

It's especially important that people of color participate in this research. All of the people below are more likely than white people to need a hospital for health conditions related to COVID-19.

- **American Indian or Alaska Native: 3.1x more likely**
- **Black or African American: 2.4x more likely**
- **Hispanic or Latino: 2.3x more likely**
- **Asian American or Pacific Islander: 0.8x more likely**

Other people may be more at risk for Long COVID due to the same circumstances or health inequities that put them at high risk for COVID-19. These groups include:

- **Older adults**
- **People with disabilities**
- **People with lower incomes**

### **Research volunteers are more protected than ever before**

Mistrust and other barriers to participation have kept many people, including those in the communities hardest hit by the pandemic, from volunteering for research studies. Although the mistrust has been earned — through historical injustices and exclusions from research in the past — including people from every community is very important. It gives us better information about how drugs or vaccines work for different people. Today, volunteers' rights and well-being are protected when they volunteer for a research study.

Researchers are required to protect personal information but cannot reduce risks to zero. All studies funded by the U.S. government, including RECOVER, have several groups that watch over the research. Every study goes through careful review at each phase: before, during, and afterwards. These reviews

include independent reviewers, some of them patients, who are separate from the people conducting the studies and make the safety and well-being of participants the top priority.



Read more about some of the people working to protect research participants and make research studies as safe as possible at every step along the [Scientific Pathway to COVID-19 Research](#) (from CEAL).



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Learn more about the RECOVER Initiative and its research studies at [recovercovid.org](https://recovercovid.org).

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PATIENT RESOURCE

LONG COVID-19/PASC

## Long COVID DESCRIPTION AND RESEARCH EFFORTS



As many as 23 million Americans may have symptoms of Long COVID. Many are unaware that their symptoms were brought on by a COVID-19 infection.

You can help education your friends and family by sharing this information with them. Encouraging them to participate in research studies about Long COVID will help us all learn more about this long term affect of COVID.



## What is Long COVID?

Long COVID is defined as signs, symptoms, and conditions that continue or develop after initial infection with SARS-CoV-2 (the virus that causes COVID-19).

Long COVID may also be called:

- Long-haul COVID-19
- Post-COVID-19 conditions
- Chronic COVID-19
- PASC, or Post-acute sequelae of SARS-CoV-2

It affects people for weeks, months, or even longer after getting COVID-19. People may have difficulty carrying out daily activities because of their symptoms. Roughly 1 million people are out of the workforce at any given time due to Long COVID.

## What are common symptoms?

- Feeling weak and tired
- Trouble breathing
- Trouble thinking
- Fast-beating or pounding heart
- Trouble sleeping
- Headache
- Fever
- Feeling anxious or depressed

Symptoms may:

- Start soon after infection or after recovery from COVID-19 come and go
- Be different than the symptoms of COVID-19
- Go away with time

Some people who didn't feel sick when they first got infected may still go on to develop Long COVID.

Long COVID does not affect everyone the same way. We are only beginning to understand the nature of the symptoms. Long COVID may include some well-known illnesses related to COVID-19 such as heart inflammation, lung damage, or diabetes. Health care providers can follow known medical approaches to treat these illnesses.

## Who is more likely to get Long COVID?

Scientists are working to answer this question. They think people are more at risk if they:

- Had severe COVID-19, for example, if they were sick enough to be hospitalized
- Had other health conditions such as diabetes or a lung condition before getting COVID-19
- Did not get a COVID-19 vaccine

## How can Long COVID be prevented?

The best prevention is to avoid getting COVID-19 in the first place. Vaccination lowers the chances of getting COVID-19 and then getting Long COVID. People should also take other steps to avoid COVID-19, like wearing a mask indoors in areas with high [CDC COVID-19 Community Levels](#).

Find [more information on services and support](#) for Long COVID.



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## LONG COVID RESEARCH

### Volunteers can help scientists understand Long COVID

The Researching COVID to Enhance Recovery (RECOVER) Initiative aims to understand, prevent, and identify treatments for Long COVID. RECOVER can help us understand how many people have Long COVID, who is at risk, and why some people recover while others do not.

Anyone can help us learn more about Long COVID by volunteering to participate in RECOVER research studies. This includes people with Long COVID, as well as people who currently have COVID-19, people who had COVID-19 in the past, and people who have never had COVID-19. [Recovercovid.org](https://recovercovid.org) has more about how to join studies.

### Diversity in Long COVID research

It is important that people from all walks of life participate in research. To better understand how Long COVID affects different people, studies need to include volunteers of all:

- Races and ethnicities
- Genders
- Ages
- Jobs, education levels, and incomes
- Health conditions
- U.S. locations

