

Identification of over 200 Long COVID symptoms by patient-led research team prompts call for robust clinical guidelines

Researchers at the Patient-Led Research Collaborative and University College London identified over 200 Long COVID symptoms in the largest international study of Long COVID (Post-Acute Sequelae of COVID-19) to date.

The study, published in the Lancet's *EClinicalMedicine*, was conducted by a patient-research team through a web-based survey administered from September - November 2020. In patients who experienced symptoms from confirmed or suspected COVID-19 for at least 28 days, the team characterized the profile and time course of symptoms, as well as the impact of symptoms 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." Systemic, neurological, and cognitive symptoms were the most likely to persist from onset to month 7 of symptoms.

Particularly concerning was the impact of memory and cognitive dysfunction on daily life and ability to work, with over 70% having difficulty communicating their thoughts, and over 80% having difficulty working. Nearly 70% of those who were unrecovered reported reduced work hours or were unable to work at all.

While the majority of respondents were untested or tested negative for COVID-19, the symptom trajectories in this group were nearly identical to those in the positively-tested group, suggesting negative or absent PCR and antibody tests are not sufficient to rule out Long COVID.

The paper also highlighted less well-known Long COVID symptoms, including reproductive and menstrual changes, sensorimotor symptoms, and hearing and vision issues, indicating a need for further research and whole-patient rehabilitation.

The research team is now calling for the development of a robust set of clinical guidelines on assessing Long COVID which address symptoms from all organ systems. Additionally, the researchers urge all future research on Long COVID to build off these results and findings from research on related illnesses like ME/CFS, POTS, and MCAS.

Patient-Led Research Collaborative was formed through the Body Politic online COVID-19 support group in April 2020 and is composed of thirty patients with research, public policy, and clinical backgrounds who have all had or continue to have Long COVID. Through this unique approach combining interdisciplinary patient voices, the team has established a foundation of evidence for medical investigation, improvement of care, and advocacy for the Long COVID population, demonstrating the immense value of patient-led and patient-centered research.

More Information for Editors

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.

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.

Hannah E. Davis, Gina S. Assaf, Lisa McCorkell, Hannah Wei, Ryan J. Low, Yochai Re'em, Signe Redfield, Jared P. Austin, and Athena Akrami, '*Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact*', has been published in the Lancet's *EClinicalMedicine* on Thursday 15 July 2021, 10:00 (UK Time) / 05:00 (US Eastern Time).

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For more information or to speak to the researchers involved, please contact team@patientledresearch.com or visit <https://patientresearchcovid19.com/>.

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