anyone with persistent symptoms, including those who were never admitted to hospital.
10/03/2021	Evidence to the Welsh Health Social Care and Sport Committee	Not available publicly	
29/03/21	Long Covid Support Employment Group	Collaboration with Society of Occupational Medicine to produce guidance for Employers and Employees on return to work	This leaflet offers guidance from Occupational Health (OH) Professionals on how managers can support workers to get back to work with ongoing symptoms following COVID-19 infection and Long COVID.
March 21	Long Covid Support Employment Group provided evidence to the health and safety executive report on return to work after long covid.	HSE report	This report aims to provide insight on the impact of long COVID on work and return to work. We know that some people recovering from COVID-19 still experience symptoms weeks or even months after their infection, which can impact on their daily functioning, including their ability to work
March 21	Long Covid Clinics survey updated report	Long Covid Assessment Services Patient Feedback	Updated analysis of data from our ongoing survey into patient experience of seeking referral to Long Covid clinics in England. There remain significant gaps in care, although a growing proportion of patients are securing referrals.
March 21	BMC Medicine	Research priorities for Long Covid: refined through an international multi-stakeholder forum	“While many who have been infected have uncomplicated recoveries, some have prolonged illness. Prolonged course of illness has been reported in adults and children and is affecting both those who were hospitalised with COVID-19 and those who were not”
March 21	preprints.org	Clinical Characteristics, Activity Levels and Mental Health Problems in Children with Long	Analysis of survey

		COVID: A Survey of 510 Children	
01/04/2021	BMJ Editorial	Fresh evidence on the scale and scope of long covid	As our understanding of the scale and scope of long covid improves, it is clear that sizeable populations of the UK and that the NHS will face a substantial burden due to additional morbidity and long-term conditions as a result of covid-19. The term long covid embraces a wide spectrum of organ involvement, with no clear evidence yet to help inform efficient diagnostic pathways or specific treatments or to indicate probable prognosis.
April 21	Long Covid Assessment Services Patient Survey report	https://drive.google.com/file/d/1QP8pVE75tiH8QKiFlu8XE5Is10etaeII/view	Survey
April 21	Journal of Orthopaedic and Sports Physical Therapy	Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome	“The term <i>long COVID</i> was coined by patients to describe the long-term consequences of COVID-19. One year into the pandemic, it was clear that all patients—those hospitalized with COVID-19 and those who lived with the disease in the community—were at risk of developing debilitating sequelae that would impact their quality of life.”
April 21	Chartered Society of Physiotherapists	Rehabilitation of adults who are hospitalised due to acute COVID-19 or long Covid: physiotherapy service delivery April 2021	Standards of rehabilitation
May 21	Long Covid Assessment Services Patient feedback	https://drive.google.com/file/d/1UFEUgw1LEOz4Jx_wGwknrtdGHt0TkZk9/view	Updated analysis of data from our ongoing survey into patient experience of seeking referral to Long Covid clinics in England. This presentation also includes feedback from our Facebook support group
June 21	TUC	Workers’ experiences of long Covid	Report on survey of workers’ experience of Long Covid

June 21	Long Covid Support Employment Working group submit written evidence to Work and Pensions Committee	https://committees.parliament.uk/writtenevidence/106644/pdf/	“17% of respondents to our survey had lost jobs via dismissal, resignation, redundancy or medical retirement, with a further 1.5% retired. 65% of respondents had not yet claimed any form of benefits. Of the people citing factors that stopped them applying, 46% were unsure if they were eligible and more than one in five found the process confusing and overwhelming. Consequently, some people with Long Covid are experiencing significant financial hardship”
July 21	Long Covid Clinics survey updated report added to RSM reading list	https://www.rsm.ac.uk/media/5475131/spotlight-on-long-covid-reading-list-9-july-21.pdf Show less	After Long Covid Support members participated in a film made by the Royal Society of Medicine, our clinics survey was included in this RSM reading list as part of the organisation's repository of resources on Long Covid.
August 21	The Lancet Regional Health	Long Covid in adults discharged from UK hospitals after COVID-19: A prospective, multicentre cohort study using the ISARIC WHO Clinical Characterisation Protocol	This study sought to establish the long-term effects of Covid-19 following hospitalisation.
September 21	BMJ Epidemiology and Community Health	Characteristics of Long Covid: findings from a social media survey	Report on social media survey
September 21	BMJ Global Health	Characterising long COVID: a living systematic review	“This study aims to regularly synthesise evidence on long COVID characteristics, to help inform clinical management, rehabilitation strategies and interventional studies to improve long-term outcomes”
October 21	Written evidence HAB0126	The Long Covid Support Employment Group submitted written evidence to the Work and	There are 1.3 million people living with Long Covid in the UK. Many of these people with Long Covid are facing significant financial hardship, either as individuals and/or as parents with

		Pensions Committee.HAB0126 - Health assessments for benefits (published May 2022)	children with Long Covid due to job loss * and the extra costs associated with having a long-term condition and disability. Therefore, timely and easy access to support to social security benefits is vital and delays and denials to such benefits are impacting on recovery, physical and mental health, and wellbeing
October 21	Shaping Future Support: The Health and Disability Green paper	Consultation response https://drive.google.com/file/d/1cDOOxiHLjDRn6P8knMztNHdbWVn8oUi6/view	Long Covid Support Employment Group have submitted a response to the Department for Work and Pensions, Shaping Future Support: The Health and Disability Green Paper consultation on 11th October 2021
October 21	Europe PMC	Long Covid and menopause - the important role of hormones in Long Covid must be considered	Abstract unavailable
November 21	Information Leaflet by Long Covid Support and Long Covid Kids	See leaflet	To educate the public on the symptoms of Long Covid, signpost to our support group and to seek medical help where necessary. The leaflet was produced by people with lived experience of Long Covid, including GP's and reviewed by the Patient Information Forum. Long Covid can be difficult to diagnose, and some people might not realise their symptoms could be linked to prior COVID-19 infection.
22/11/2021	Nature Journal	Understanding and tracking the impact of Long Covid in the United Kingdom	There are a wide range of outstanding research priorities, including defining long COVID, identifying its pathogenesis, describing its clinical presentation and health impacts, characterising the longer-term burden and predictive risk factors and developing clinical interventions
November 21	British Journal of General Practice	Recommendations for the recognition, diagnosis and management of Long Covid: a Delphi study	Recommendations were generated relating to the investigation and management of long COVID

November 21	Royal College of Occupational Therapists	RCOT Guides for Occupational Therapists working with People/Children with Long Covid	These guides outline the unique role of occupational therapists in supporting adults, children and young people to manage and recover from Long Covid.
November 21	The Lancet	Global surveillance, research, and collaboration needed to improve understanding and management of long COVID	“The scale of chronic ill health and disability after COVID-19 has been described as the next big global health challenge”
01/12/21	Response submitted by Long Covid Support Group to Department of Business Energy and Industrial Strategy consultation on flexible worked	Document not published - available upon request	
19/01/2022	Thorax	Joint patient and clinician priority setting to identify 10 key research questions regarding the long-term sequelae of COVID-19	Identification of resource and research efforts
February 22	Long Covid Support Group evidence to the Parliamentary Inquiry on health benefits	See Link	See evidence in link
February 22	BMC Medicine	Studying the post-COVID-19 condition: research challenges, strategies, and importance of Core Outcome Set development	“While the number of studies investigating the <i>post-COVID-19 condition</i> is increasing, there is no agreement on how this new disease should be defined and diagnosed in clinical practice and what relevant outcomes to measure.”

February 22	CIPD	Working with long COVID: research evidence to inform support	Guide to “inform support”
March 22	APPG on Coronavirus	Publication of APPG report on Long Covid	<p>Recommendations include: Long Covid is having a significant impact on the UK workforce and, as the UK response transitions from pandemic to endemic, then learning to live with Covid means living with Long Covid too. The APPG recommends that the UK Government add Long Covid to the existing list of considerations when making public health policy.</p>
March 22	CIPD	Working with Long Covid-Guidance to provide support	Guide to “inform support”
March 22	BMJ Open	Long COVID and episodic disability: advancing the conceptualisation, measurement and knowledge of episodic disability among people living with Long COVID - protocol for a mixed-methods study	“As the prevalence of Long COVID increases, there is a critical need for a comprehensive assessment of disability.”
April 22	MedRxiv	Protocol for mixed-method study by Long Covid Multidisciplinary consortium: Optimising Treatments and Services Across the NHS (LOCOMOTION)	“Long COVID, a new condition whose origins and natural history are not yet fully established, currently affects 1.5 million people in the UK. Most do not have access to specialist long COVID services”
May 22	The Lancet	Long COVID: aiming for a consensus	“The spectrum of signs and symptoms that can newly occur and persist for months to years after SARS-CoV-2 infection was initially named long COVID.”

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May 22	Medrxiv	Long Covid stigma: estimating burden and validating scale in a UK-based sample	“Long Covid is a predominantly multisystem condition that occurs in people with a history of SARSCoV2 infection, often resulting in functional disability.”
June 22	The BMJ	Comorbidities and COVID-19	“Better understanding is essential for health system planning”
June 22	Long Covid Support Employment Group	Claiming Personal Independence Payment (PIP) for people living with Long Covid	The Long Covid Support Employment Group together with Long Covid Occupational Therapists produced a guide on PIP
June-22	The Lancet Respiratory Medicine	A core outcome set for post-COVID-19 condition in adults for use in clinical practice and research: an international Delphi consensus study	“An international consensus study, which included a comprehensive literature review and classification of outcomes for post-COVID-19 condition that informed a two-round online modified Delphi process”
June-22	Personnel Today	https://www.personneltoday.com/hr/employers-long-covid-support/	Extract not available without log-in
June-22	GAVI	https://www.gavi.org/vaccineswork/long-covid-and-workplace-what-employers-could-do-better	Lesley Macniven, LCS interview



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Appendix 3 Media relating to Long Covid Support¹

Date	Publication	Link / Summary
08.04.20	Radio 4 Today	https://www.bbc.co.uk/news/business-52169825
05.08.20	APPG	https://www.youtube.com/watch?v=5osi_T7W8z0
05.08.20	The Guardian	https://www.theguardian.com/world/2020/aug/05/asleep-at-the-wheel-families-of-COVID-19-dead-lament-no-10-response
05.08.20	Channel 4 News	https://www.channel4.com/news/long-covid-sufferers-say-they-need-more-support
05.08.20	Telegraph	https://www.telegraph.co.uk/politics/2020/08/05/mps-hear-aftereffects-coronavirus-can-linger-months-cause-lasting/
06.08.20	The Week	https://www.theweek.co.uk/107329/coronavirus-damage-could-last-for-life
20.08.20	Sky News	https://news.sky.com/story/coronavirus-study-into-long-covid-finds-3-in-4-patients-suffering-symptoms-months-later-12052795
24.08.21	Granada News	https://www.itv.com/news/granada/2021-08-24/should-long-covid-be-recognised-as-a-disability
26.08.20	Times Radio	https://twitter.com/ClaireHastie1/status/1298721255080644608?s=20
15.09.20	Irish Times	https://www.irishtimes.com/life-and-style/health-family/covid-and-the-brain-this-has-taken-almost-everything-that-is-me-away-from-me-1.4343793

¹ Please note this list is not exhaustive; links are provided where available.

17.09.20	BBC South East Today	https://www.facebook.com/groups/longcovid/posts/716884342229230
25.09.20	Independent SAGE	https://www.facebook.com/watch/?v=1385201985204415
30.09.20	ABC	https://www.abc.net.au/news/2020-10-01/uk-long-COVID-19-survivors-form-group-to-discuss-symptoms/12701112
05.10.20	Mirror	https://www.mirror.co.uk/news/uk-news/nhs-recognise-long-covid-help-22797505
05.10.20	Westmorland Gazette	https://www.thewestmorlandgazette.co.uk/news/national/18771381.new-guidance-prevent-inconsistent-care-long-covid-patients/
05.10.20	Mirror	https://www.mirror.co.uk/news/uk-news/nhs-recognise-long-covid-help-22797505
07.10.20	Somerset Live	https://www.somersetlive.co.uk/news/uk-world-news/mum-who-coronavirus-six-months-4582633
08.10.20	BBC Radio 5 Live	
08.10.20	LBC	https://www.lbc.co.uk/radio/presenters/nick-ferrari/long-covid-cyclist-has-been-wheelchair-bound-with-symptoms-for-6-months/
14.10.20	BBC Five Live	
15.10.20	BBC World News	https://www.youtube.com/watch?v=yUXzPnuQQUs
15.10.20	ITV Central	https://twitter.com/ITVCentral/status/1316793178469605381?s=20

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15.10.20	ITV Central	https://www.itv.com/news/central/2020-10-15/long-covid-two-midlands-women-whose-lives-have-been-impacted-by-the-virus
15.10.20	The Times	https://www.thetimes.co.uk/article/long-covid-can-affect-even-those-who-had-virus-mildly-study-finds-0cb6k5k2t
24.10.20	Mirror	https://www.mirror.co.uk/news/uk-news/long-covid-sufferer-27-has-22900695
18.12.20	Sky News	https://twitter.com/SkyNews/status/133984353335773184?s=20
18.12.20	Sky News	https://news.sky.com/story/long-covid-sufferers-to-be-offered-help-at-more-than-60-clinics-in-england-12165947
18.12.20	Sky News	https://news.sky.com/video/im-yet-to-have-a-symptom-free-day-12166045
05.01.21	Daily Mail	https://www.msn.com/en-gb/news/courts/claire-hastie-and-lucille-whiting-talk-experience-of-long-covid/vp-BB1cvbBF
08.01.21	Times Radio	https://twitter.com/TimesRadio/status/1347663949010006019?s=20
14.01.21	Euronews	https://www.euronews.com/2021/01/14/long-covid-sufferer-speaks-of-constant-symptoms-and-struggles-since-contracting-virus-10-m
15.01.21	Independent	https://www.independent.co.uk/life-style/health-and-families/long-covid-symptoms-meaning-study-a9679876.html
18.01.21	LBC	https://www.lbc.co.uk/news/uk/nhs-increase-long-covid-clinics-to-69-for-hundreds-of-sufferers/
29.01.21	Independent SAGE	https://twitter.com/IndependentSage/status/1355200666977890305?s=20
22.03.21	BBC Radio WM	https://www.bbc.co.uk/programmes/p09bhj26
23.03.21	Guardian	https://www.theguardian.com/world/2021/mar/23/ive-lost-who-i-was-uk-pauses-to-reflect-on-year-of-covid?fbclid=IwAR0wB_rNy8b2Vyl14MQKlAUvLK9Okgo7iAjr3A0aQdqjaVtKDd3OCuyg1ec

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24.03.21	Channel 5 News	https://twitter.com/5_News/status/1374803240227909645?s=20
24.03.21	Channel 5 News	https://twitter.com/5_News/status/1374803240227909645?s=20
24.03.21	Channel 5 News	https://www.youtube.com/watch?v=QB41J5aU9Ww
24.03.21	Channel 5 News	https://twitter.com/5_News/status/1374803240227909645?s=20
01.04.21	LBC	https://twitter.com/LBC/status/1377679337734991876?s=20
01.04.21	Birmingham Mail	https://www.birminghammail.co.uk/news/midlands-news/locked-inside-herself-year-after-20297524
14.04.21	Times Radio,	
March 2021	BBC World News	
March 2021	BBC Local Radio	Carousel of interviews: BBC WM, BBC Cumbria, BBC Scotland, BBC 3 Counties, BBC Jersey and Guernsey, BBC Lancashire, BBC Devon, BBC Cornwall
March 2021	BBC Radio 4 Today	
April 2021	Slideshare	Occupational Therapy, Work, HR and Long Covid

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April 2021	You Tube – AHP Webinar	AHP Leader Webinar on Vocational Rehabilitation and Return to Work
May 2021	Podcast – You Tube	Return to Work Podcast
19.05.21	BBC Radio CWR	https://www.bbc.co.uk/programmes/p09hzmc9
09.06.21	Channel 5 News	https://twitter.com/clairehastie1/status/1402705576958861312?s=21
09.06.21	Nature	https://www.nature.com/articles/d41586-021-01511-z?fbclid=IwAR3gOA9Zc586M5ALC-MzNS7-p9R1O7lPSFCZ-IK5j1IJuzzQPsq3gAo9Nbk
09.06.21	Nature magazine	https://twitter.com/nature/status/1402632418008481804?s=21
15.06.21	Wimbledon Guardian	https://www.wimbledonguardian.co.uk/news/national/19372265.long-covid-services-launched-children/
15.06.21	Evening Standard	https://www.standard.co.uk/news/uk/nhs-england-ons-facebook-b940617.html
16.06.21	Sky	https://news.sky.com/story/COVID-19-nhs-to-launch-long-covid-services-for-children-12332812
16.06.21	The World PRI	https://www.pri.org/file/2021-06-16/patients-put-spotlight-post-covid-symptoms
18.06.21	Metro	https://metro.co.uk/2021/06/18/experts-unsure-if-jabs-will-stop-long-covid-but-hopes-grow-for-current-sufferers-14795425/

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18.06.21	CNN	https://edition.cnn.com/videos/world/2021/06/18/uk-children-COVID-19-vaccine-black-dnt-vpx.cnn?fbclid=IwAR0EghqFRUCaimusBBoBRWwZ8VQA5qZqgOnMSSeptemeberhdqSyXct9cqZqI7nVks
23.06.22	Scottish Business News	https://scottishbusinessnews.net/long-covid-and-mental-health-most-critical-issues-for-workplace-health/
01.07.21	Times Radio	https://m.youtube.com/watch?fbclid=IwAR37JDUyydeMj5OLMKZ6cUThfEkw_ZSDZAsOjocs474ONpS22WV27K-vne4&v=sUVIMAYnZuA&feature=youtu.be
05.07.21	Sky News	https://www.youtube.com/watch?v=F5jdiik2-vI
08.07.21	RSM webinar	https://twitter.com/stillillcorona1/status/1412722463004413953?s=20
08.07.21	Independent SAGE	https://www.pscp.tv/w/1DXxyRRWWYZKM?t=1h17m23s&fbclid=IwAR0MxCduKyPWDoDCsgUhQgQf2lu6Q8ORo7PZz1pjoz1JypvQcFFfXs6EDYg
15.07.21	Financial Times	https://www.facebook.com/claire.hastie.94/posts/10165512003420484
15.07.21	BBC News Channel	https://www.facebook.com/claire.hastie.94/posts/10165512003420484
19.07.21	Independent SAGE film	https://www.youtube.com/watch?v=3hplyCLO1qw
22.07.21	Al Jazeera	
28.07.21	ITV Meridian	
28.07.21	BBC South	

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10.08.21	The Guardian	https://www.theguardian.com/society/2021/aug/10/what-is-happening-to-me-teenagers-long-covid
10.08.21	German public radio	
20.08.21	The Times	https://www.thetimes.co.uk/article/long-covid-and-chronic-fatigue-your-questions-answered-qpv3xrwx
21.08.21	Mail on Sunday	https://www.dailymail.co.uk/health/article-9914951/Why-hard-patient-treatment-long-Covid.html
27.08.21	ITV North West	https://www.itv.com/news/granada/2021-08-24/should-long-covid-be-recognised-as-a-disability
27.08.21	Midlands Today	
09.09.21	The Guardian	https://www.theguardian.com/society/2021/Septemeber/09/i-found-myself-how-covid-pandemic-brought-out-the-best-in-people
10.09.21	Times Radio	
10.09.21	Times Radio	https://www.youtube.com/watch?v=NV2imAcZ7ac
12.09.21	The Independent on Sunday	https://www.independent.co.uk/news/health/long-covid-nhs-clinic-support-treatment-b1917924.html
19.09.21	Telegraph	https://www.telegraph.co.uk/health-fitness/body/truth-long-covid/
30.09.21	Metro	https://metro.co.uk/2021/09/30/children-should-get-two-jabs-to-prevent-them-getting-long-covid-15341618/?ito=socialmetrouktwitter

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30.09.21	Birmingham Mail	https://www.birminghammail.co.uk/news/midlands-news/russian-roulette-warning-over-long-21721751
October 2021	Queen Mary University	Long Covid and Work Podcasts with Professor Cathy Bulley
23.10.21	The Telegraph Magazine	https://twitter.com/TelegraphMag/status/1451785959163396100?s=20
25.10.21	Channel 5 News	https://twitter.com/5_News/status/1452682226848747523?s=20
23.10.21	New Scientist	https://twitter.com/ClaireHastie1/status/1453349896472481797?s=20
30.10.21	The Independent	https://www.independent.co.uk/news/health/long-covid-symptoms-treatment-job-b1947923.html
02.11.21	The Times	https://www.thetimes.co.uk/article/my-long-covid-agony-fatigue-pain-and-the-nhs-cant-help-7tnnljr8h
20.11.21	iNews	https://inews.co.uk/news/nhs-figures-reveal-a-huge-shortfall-in-long-covid-treatment-1310377
23.11.21	Channel 4 News	https://www.channel4.com/news/number-of-long-covid-cases-probably-beyond-current-capacity-of-nhs-says-professor
Nov 21	Each Other Independent Journalist	https://eachother.org.uk/how-does-sick-leave-protect-your-rights/
10.12.21	Independent	https://www.independent.co.uk/news/health/long-covid-nhs-staff-latest-omicron-b1973157.html
10.12.21	Times Radio	

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31.12.21	Chronicle	https://t.co/FIjdxk8y4K
30.12.21	BBC Good Morning Scotland	https://twitter.com/longcovidpod/status/1476920777844961290?s=21
05.01.22	Metro	https://metro.co.uk/2022/01/05/long-covid-sufferers-on-living-with-the-condition-for-two-years-15863358/
17.01.22	BBC Radio Kent	
28.01.22	Independent SAGE	https://twitter.com/longcovidadvoc1/status/1487505377969295364?s=21
28.01.22	5 News podcast	https://anchor.fm/5-news/episodes/I-never-had-an-illness-like-it-the-1-3-million-people-living-with-long-Covid-e1e7k65
February 22	The Financial Times	https://www.ft.com/content/33444f29-bab1-4655-85b5-c0b1f68d9653
March 2022	The Long Covid Podcast	The Aftermath of Leaving Work
05.03.22	The Times	https://www.thetimes.co.uk/article/inside-britains-long-covid-clinic-r7d5h0vhr
16.03.22	Global News (Canada)	https://twitter.com/jamiemauracher/status/1504255541719273472?s=21
19.04.22	The Independent	https://www.independent.co.uk/news/health/long-covid-disability-benefit-support-latest-b2046382.html

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April 22	The Financial Times	https://www.ft.com/content/8b9166af-2e85-4429-ab1f-362c189e46f2
May 22	BMJ Podcast	Sustainable return to nursing with Long Covid, advice from the experts
June 22	The Times	https://www.thetimes.co.uk/article/is-long-covid-to-blame-for-our-army-of-absent-workers-w8x0phsj6

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