

Identifying Long COVID Based on Symptoms Reported by Adults in the RECOVER Study

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This research at a glance

Main Question

How was Long COVID identified in this study?

Were certain participants more likely to get Long COVID?

Answer

Researchers looked at 37 symptoms that participants who had COVID reported more often 6 months or more after having COVID compared to participants who never had COVID. Out of these symptoms, 12 symptoms could best identify participants with Long COVID, including feeling tired and unwell after activity, feeling weak and tired (fatigue), and brain fog (though there are people who have Long COVID who do not have these symptoms).

Yes. Participants who had Long COVID were more likely to have had COVID for the first time before December 2021 (before the Omicron variant), had it more than once, and not gotten a COVID vaccine.

This research brings us closer to identifying people with Long COVID based on symptoms. However, more research is needed before this can be used to treat patients.



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Why was this research needed?

Researchers want to better understand Long COVID, including its causes and potential treatment. Looking at symptoms in this study helped researchers identify people who may have Long COVID. Knowing more about the symptoms of Long COVID could also help to learn if certain groups of people are more likely to get Long COVID.

Long COVID is a condition in which a person is sick months after getting COVID. It can cause many new, ongoing, or returning symptoms. Researchers are still learning which symptoms are more common or happen together.

RECOVER has observational cohort studies in which large groups of participants answer survey questions and have checkups and tests. Researchers use the data to learn how COVID affects people over time. **Observational cohort studies** do not give participants a medicine or treatment for COVID or change their regular health care. Participants keep living their lives as usual and share their health information with researchers.

The goal of this research was to answer these questions:

- What are the identifying symptoms of Long COVID?
- Were certain participants more likely to get Long COVID?



What happened during this research?

Researchers used data from the RECOVER observational cohort study in adults ages 18 and over, including people who were pregnant.

The researchers looked at:

- Symptoms participants reported in surveys
- If and when they had COVID
- How many times they had COVID
- If they had gotten a COVID vaccine

Whose data was included in this research?

This research included about 10,000 participants who joined the RECOVER adult study before April 10, 2023. Participants had at least one study visit and had taken a survey about their symptoms. This included:



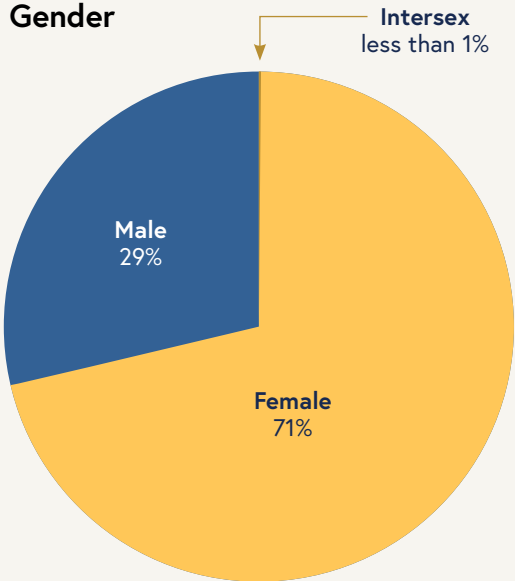
About 1,000
participants who never had COVID (uninfected)



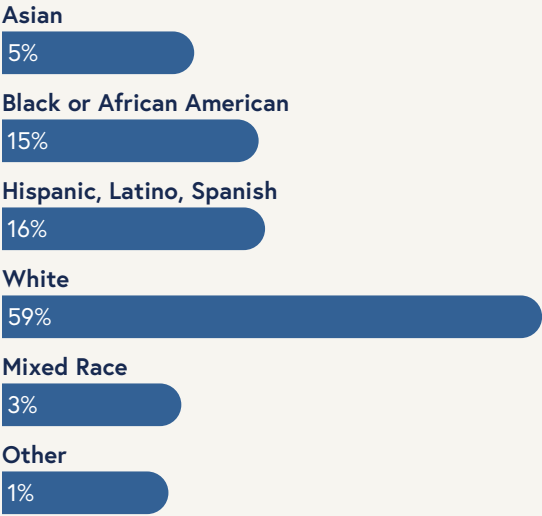
About 9,000
participants who had COVID before they joined the study

The participants' average age was 47.

Gender



Race and Ethnicity





What were the main results?

What were the identifying symptoms of Long COVID?

There were 37 symptoms that participants who had COVID reported more often 6 months or more after having COVID compared to participants who never had COVID. The symptoms affected many different body parts.

Out of the symptoms, 12 could best identify participants with Long COVID (though there are people with Long COVID who do not have these symptoms). The 12 symptoms were:



Feeling tired and unwell that gets worse after physical or mental activity (post-exertional malaise)



Loss of sexual desire or ability



Feeling weak and tired (fatigue)



Loss of, or change in, taste or smell



Brain fog



Feeling thirsty



Dizziness



Long-term (chronic) cough



Symptoms that affect the stomach and digestion (gastrointestinal symptoms)



Chest pain



Fluttering or pounding heartbeats (palpitations)



Unusual movements (abnormal movements)

Out of all 9,000 participants who had COVID, 23% (about 2,000 participants) got Long COVID based on symptoms they reported 6 months or more after having COVID.

Were certain participants more likely to get Long COVID?

Yes. Participants who had Long COVID were more likely to have:

- Had COVID for the first time before December 2021 (before the Omicron variant)
- Had COVID more than once
- Not gotten a COVID vaccine

More research is needed to know who is more likely to get Long COVID and the reasons why.



How has this research helped?

This study used symptom scoring to identify people who may have Long COVID. This is important because currently, there is no definition that researchers can use to identify Long COVID. A definition could help future research and treatment.



Where can I learn more about this research?

Read the full paper published in The Journal of the American Medical Association (JAMA) in May 2023 at:

<https://bit.ly/symptomspaper>

Full paper title: Development of a Definition of Postacute Sequelae of SARS-CoV-2 Infection: RECOVER Adult Cohort Study

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About RECOVER

RECOVER is a research project that aims to learn about the long-term health effects of COVID. We're hopeful that this project will help us better prevent and treat Long COVID in the future. RECOVER is paid for by the National Institutes of Health (NIH).

Learn more at: RECOVERcovid.org