



Where Are We Now, and Where are We Going?

Marshall L. Post, BHS, RRT
MarshallpostRRT@gmail.com

Kansas Respiratory Care Society
September 22, 2023



PCC

LONG
COVID

CHRONIC
COVID

PASC

LONG-HAUL
COVID

As of mid-September,
over **770 million**

people around the world have had COVID. It's possible that millions of them could have long-term health effects.



A BRIEF



OF LONG-COVID

April 2020

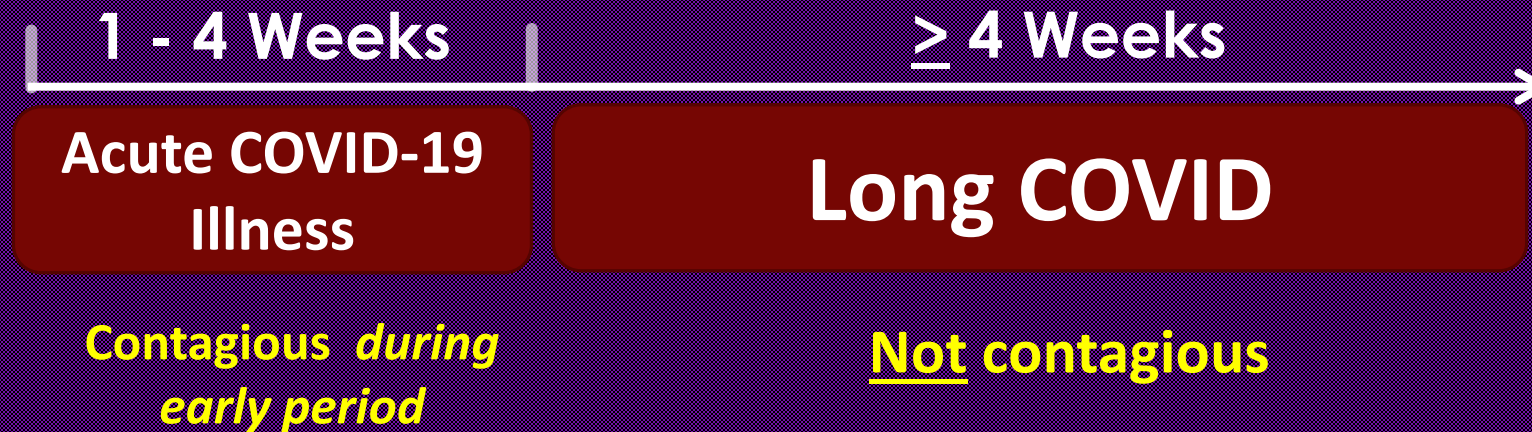
- ▶ Anecdotal reports from patients who were not fully recovering from an infection with COVID-19, and the term “Long COVID” was coined
- ▶ President Biden issued the Memorandum on Addressing the Long-Term Effects of COVID-19 outlining actions needed to support the American people in addressing the longer term effects of COVID-19
- ▶ U.S. Census Bureau Pulse Survey instituted (First landmark survey cataloguing breadth of symptoms experienced by people with Long COVID)

November 2020

- ▶ Post-COVID-19 Conditions (PCC) conceptually first described by CDC

Broad Definition

Signs, symptoms, and conditions that continue or develop after acute Covid-19 (SARS-Cov-2) infection



Broad Definition

Signs, symptoms, and conditions that continue or develop after acute Covid-19 (SARS-Cov-2) infection

Requires two criteria:

- Prior COVID-19 illness (confirmed or presumed)
- Lingering symptoms or health effects (>4 weeks)

2021- Present

- **Controlled Large scale studies provide a detailed systematic characterization of the condition**
 - **Researching COVID to Enhance Recovery (RECOVER), NIH Initiative formed February 2021**
 - **Innovative Support For Patients with SARS-CoV-2 Infections (INSPIRE), CDC funded study with multiple academic and health systems**
- **July 2021, Long COVID was added as a recognized condition that could result in a disability under the Americans with Disabilities Act (ADA). Learn more: Guidance on “Long COVID” as a Disability Under the ADA**

U.S. CENSUS BUREAU *HOUSEHOLD PULSE SURVEY*

- **20-minute online survey designed to study the coronavirus pandemic and other emergent issues from a social and economic perspective**
- **Collects real-time data on how people's lives have been impacted by the COVID-19 pandemic to guide federal and state response and recovery planning**

Data collections phases

Phase 1: April 23, 2020 - July 21, 2020

Phase 2: August 19, 2020 - October 26, 2020

Phase 3: October 28, 2020 - March 29, 2021

Phase 3.1: April 14, 2021 - July 5, 2021

Phase 3.2: July 21, 2021 – October 11, 2021

Phase 3.3: December 1, 2021 – February 7, 2022

Phase 3.4: March 2, 2022 – May 9, 2022

Phase 3.5: June 1, 2022 – August 8, 2022

Phase 3.6: September 14, 2022 – November 14, 2022

Phase 3.7: December 9, 2022 – February 13, 2023

Phase 3.8: March 1, 2023 – May 8, 2023

Phase 3.9: June 7, 2023 – August 7, 2023

Phase 3.10: August 23, 2023 – October 30, 2023

Included questions about the presence of symptoms of COVID that lasted three months or longer

Long COVID

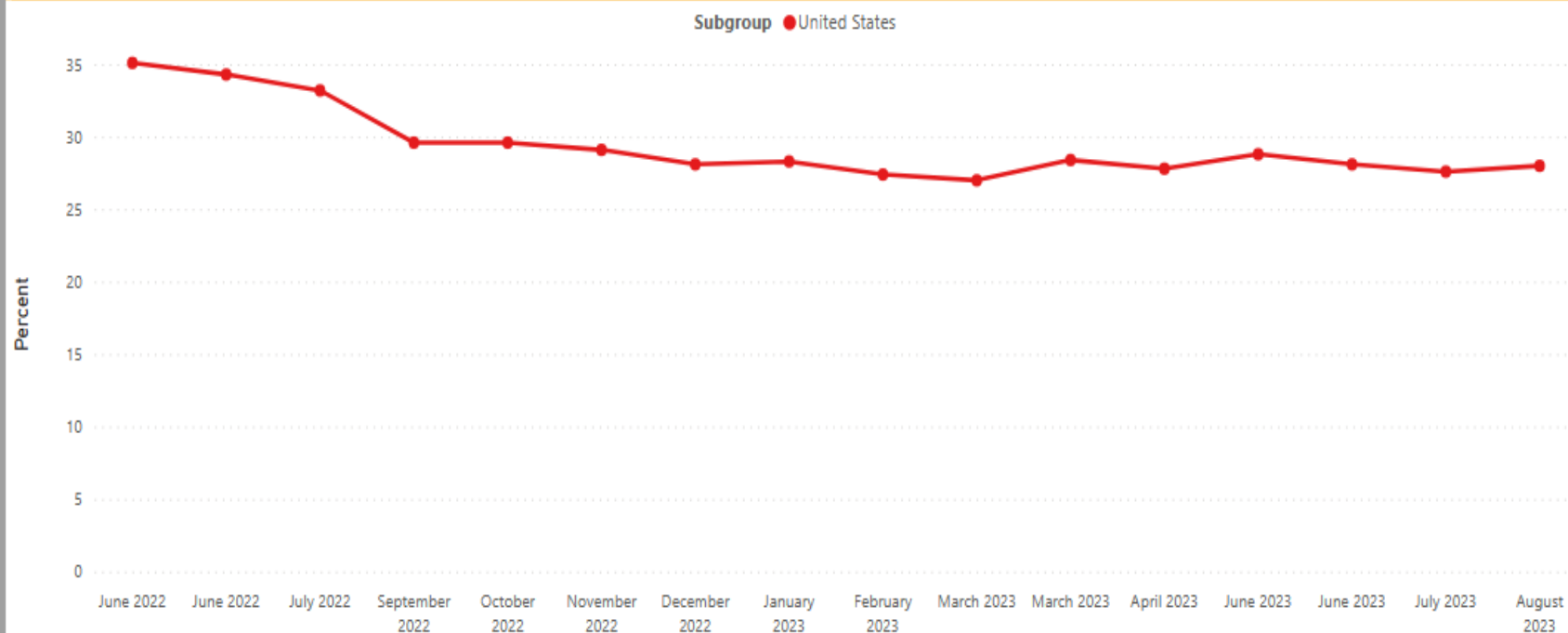
Select Indicator

Ever experienced long COVID, as a percentage of adults who ever had COVID

Select Group

National Estimate

Ever experienced long COVID, as a percentage of adults who ever had COVID



NOTE: All estimates shown meet the NCHS standards of reliability. See Technical Notes below for more information about the content and design of the survey.

SOURCE: U.S. Census Bureau, Household Pulse Survey, 2022-2023

Data Table

National Estimates

State Estimates

[Long COVID - Household Pulse Survey - COVID-19 \(cdc.gov\)](https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm)

Sept. 14-26, 2022

National Est. = 29.6%

Kansas Est. = 33.5% (13TH)

Mar. 1-13, 2023

National Est. = 27%

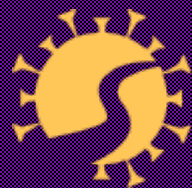
Kansas Est. = 27.9% (24TH)

Aug. 23 - Sept. 4, 2023

National Est. = 28%

Kansas Est. = 27.3% (13TH)

National Center for Health Statistics. U.S. Census Bureau, Household Pulse Survey, 2022-2023. Long COVID. Generated interactively: from <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>



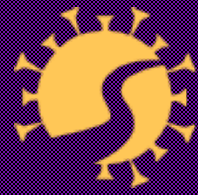
RECOVER

Researching COVID to Enhance Recovery

**\$1.15 billion Initiative
funded by The National
Institutes of Health (NIH)
over 4 years**



recoverCOVID.org



RECOVER

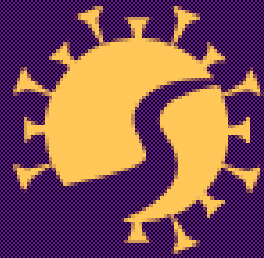
Researching COVID to Enhance Recovery

SCIENTIFIC AIMS

- Understand the range of recovery and changes in our bodies over time
- Define risk factors, number of people getting Long COVID, and if there are specific, different Long COVID types
- Study how Long COVID progresses over time and how that may relate to other illnesses
- Identify possible treatments to help with Long COVID symptoms



recoverCOVID.org



RECOVER

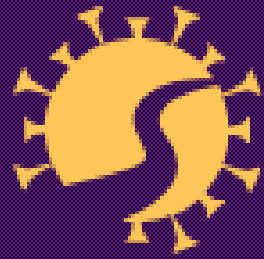
Researching COVID to Enhance Recovery

Studies are currently ongoing at multiple academic and healthcare systems and are trying to find out:

- **How many people may have long-term effects from COVID**
- **What their symptoms are**
- **How the effects occur in the body and how COVID affects body tissues**



recoverCOVID.org

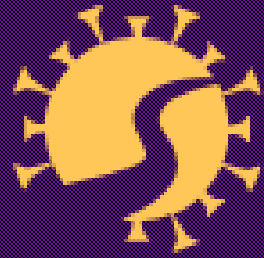


RECOVER

Researching COVID to Enhance Recovery

Research Process

- Observational cohort and clinical trial studies of **adults (Goal=12,580)**, **pregnant people (Goal=2300)**, and **children (Goal=19,300)** at clinical trial sites across the United States
- ALL participants are enrolled in studies on a voluntary basis only
- In initial studies, Participants do not receive any treatment for Long COVID (Later studies address treatments)



RECOVER

Researching COVID to Enhance Recovery

First Research Summary published May 23, 2023

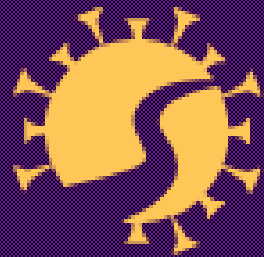
Participants: (Adults Only)

Have had COVID = 8,646

Have not had COVID = 1,118

9,764

(Study is still ongoing at Multiple institutions)



RECOVER

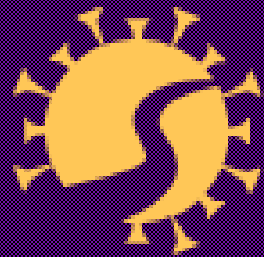
Researching COVID to Enhance Recovery

First Research Summary published May 23, 2023
(Adult Participants only)

Goal: To answer these questions

What are the identifying symptoms of Long COVID?

Were certain participants more likely to get Long COVID?



RECOVER

Researching COVID to Enhance Recovery

First Research Summary published May 23, 2023

(Adult Participants only)

How 'Long COVID' was identified in this study

- 37 symptoms (affecting many body parts) that participants who had COVID recorded more often 6 months or more after having COVID compared to participants who never had COVID
- Out of these symptoms, **12** could best identify participants with Long COVID (though there were people with Long COVID who did not have these symptoms)

12 symptoms best identified by Participants with Long COVID



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



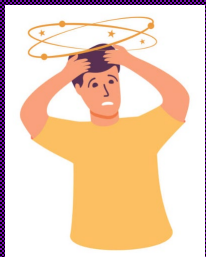
Brain
Fog



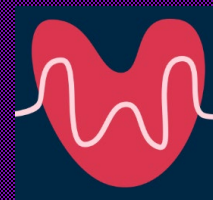
Feeling
weak and
tired



Gastrointestinal
Symptoms



Dizziness

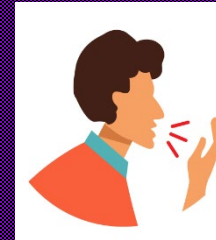


Pounding or
fluttering
heartbeats
(palpitations)

12 symptoms best identified by Participants with Long COVID (cont)



**Loss of sexual
desire or ability**



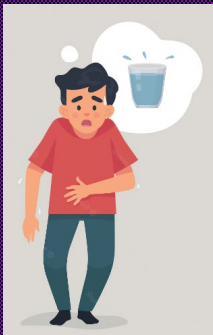
**Long-term
(chronic)
cough**



**Loss of, or
change in,
taste or smell**



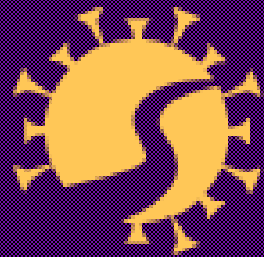
Chest Pain



**Feeling
Thirsty**



**Unusual
(abnormal)
movements**

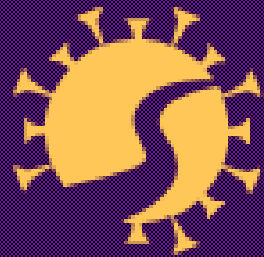


RECOVER

Researching COVID to Enhance Recovery

Main Question #2

Were certain participants more likely to get Long-COVID in this study?



RECOVER

Researching COVID to Enhance Recovery

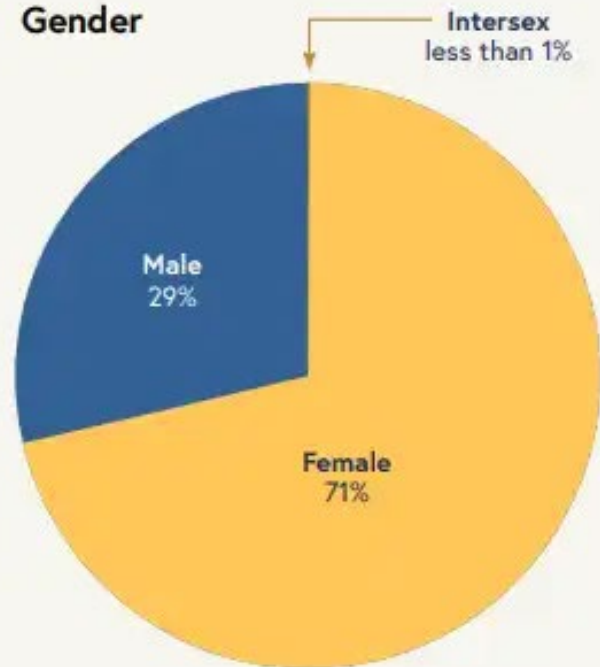
First Research Summary published May 23, 2023*

**Adult Participants only*

Participants had at least one study visit and had taken a survey about their symptoms

The participants' average age was 47.

Gender



Race and Ethnicity

Asian

5%

Black or African American

15%

Hispanic, Latino, Spanish

16%

White

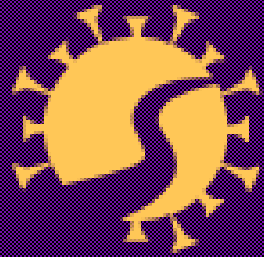
59%

Mixed Race

3%

Other

1%



RECOVER

Researching COVID to Enhance Recovery

Researchers found that:

- *Long COVID* (as measured by this study's scoring system) was more common in participants infected in the pre-Omicron era (2021)
- Those who had covid *pre-Omicron* were more likely to have *severe cases of Long-COVID*
- *Long COVID* was more common in those who were unvaccinated at the time of infection
- Reinfections were linked to higher *Long COVID* frequency and severity



National Institutes of Health
Researching COVID to Enhance Recovery

Some groups and communities are more likely to go to the hospital for health issues related to COVID-19.

AMERICAN INDIAN OR ALASKA
NATIVE

2.5

times more likely
to go to the
hospital

BLACK OR AFRICAN AMERICAN

2.1

times more likely
to go to the
hospital

HISPANIC OR LATINO

1.9

times more likely
to go to the
hospital

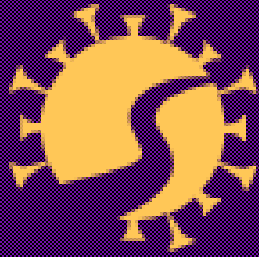
ASIAN

0.7

times more likely
to go to the
hospital

WHY?

- People don't have equal access to health care and information about COVID
- Some people live or work in places where they are more likely to catch COVID-19



RECOVER

Researching COVID to Enhance Recovery

Phase 2 Clinical Trials begun July 31, 2023

- Enrollment opened for clinical trials that will evaluate at least four potential treatments for long COVID
- Trials will focus on several of the symptoms described as most burdensome by people experiencing long COVID
- Additional clinical trials to test at least seven more treatments expected in the coming months



Innovative Support For Patients with SARS-CoV-2 Infections Registry (INSPIRE), CDC funded study with multiple academic and health systems

GOAL

Study to understand long-term effects of COVID-19 infection



METHOD

Participants complete online surveys (Adults only) and share their medical information via a secure personal health platform every three months for 18 months

PARTICIPANT REQUIREMENTS

- 18 years of age or older
- Have had suspected symptoms of Covid-19 within the last 6 weeks
- Tested for Covid-19 within the last 6 weeks (regardless of test result)*
- Have access to computer device, tablet, or smart phone

*Participants should not have a previously confirmed COVID-19 diagnosis outside the 42-day testing period or in the months prior to study enrollment.

Updated July 2023

- **There is no single test that determines if symptoms or conditions are due to COVID-19**
- **While most people with *Long COVID* have evidence of infection or COVID-19 illness, in some cases, a person with *Long COVID* may not have tested positive for the virus or known they were infected**
- ***Long COVID* occurs more often in people who had severe COVID-19 illness, but anyone who has been infected with the virus that causes COVID-19 can experience it (either diagnosed or undiagnosed)**
- **It is possible to be reinfected with SARS-CoV-2 multiple times**

Updated July 2023

- **Each time a person is infected or reinfected with SARS-CoV-2, there is a risk of developing Long COVID**
- **May present with relapsing-remitting pattern and progression or worsening over time, and with possibility of severe and life-threatening events months or years after infection**
- **May develop or continue to have symptoms that are hard to explain and manage**
- **People who are not vaccinated against COVID-19 and become infected may have a higher risk of developing *Long COVID* compared to people who have been vaccinated**

<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/>



Important Take Home Messages

1. **Post-COVID conditions are heterogeneous – Standard surveillance methods may not capture all disease – Epidemiologic studies must characterize different phenotypes, risk factors, and biomarkers**
2. **Studies will be ongoing for a currently unspecified period of time**
3. **Management of post-COVID conditions will require consistent engagement with patients and continued collaboration**
4. ***Post-COVID conditions will remain a public health concern into the future – Follow-up times will be measured in years, not weeks or months***

Resources

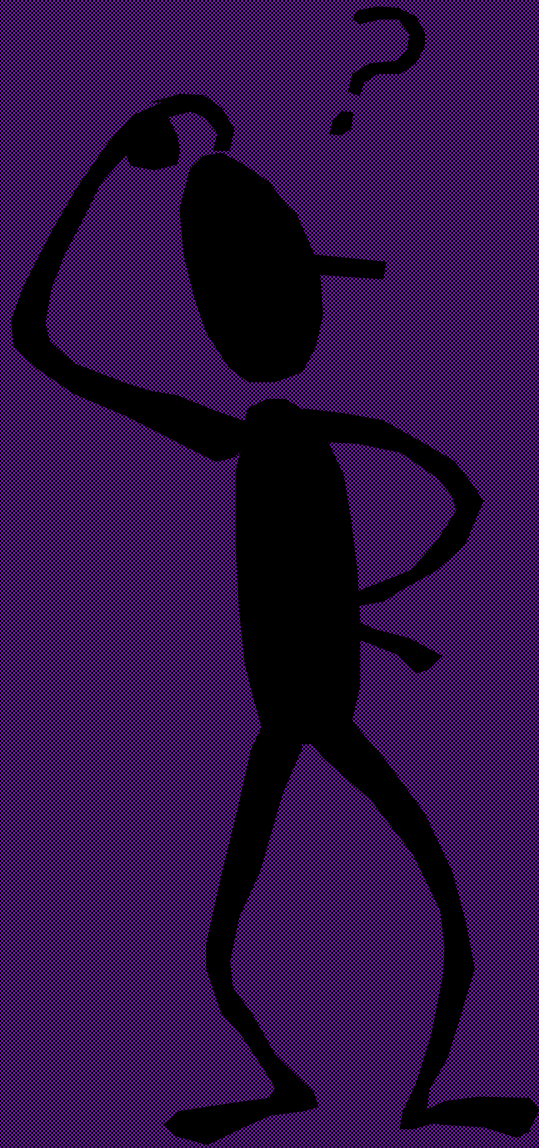
COVID.gov – Find Covid–19 guidance for your community. Published 2023. Accessed September 20, 2023. <http://covid.gov>

Horwitz LI, Thaweethai T, Brosnahan SB, et al. “*Researching COVID to Enhance Recovery (RECOVER) Adult Study Protocol: Rationale, Objectives, and Design.*” Published online June 23, 2023. <https://doi.org/10.1371/journal.pone.0286297> Accessed September 20, 2023.

Lukkahatai N, Rodney T, Ling C, Daniel B and Han H-R (2023) Long COVID in the context of social determinants of health. *Front. Public Health* 11:1098443. doi: 10.3389/fpubh.2023.1098443, Accessed September 20, 2023.

National Center for Health Statistics. U.S. Census Bureau, Household Pulse Survey, 2022–2023. Long COVID. Generated interactively: from <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>, Accessed September 20, 2023.

Thaweethai T, Jolley SE, Karlson EW, et al. “*inDevelopment of a Definition of Postacute Sequelae of SARS-CoV-2 infection.*” *JAMA*. Published onle May 25, 2023. doi:10.1001/jama.2023.8823, Accessed September 20, 2023.



**“ALWAYS TRY TO
STOP TALKING
BEFORE PEOPLE
STOP LISTENING”**

AUTHOR, UNKNOWN