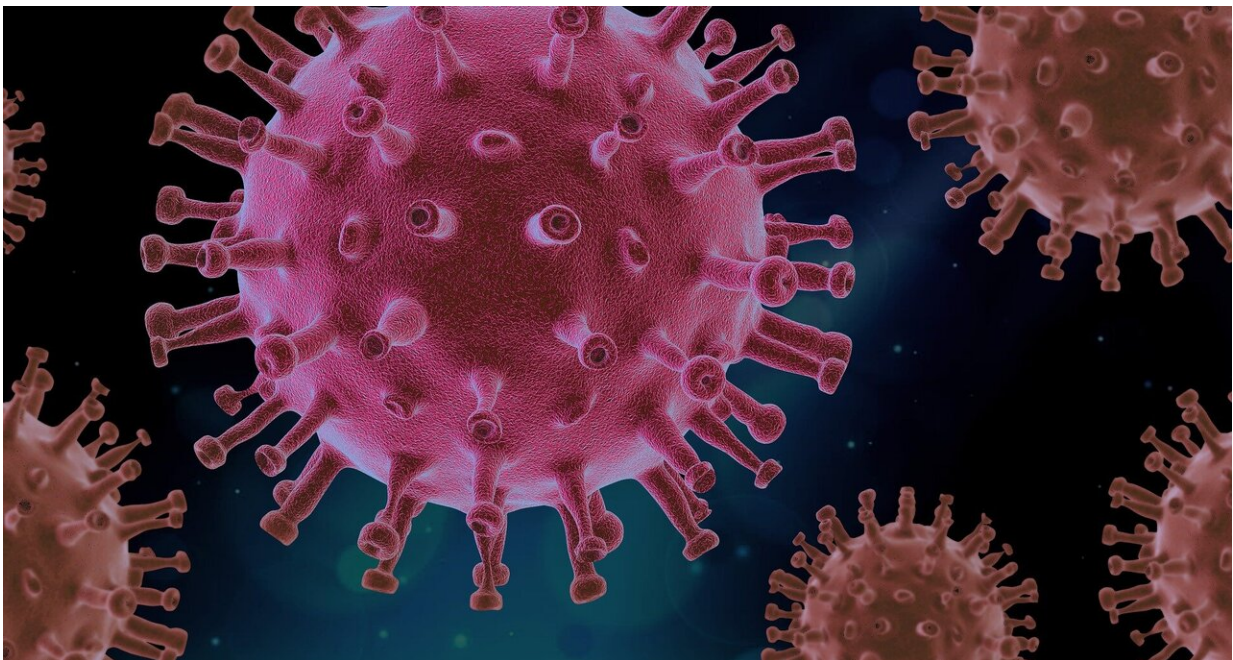


Identification of over 200 long COVID symptoms prompts call for UK screening programme

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Patients who experience long COVID have reported more than 200 symptoms across 10 organ systems, in the largest international study of 'long-haulers' to date, led by UCL scientists together with a patient-led research collaborative.

For the study, published in The Lancet's *EClinicalMedicine*, patient researchers who connected through the Body Politic online COVID-19 support group created a web-based survey designed to characterise the symptom profile and time course in patients with confirmed or suspected long COVID, along with the impact on daily life, work, and return to health.

With responses from 3,762 eligible participants from 56 countries, the researchers identified a total of 203 symptoms in 10 organ systems; of these, 66 symptoms were tracked for seven months. The most [common symptoms](#) were fatigue, post-exertional malaise (the worsening of symptoms after physical or mental exertion), and [cognitive dysfunction](#), often called brain fog.

Of the diverse range of symptoms, others included: visual hallucinations, tremors, itchy skin, changes to the menstrual cycle, [sexual dysfunction](#), heart palpitations, bladder control issues, shingles, memory loss, blurred vision, diarrhea, and tinnitus.

The research team, who have all had or continue to have long COVID, are now calling for clinical guidelines on assessing long COVID to be significantly widened beyond currently advised cardiovascular and respiratory function tests to include neuropsychiatric, neurological, and activity intolerance symptoms.

Furthermore, with large numbers of long haulers 'suffering in silence', the authors advocate that a national screening programme, accessible to anyone who thinks they have long COVID, should be undertaken. Given the heterogeneous (diverse) make-up of symptoms that affect multiple organ systems, it is only by detecting the root cause that patients will receive the correct treatment.

Explaining the study, senior author Dr. Athena Akrami (neuroscientist at

the Sainsbury Wellcome Centre at UCL) said: "While there has been a lot of public discussion around long COVID, there are few systematic studies investigating this population; hence relatively little is known about its range of symptoms, and their progression over time, the severity, and expected clinical course (longevity), its impact on daily functioning, and expected return to baseline health. In this unique approach, we have gone directly to 'long haulers' around the world in order to establish a foundation of evidence for medical investigation, improvement of care, and advocacy for the long COVID population. This is the most comprehensive characterisation of long COVID symptoms, so far."

The survey was open to those aged 18 or over who had experienced symptoms consistent with COVID-19, including those with and without positive SARS-CoV-2 test. It consisted of 257 questions.

In order to characterise long COVID symptoms over an extended duration, analysis of survey data was limited to respondents with illnesses lasting longer than 28 days and whose onset of symptoms occurred between December 2019 and May 2020, allowing analysis of symptoms from week one to month seven.

While the study did not estimate how common long COVID is overall, other studies have estimated that one in seven people have some symptoms 12 weeks after a positive test result (from the Office for National Statistics), or almost 30% of people 12 weeks after symptomatic disease (from Imperial College London's REACT study).

Survey summary

In this long COVID cohort, the probability of symptoms lasting beyond 35 weeks (eight months) was 91.8%. Of the 3,762 respondents, 3,608 (96%) reported symptoms beyond 90 days, 2,454 (65%) experienced

symptoms for at least 180 days (six months) and only 233 had recovered.

In those who recovered in less than 90 days, the average number of symptoms (11.4 out of 66 symptoms that were measured over time) peaked at week two, and for those who did not recover in 90 days, the average number of symptoms (17.2) peaked at month two. Respondents with symptoms over six months experienced an average of 13.8 symptoms in month seven. During their illness, participants experienced an average of 55.9 symptoms (out of the longer list of 203 measured in the study), across an average of 9.1 [organ systems](#).

89.1% of participants experienced relapses, with exercise, physical or mental activity, and stress as the main triggers. 45.2% reported requiring a reduced work schedule compared to pre-illness and 22.3% were not working at all at the time of the survey.

Dr. Akrami said: "For the first time this study shines a light on the vast spectrum of symptoms, particularly neurological, prevalent and persistent in patients with long COVID.

"Memory and cognitive dysfunction, experienced by over 85% of respondents, were the most pervasive and persisting neurologic symptoms, equally common across all ages, and with substantial impact on work.

"Headaches, insomnia, vertigo, neuralgia, neuropsychiatric changes, tremors, sensitivity to noise and light, hallucinations (olfactory and other), tinnitus, and other sensorimotor symptoms were also all common, and may point to larger neurological issues involving both the central and peripheral nervous system.

"Along with the well-documented respiratory and cardiovascular symptoms, there is now a clear need to widen medical guidelines to

assess a far wider range of symptoms when diagnosing long COVID. Furthermore, there are likely to be tens of thousands of long COVID patients suffering in silence, unsure that their symptoms are connected to COVID-19. Building on the network of long COVID clinics, which take GP referrals, we now believe a national programme could be rolled out into communities able to screen, diagnose and treat all those suspected of have long COVID symptoms."

The research team's future work will focus on emerging topics in long COVID: mental health outcomes, diagnostic and antibody testing, [symptom](#) clustering, and socioeconomic impact from the illness.

Study limitations

There are several limitations to this study. First, the retrospective nature of the study exposes the possibility of recall bias. Second, as the survey was distributed in online support groups, there exists a sampling bias toward long COVID patients who joined support groups and were active participants of the groups at the time the survey was published. Additionally, despite eight translations and inclusive outreach efforts, the demographics were strongly skewed towards English speaking (91.9%), white (85.3%) respondents.

Symptom prevalence—summary

Top three symptoms: Fatigue 98.3%, post-exertional malaise (PEM) 89.0%, and brain fog and cognitive dysfunction in 85.1% (3,203) of respondents.

The top three most debilitating symptoms listed by patients were: fatigue (2,652 patients), breathing issues (2,242), and cognitive dysfunction (1,274).

Symptoms remaining at six months

A total of 2,454 (65.2%) respondents were experiencing symptoms for at least six months. Over 50% experienced the following symptoms: fatigue (80%) post-exertional malaise (73.3%), cognitive dysfunction (58.4%), sensorimotor symptoms (55.7%), headaches (53.6%), and memory issues (51%). In addition, between 30%-50% of respondents were experiencing the following symptoms after six months of symptoms: insomnia, heart palpitations, muscle aches, shortness of breath, dizziness and balance issues, sleep and language issues, joint pain, tachycardia, and other sleep issues.

More information: *EClinicalMedicine* (2021). [DOI: 10.1016/j.eclinm.2021.101019](https://doi.org/10.1016/j.eclinm.2021.101019)

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