

# New Definition for Long COVID Could Aid in Consistent Diagnosis, Documentation and Treatment

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A new National Academies of Sciences, Engineering, and Medicine <u>report</u> says the federal government, state and local authorities, clinicians, medical societies and organizations, public health practitioners, employers, educators, and others should adopt a new definition for "Long COVID" — that it is an infection-associated chronic condition that occurs after COVID-19 infection and is present for at least three months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.

Long COVID has profound medical, social, and economic consequences worldwide. While several working definitions currently exist, no common definition for Long COVID has been agreed upon. The lack of a consensus definition presents challenges for patients, clinicians, public health practitioners, researchers, and policymakers. For patients, varying presentations of the disease and competing definitions can lead to difficulties accessing medical care or obtaining support, skepticism and dismissal of their experiences, delayed or denied treatment, and social stigma.

Recognizing the need for broad input and an improved definition, the Administration for Strategic Preparedness and Response (ASPR) and the Office of the Assistant Secretary for Health (OASH) asked the National Academies to take up the issue of defining Long COVID. The committee that wrote the report <a href="mailto:engaged">engaged</a> more than 1,300 participants in its activities, with a focus on interdisciplinary dialogue and the patient perspective.

The report says the new Long COVID definition can be applied to many purposes — including clinical care and diagnosis; eligibility for health services, insurance coverage, disability benefits, and school or workplace accommodations; public health; social services; policymaking; epidemiology and surveillance; private and public research; and public awareness and education, especially for patients and their families and caregivers.

"The lack of a consistent definition for Long COVID has hampered research and delayed diagnosis and care for patients," said Harvey Fineberg, president of the Gordon and Betty Moore Foundation, and chair of the authoring committee. "Our committee hopes this single definition, crafted with input from across research and patient communities, will help to educate the public about this widespread and highly consequential disease state."

The report recommends OASH's Office of Long COVID Research and Practice and the Long COVID Coordination Council, comprised of 14 federal agencies, lead wide dissemination and implementation of the new definition. OASH should reexamine and update the definition for Long COVID in no more than three years, or when triggered by the emergence of new evidence — such as improved testing or changes in Long COVID demographic patterns or in special populations.

"Long COVID is a devastatingly persistent result of the COVID-19 pandemic that the medical community has yet to fully address," said Victor J. Dzau, president of the National Academy of Medicine. "Serving this patient population through better-coordinated care, more definitive diagnoses, and more efficient and streamlined research are important next steps for addressing its impact."

### **Full Definition**

Long COVID (LC) is an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least three months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.

LC manifests in multiple ways. A complete enumeration of possible signs, symptoms, and diagnosable conditions of LC would have hundreds of entries. Any organ system can be involved, and LC patients can present with:

- Single or multiple symptoms, such as shortness of breath, cough, persistent fatigue, postexertional malaise, difficulty concentrating, memory changes, recurring headache, lightheadedness, fast heart rate, sleep disturbance, problems with taste or smell, bloating, constipation, and diarrhea.
- Single or multiple diagnosable conditions, such as interstitial lung disease and hypoxemia, cardiovascular disease and arrhythmias, cognitive impairment, mood disorders, anxiety, migraine, stroke, blood clots, chronic kidney disease, postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), mast cell activation syndrome (MCAS), fibromyalgia, connective tissue diseases, hyperlipidemia, diabetes, and autoimmune disorders such as lupus, rheumatoid arthritis, and Sjögren's syndrome.

# Important features are:

- LC can follow asymptomatic, mild, or severe SARS-CoV-2 infection. Previous infections may have been recognized or unrecognized.
- LC can be continuous from the time of acute SARS-CoV-2 infection or can be delayed in onset

for weeks or months following what had appeared to be full recovery from acute infection.

- LC can affect children and adults, regardless of health, disability, or socioeconomic status, age, sex, gender, sexual orientation, race, ethnicity, or geographic location.
- LC can exacerbate preexisting health conditions or present as new conditions.
- LC can range from mild to severe. It can resolve over a period of months or can persist for months or years.
- LC can be diagnosed on clinical grounds. No biomarker currently available demonstrates conclusively the presence of LC.
- LC can impair individuals' ability to work, attend school, take care of family, and care for themselves. It can have a profound emotional and physical impact on patients and their families and caregivers.

### Attribution to Infection

Long COVID occurs after COVID-19 infection but does not require laboratory confirmation or other proof of the initial infection. The definition emphasizes that Long COVID can follow infections of any severity, including asymptomatic infections, whether they were initially recognized or not.

### Onset and Duration

The definition says symptoms should be present for at least three months, whether consistent or relapsing and remitting, for a Long COVID diagnosis to be made. Because there is still ambiguity regarding the relationship between the timing of COVID-19 infection relative to Long COVID onset, the committee chose not to include a maximum latency period.

## **Symptoms**

The definition does not list any symptoms or conditions as being required or any as being exclusionary. While some examples of specific symptoms are included in the definition, they are not meant to be exhaustive or to dismiss the significance of other symptoms or conditions. A complete enumeration of signs, symptoms, and diagnosable conditions of Long COVID would have more than 200 entries.

# Functional Impairment

The definition emphasizes that some individuals with Long COVID are severely affected and can have a variety of activity limitations. This can profoundly affect patients' and caregivers' lives and is an important feature of Long COVID.

# Equity

The report recognizes that socioeconomic factors, inequality, discrimination (based on race and gender, among others), bias, and stigma affect whether patients can receive a diagnosis and benefit from Long

COVID-targeted health care or services. These factors include but are not limited to access to COVID-19 testing during acute illness, access to evaluation for possible Long COVID, willingness of physicians to diagnose a particular patient, access to insurance benefits, and patients' fears of stigmatization that could result from having a Long COVID diagnosis.

### Further Research

A research agenda centered around improving the definition could focus on the key definition elements articulated in the report: attribution to infection, time, clinical features, equity, functional impairment, exclusions and alternative diagnoses, biomarkers and laboratory criteria, and risk factors.

Undertaken by the <u>Committee on Examining the Working Definition for Long COVID</u>, the study was sponsored by the Administration for Strategic Preparedness and Response and the Office of the Assistant Secretary for Health.

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