

Written evidence submitted by LongCovidSOS (CBP0069)

LongCovidSOS, a patient advocacy group and [campaign](#), was established in June 2020 and is an important voice in the Long Covid community. Members of the team – all of whom are volunteers – are part of the NHS England Long Covid Taskforce, belong to the NICE Expert Panel on Long Covid and NIHR Expert Group on Long Covid and also perform advisory roles in NIHR-funded research projects. LongCovidSOS has worked closely with the WHO, the DHSC and the ONS in order to further their aims of ‘recognition, research and rehabilitation’ for this condition. The campaign has featured extensively in the press both in the UK and abroad. LongCovidSOS recently published the results of the largest [study](#) to date on Covid-19 vaccination and Long Covid. The campaign has written several [open letters](#) to government, [two](#) of [which](#) have been published in the British Medical Journal.

We were asked to submit evidence to this enquiry by a specialist member of the Committee

This submission will primarily consider the question **“To what extent is Long Covid contributing to the backlog of healthcare services? How can individuals suffering from long-covid be better supported?”** as well as responding to some of the other questions from the perspective of those living with Long Covid.

Introduction

According to the Office for National Statistics, as of 1st August 2021 ([ONS September bulletin](#)) 970,000 people were estimated to be living with Long Covid in the UK with symptoms following a Covid-19 infection lasting longer than 4 weeks. The [NICE guidelines on Long Covid](#) suggest that referral to an “integrated multidisciplinary assessment service” should be carried out any time from 4 weeks after the start of acute Covid-19. They advise that ‘appropriate’ support and management will be dependent on the extent to which symptoms impact people’s lives. The ONS estimate that for 643,000 people Long Covid symptoms impact their lives to some extent, and of these 188,000 are severely impacted. These figures can offer a guide as to how many people should ideally receive an appropriate biomedical assessment.

The same ONS bulletin calculated that of the 970,000 with Long Covid, 40% have had symptoms for at least 12 months. Although the size of this cohort has remained steady over recent months, we anticipate that as the anniversary of the second wave of infections in the UK approaches, it will grow significantly. Research suggests that sequelae from the first SARS epidemic resulted in many unable to return to work [two years](#) later; it may be some time before we arrive at accurate estimates of length of illness following SARS-CoV-2 infection.

We are currently in a period of very high infections sustained over a relatively long period. Many of those currently falling sick with Covid-19 are younger people who are unvaccinated. These members of society are those who are making a significant contribution to the economy and are expected to continue to do so for many years. This group also includes many children who are also [susceptible](#) to Long Covid. Earlier in the summer epidemiologists suggested that as many as [half a million young people](#) could develop Long Covid during this current ‘third wave’ and although the calculation was

based on higher projected daily Covid infection rates, if cases increase as predicted during the autumn these forecasts are likely to be accurate.

Pent-up demand for Long Covid services

Long Covid patients represent a huge unmet need, although quantifying it is challenging. Due to the difficulty many have had getting referred to the Long Covid clinics¹, which are only operational in England, and to specialists, many do not register as a number on any wait list. Below are some of the reasons for the hidden nature of this demand:

1. Lack of information for GPs as to which clinics are operational and where they are located
2. Problems experienced by GPs in making referrals – due to technological or administrative issues
3. GP referrals can be refused
4. A lack of appropriate diagnostics and assessment at many clinics which means that onward referral to specialists is not taking place for those who need it
5. Patients told pre-referral that they are not eligible for clinics and that they need to self-manage using the Your Covid Recovery (YCR) website or an app.
6. Patients told after a triage telephone appointment at a Long Covid clinic (often virtual) that they are to be discharged and treated remotely via online rehab, apps or YCR website
7. We have heard anecdotal claims that some are being denied Long Covid services due to the absence of antibodies to SARS-Cov-2. This contravenes NICE [guidance](#) and does not take into account [evidence](#) that a high proportion of people who are infected with Covid-19 do not seroconvert
8. We know of many Long Covid patients who have resorted to paying for private healthcare out of their own pockets

Unfortunately, as a voluntary organisation we do not at present have the resources to carry out the in-depth research needed to generate estimates of the numbers of people unable to access Long Covid services. NHS England is gathering data on patients who have been seen in the clinics and indicated that some information should be available in September but at the time of writing nothing has been published.

When considering the likely demand for care from Long Covid patients, it should be noted that there may be many people with sub-optimal health who do not associate their problems with a prior Covid-19 infection. Long Covid can manifest after a period of recovery from acute infection, and this could mean that a deterioration in a person's health is not attributed to Covid-19 sequelae, especially if the original disease was mild or even asymptomatic. We see evidence that Long Covid can [exacerbate](#) existing chronic illness and this deterioration could be put down to ageing or spontaneous illness progression by the person experiencing these changes as well as their GP. Those affected will nevertheless need more healthcare support than they did before they contracted Covid-19.

¹ or 'assessment services': these terms are used interchangeably

To what extent are the required resources in place, including the right number of staff with the right skills mix, to address the backlog?

When we first [campaigned](#) for recognition for those with Long Covid we asked for:

- *The development of protocols and care pathways to ensure that all practitioners are empowered to treat long-term Covid-19 patients appropriately*
- *The creation of multidisciplinary clinics in all parts of the UK for the assessment, testing, diagnosis and care of long-term Covid-19 patients*

A one-stop shop with a mix of specialties, professionals allied to healthcare and, importantly, a point of contact for the patient is what we would consider the benchmark for Long Covid care.

Interventions should be appropriate for the highly diverse needs of those suffering from this condition and should not put patients at risk. Many centres are far from providing this, and a number of issues raise concerns:

- Adherence to pathways developed and disseminated by NHS England seems to vary widely, resulting in a postcode-lottery in standards of assessment and care. We would like to see more collaboration between clinics so that best practice can be shared
- Patients who have symptoms that impact their daily lives are in some cases not being accepted into the assessment services and are instead being directed to online 'rehab' programmes and apps
- Some centres are referring patients to pulmonary rehab which includes goal-setting and graded exercise therapy, which can exacerbate symptoms and prolong illness (see below)
- Patients may be referred to IAPT or psychological services without thorough investigation of the causes of their symptoms. We have heard of cases where refusal to attend 'talking therapies' results in them being discharged from the system.
- Many services are not multi-disciplinary meaning that patients return to their GPs for onward referral and then join the existing specialist waitlists. Clinicians have expressed concern that patients should not be sent back and forth between different teams and but unfortunately it is frequently the case
- Long Covid services ought to be headed up by a qualified doctor, however we understand that this is not always the case
- Appropriate diagnostic tools required to establish the cause of symptoms (e.g. micro clotting, heart damage) are not available or offered at many centres and as a result patients are told there is no biomedical reason for their illness
- Huge numbers of people have been waiting for access to clinics for many months or sometimes more than a year during which time they have had to self-manage their symptoms, advocate or even fight for treatment, and then struggle to obtain a referral. This experience is exhausting, has been described by some as 'traumatic' and can lead to a deterioration in health. Patients have reported that, after eventually gaining access to a Long Covid assessment service, they find the experience of navigating the system profoundly bewildering, eventually leaving them in a position where they must once again co-ordinate their care themselves.

The Your Covid Recovery online tool and apps are useful for some patients, however goal-setting and graded exercise can exacerbate symptoms if they suffer from Post Exertional Malaise (PEM)

which is very common. Exercise is also [contraindicated](#) in patients who may have organ damage, e.g. myocarditis, which is also frequently found. Long Covid patients are likely to leave these programmes if they are unable to manage the exercises. Long Covid and ME patients have a similar problem with PEM, and NICE recently revised their [advice](#) on Graded Exercise for ME patients, although publication of the latest guidance has been delayed. Regrettably the NHS England [Long Covid Plan](#) includes 'exercise and education' as an example of rehabilitation and we have asked them to revise this.

Some clinics are providing an excellent service to those able to access them. UCLH, for example, leads the way in terms of multi-disciplinary assessment, an innovative approach to treatment and growing understanding of the needs of this group. There are others which similarly provide assessment and integrated ongoing care which is appropriate to the needs of Long Covid patients, although the lack of any evidence-based treatment protocols will limit the ability of medical staff to do much more than alleviate symptoms and help patients manage their recovery.

To what extent is the financial investment received to date adequate to manage the backlog?

There has been insufficient financial investment to date to cater for the needs of those with Long Covid: we hear of waiting times of six or more months before a patient can gain access to one of the assessment centres.

The data from ONS on Long Covid prevalence is invaluable and widely cited. However, the epidemic of long-term morbidity following the COVID-19 pandemic must also be quantified in terms of economic, societal, and healthcare costs. As far as we are aware, there have been no studies published which aim to determine the likely cost to the nation of Long Covid.

Our calculations suggest that the **minimum** assessment and most basic diagnostics for those 643,000 people who have symptoms which impact their daily lives, could cost **at least £520 million**, based on the NHSE [National Tariff](#) (see appendix). This is based on the assumption that assessment centres are operating as they should and following the standard set by UCLH. This estimate does not include referral to specialists or any advanced diagnostic tests, physiotherapy and other interventions. The healthcare burden is therefore likely to be significantly greater especially given the multi-system nature of Long Covid.

The true cost of Long Covid is many times higher. Most people with Long Covid are of working age, and studies suggest that [up to 67%](#) are either unable to work or cannot return to previous working hours. This percentage correlates closely with the proportion ONS found reporting that their symptoms impact daily life.

- Loss of income tax revenue and national insurance payments could be around **£2.4 billion per year** based on [average earnings](#) and [tax rates](#) (see appendix).
- This cost to the exchequer does not take into account the productivity loss to the economy as a result of this very large group of people being unable to contribute to the workforce as well as other related opportunity costs
- Benefits claims for loss of income, disability benefit and sick pay could add another **£1.25 billion** in Universal Credit payments.

- Other areas of concern are hidden costs such as those relating to social care: the burden of caring for relatives is likely to be too onerous for those who find their symptoms disabling and alternative sources of care will need to be found.
- The social care needs of older people with Long Covid, or those with existing disabilities or chronic illnesses are bound to increase.

We are aware that work is ongoing at the DHSC to calculate data for QALY loss and DALYs connected to post COVID illness. We anticipate that these data are likely to demonstrate the considerable burden that Long Covid places on people's lives and their ability to contribute to society

In our view people with Long Covid need to be treated early to avoid the development of chronic illness and wider societal and economic damage. Those who have been suffering for months need to be assessed as a matter of urgency. Steps need to be taken to prevent more people developing this condition; there is some evidence that [vaccination](#) may reduce prevalence but avoiding infection is the best approach. Research into early prevention and treatment is still in its infancy, and we have much to learn about the long-term repercussions of COVID-19.

Appendix

Calculation for minimum Long Covid assessment based on service provided by UCLH using NHSE National Tariff <https://www.england.nhs.uk/publication/national-tariff-payment-system-documents-annexes-and-supporting-documents/>

Intervention	Code/Description	No	Amt	Total
Outpatient appt	WF02B First Attendance - Multi Professional, respiratory medicine	1	£299.00	£299.00
Follow up	WF02A Follow-up Attendance - Multi Professional, respiratory medicine	1	£125.00	£125.00
	6 minute walk test - estimate	1	£50.00	£50.00
Stress test/ECG Holter	Electrocardiogram Monitoring or Stress Testing	1	£124.00	£124.00
Blood panel	Estimate from UCLH	1	£100.00	£100.00
X-ray		1	£26.00	£26.00
				£724.00
GP appointments		3	£30.00	£90.00
				£814.00
Estimated patients 'impacted'		643,000	Total:	£523,402,000.00

Calculations for loss of tax/NI revenue and Universal Credit payments

Average salary:	£29,900	source
Income tax	£3,464.20	source
NI payments	2,439.84	
Unable to work	188,000.00	
Loss of tax		£651,269,600.00
Loss of NI		£458,689,920.00
Work 50%	455,000.00	
Loss of tax		£788,105,500.00
Loss of NI		£555,063,600.00
Total		£2,453,128,620.00
If 50% of those impacted claim universal credit	321,500	
Source	£3 324.84/month	£ 1,253,232,720.00

References

LongCovidSOS website <https://www.longcovidsos.org/>

The Impact of COVID Vaccination on Symptoms of Long COVID. An International Survey of People with Lived Experience of Long COVID

https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3868856

Urgent SOS from Long Covid Sufferers

[https://3ca26cd7-266e-4609-b25f-](https://3ca26cd7-266e-4609-b25f-6f3d1497c4cf.filesusr.com/ugd/8bd4fe_e3779d8fa84c4c32bbd8ed43d70cd3cf.pdf?index=true)

[6f3d1497c4cf.filesusr.com/ugd/8bd4fe_e3779d8fa84c4c32bbd8ed43d70cd3cf.pdf?index=true](https://3ca26cd7-266e-4609-b25f-6f3d1497c4cf.filesusr.com/ugd/8bd4fe_e3779d8fa84c4c32bbd8ed43d70cd3cf.pdf?index=true)

The risk of long covid must be a primary consideration in policy decisions

<https://blogs.bmj.com/bmj/2021/01/12/the-risk-of-long-covid-must-be-a-primary-consideration-in-policy-decisions/>

We must take long covid into account when easing covid restrictions

<https://blogs.bmj.com/bmj/2021/07/06/we-must-take-long-covid-into-account-when-easing-covid-restrictions/>

Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 2 September 2021

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/2september2021>

COVID-19 rapid guideline: managing the long-term effects of COVID-19

<https://www.nice.org.uk/guidance/ng188>

The long-term impact of severe acute respiratory syndrome on pulmonary function, exercise capacity and health status

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7192220/>

Legacy of COVID-19 infection in children: long-COVID will have a lifelong health/economic impact

<https://adc.bmj.com/content/early/2021/05/27/archdischild-2021-321882>

Long Covid might strike half a million people during current wave, Neil Ferguson warns

<https://www.independent.co.uk/news/uk/politics/long-covid-uk-neil-ferguson-b1886076.html>

Predictors of Nonseroconversion after SARS-CoV-2 Infection

https://wwwnc.cdc.gov/eid/article/27/9/21-1042_article

Post COVID-19 Syndrome (“Long COVID”) and Diabetes: Challenges in Diagnosis and Management

<https://www.sciencedirect.com/science/article/pii/S1871402121002551>

World Physiotherapy response to COVID-19 Briefing paper 9

<https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf>

Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management

<https://www.nice.org.uk/guidance/cg53>

Long COVID: the NHS plan for 2021/22

<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/06/C1312-long-covid-plan-june-2021.pdf>

National tariff payment system documents, annexes and supporting documents

<https://www.england.nhs.uk/publication/national-tariff-payment-system-documents-annexes-and-supporting-documents/>

Characterizing long COVID in an international cohort: 7 months of symptoms and their impact

[https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(21\)00299-6/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext)

Average household income, UK: financial year 2020

<https://www.ons.gov.uk/peoplepopulationandcommunity/personalandhouseholdfinances/incomeandwealth/bulletins/householddisposableincomeandinequality/financialyear2020>

Estimate your take-home pay

<https://www.tax.service.gov.uk/estimate-pay-take-home-pay/>

Risk factors and disease profile of post-vaccination SARS-CoV-2 infection in UK users of the COVID Symptom Study app: a prospective, community-based, nested, case-control study

[https://www.thelancet.com/journals/laninf/article/PIIS1473-3099\(21\)00460-6/fulltext](https://www.thelancet.com/journals/laninf/article/PIIS1473-3099(21)00460-6/fulltext)

Universal Credit

<https://www.gov.uk/universal-credit/what-youll-get>

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