Long COVID RECOVER Study

Arizona Participant Town Hall
Wednesday, September 27th

~BL

RECOVER
Researching COVID to Enhance Recovery

An Initiative Funded by the National Institutes of Health

ACKNOWLEDGEMENTS

We thank all the participants enrolled in the RECOVER Initiative and their families and caregivers.

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~BL

Webinar Information

- There is time set for Q & A after the presentation of information
- Chat is available to send questions directly to the hosts and panelists
- Panelists will try to answer as many questions as possible
  - Panelists can answer questions about the research and the study
  - Panelists cannot provide a diagnosis

~BL

What we will talk about today

- RECOVER Observational Study – overview and early findings
- RECOVER Trials – what they are and where they stand
- What we are doing regarding Long COVID outside of RECOVER
- Your questions and future feedback

~BL

Panelists

Janko Ž. Nikolich, MD, Ph.D
Contact PI, Arizona Adult RECOVER Site
Professor and Department Head, UA COM-T Immunobiology
Director, Aegis Consortium for Pandemic-free Future

Sairam Parthasarathy, MD
MPI, RECOVER Study and RECOVER Clinical Trials
Professor of Medicine
Chief, Division of Pulmonary, Allergy, Critical Care and Sleep Medicine

Joyce K. Lee-Iannotti, MD
PI, RECOVER Study
Neurologist
Associate Professor Neurology

Karen Lutrick, Ph.D
Co-Investigator, RECOVER Study
Associate Professor and Vice Chair of Research
Family & Community Medicine
College of Medicine-Tucson

Kristen Pogreba-Brown, Ph.D.
Co-Investigator, RECOVER Study
Associate Professor
Epidemiology and Biostatistics Department
Mel and Enid Zuckerman College of Public Health

~BL

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Overview of RECOVER Observational Studies

And What We've Learned

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Researching COVID to Enhance Recovery

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What is RECOVER?

RECOVER stands for Researching COVID to Enhance Recovery.

It's a set of research studies that aim to learn about the long-term health effects of COVID.

RECOVER includes **observational studies**, which means researchers collect information from participants. Participants **will not get treatment** for Long COVID in the observational studies. RECOVER clinical trials are just beginning.

~JN

Study Questions

- How many people are getting Long COVID?
- Why do some people get Long COVID and others do not?
- What symptoms do people feel when they get Long COVID?
- How long do people feel sick when they get Long COVID?
- Why does Long COVID happen?

~JN

RECOVER Observational Study
Adult Cohort

- **14,880** participants who are **18 years of age and older** and have reached the age of majority in their state of residence
- **People who have had COVID (12,200):** someone with a positive test showing they had an infection with the virus that causes COVID, or had symptoms that make us think they had COVID
  - **People who never had COVID (2,680)**: someone who never had a positive test for COVID and never had any symptoms that make us think they had COVID

~JN

Adult Study Overview

Recruitment in 33 states; Washington, DC; Puerto Rico
Diverse population with and without COVID-19
Adults/Pregnant people

↓

Tier 1 Surveys, labs, biospecimens, minimal exam
(14,880 participants)

↓

Tier 2 Low-risk clinical tests
(~4,000 participants per test)

↓

Tier 3 Advanced Testing
(~3,000 participants per test)

~JN

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RECOVER Participation

- Consent forms allow people to choose their level of participation
- Surveys are completed every 3 months
- You may be selected for additional tests based on your symptoms or test results
- Some people will be randomly selected for some of the additional tests

~JN

RECOVER Adult Cohort Timeline

Post-Acute Cohort

(with infection before enrollment)

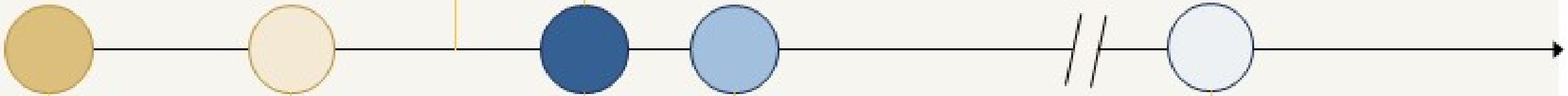
Includes pre-Omicron and Omicron variant as well as vaccinated and unvaccinated participants

Protocol developed with input from patients, patient reps, clinicians, and other scientists

Acute Cohort

(with infection around enrollment)

Almost exclusively Omicron variant and vaccinated participants



February 2020
Beginning of COVID-19 pandemic in US

December 2020
COVID-19 vaccines become available

October 2021
RECOVER Adult Cohort first participant enrolled

December 2021
Omicron variant becomes dominant strain in the US

Oct/Nov 2023
Expected last participant enrolled in RECOVER Adult Cohort

RECOVER
Researching COVID to Enhance Recovery

Development of a Definition of Postacute Sequelae of SARS-CoV-2 Infection

~JN

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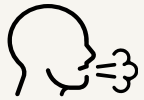
What is Long COVID?

A condition in which a person has symptoms for weeks, months, or even years after a COVID infection.

New or ongoing symptoms, such as:


Feeling short of breath


Feeling very tired


Brain fog (feeling like you can't think clearly)


Cough

Problems with certain organs, such as:


Heart


Lung


Kidneys


Brain

~JN

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It's estimated that:

76.5M

More than 76.5 million people in the US have Long COVID symptoms

Nearly 10% of people who get COVID experience symptoms of Long COVID for 6 months after infection

RECOVER Adult Self-Reported Symptoms

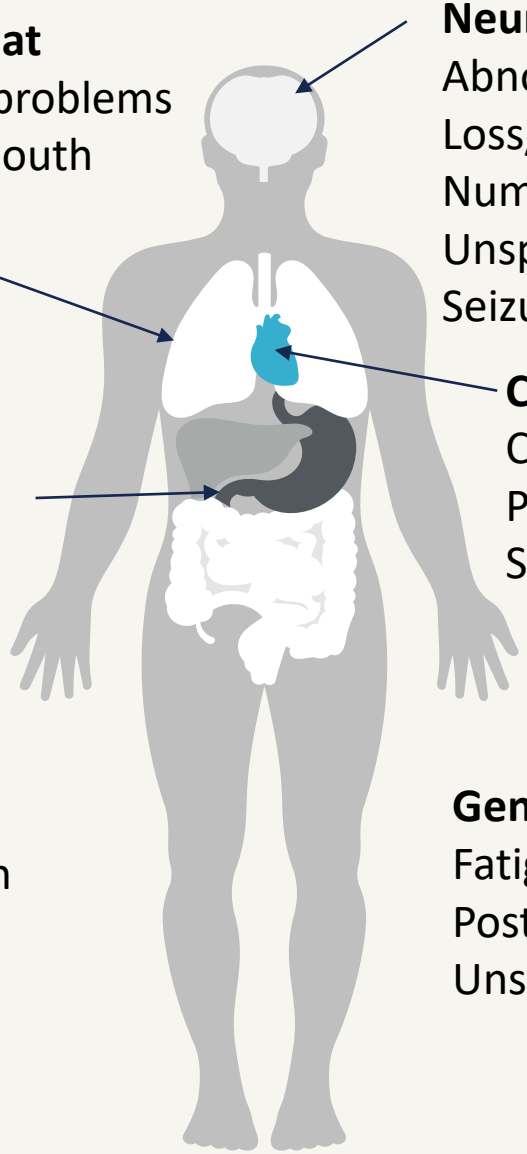
Eye, Ear, Nose, Throat
Hearing and Vision problems
Mouth pain Dry mouth

Metabolic
Thirst

Respiratory
Chronic cough
Short breadth

Dermatologic
Hair loss
Skin color
Skin pain
Skin rash

Gastrointestinal
Abdominal pain
GI symptoms
Throat pain



Neurologic
Abnormal movements
Loss/change smell/taste
Numbness/tingling
Unspecified nerve pain
Seizures
Brain Fog
Dizziness
Headache
Paralysis
Tremor

Cardiovascular
Chest pain
Palpitations
Swelling of legs

Psychiatric
Anxiety
Depression

Urinary
Bladder

Reproductive
Pelvic/genital
Sexual capacity

Musculoskeletal
Back pain Foot pain
Joint pain Muscle pain
Weakness

General
Fatigue Fever/sweats/chills
Post-exertional Malaise
Unspecified pain Sleep disturbance

~JN

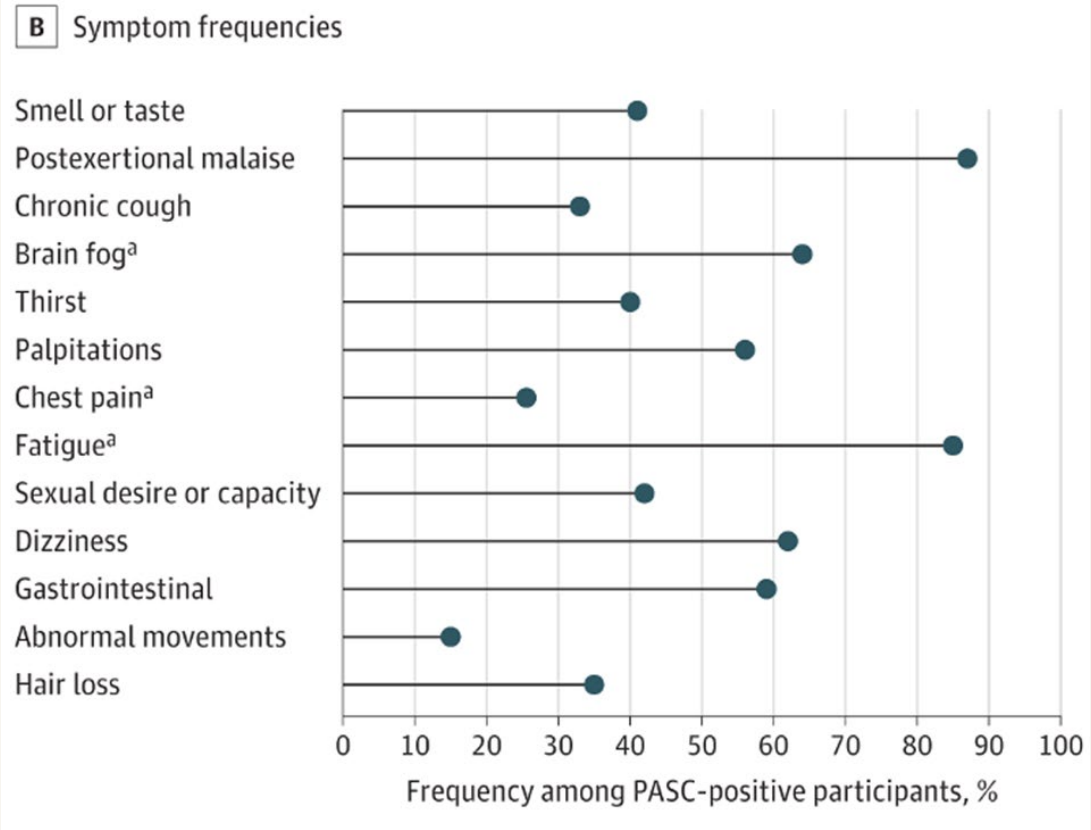
RECOVER Adult Cohort Study Design

Analysis cohort

1. Included participants with at least one visit 6 months or more after index date
2. Used first visit that occurs 6 months or more after index date

Cohort description

- 9,764 participants
- 71% female
- 16% Hispanic/Latino
- 15% non-Hispanic Black
- Median age 47 years
- 55% fully vaccinated before infection
- 41% first infection pre-Omicron



~*JN*

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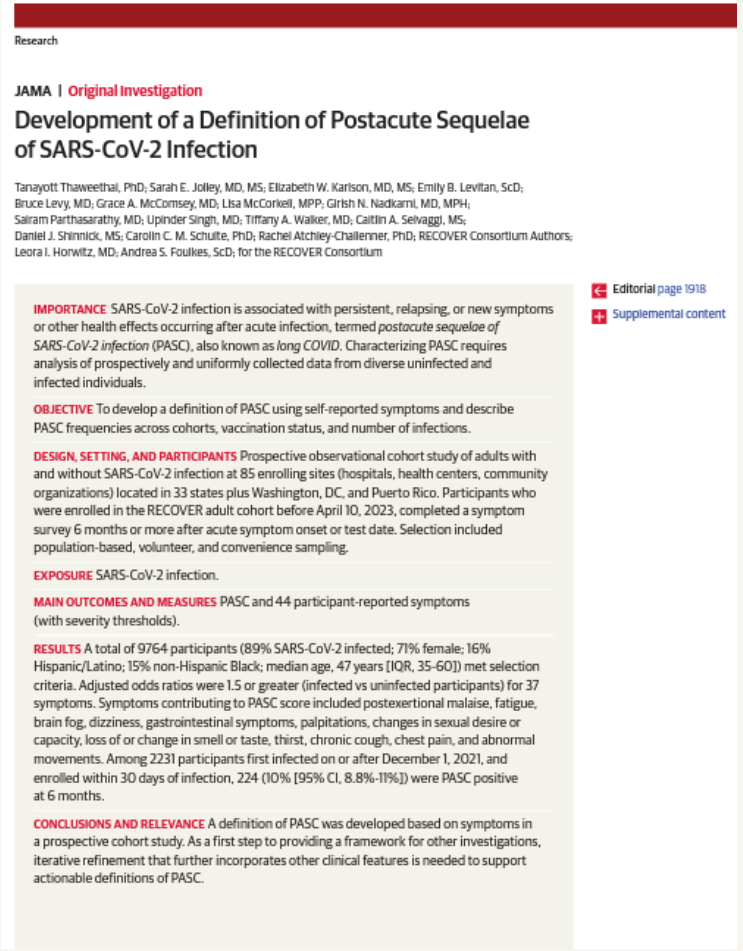
Publications

Your contributions to our study:

- Have led to over 40 published papers
- Are providing guidance for clinical trials
- Are the basis for over 250 more publications in the pipeline
- Were used to create a working definition of long COVID that was published in JAMA, June 2023
  - This article alone has been cited in over 500 news stories



Research

JAMA | Original Investigation

Development of a Definition of Postacute Sequelae of SARS-CoV-2 Infection

Tanayott Thaweethai, PhD; Sarah E. Jolley, MD, MS; Elizabeth W. Karlson, MD, MS; Emily B. Levitan, ScD; Bruce Levy, MD; Grace A. McComsey, MD; Lisa McCorkell, MPP; Girish N. Nadkarni, MD, MPH; Sairam Parthasarathy, MD; Upinder Singh, MD; Tiffany A. Walker, MD; Caitlin A. Selvaggi, MS; Daniel J. Shinnick, MS; Carolin C. M. Schulte, PhD; Rachel Atchley-Challenner, PhD; RECOVER Consortium Authors; Leora I. Horwitz, MD; Andrea S. Foulkes, ScD; for the RECOVER Consortium

Editorial page 1918
Supplemental content

IMPORTANCE SARS-CoV-2 infection is associated with persistent, relapsing, or new symptoms or other health effects occurring after acute infection, termed *postacute sequelae of SARS-CoV-2 infection* (PASC), also known as *long COVID*. Characterizing PASC requires analysis of prospectively and uniformly collected data from diverse uninfected and infected individuals.

OBJECTIVE To develop a definition of PASC using self-reported symptoms and describe PASC frequencies across cohorts, vaccination status, and number of infections.

DESIGN, SETTING, AND PARTICIPANTS Prospective observational cohort study of adults with and without SARS-CoV-2 infection at 85 enrolling sites (hospitals, health centers, community organizations) located in 33 states plus Washington, DC, and Puerto Rico. Participants who were enrolled in the RECOVER adult cohort before April 10, 2023, completed a symptom survey 6 months or more after acute symptom onset or test date. Selection included population-based, volunteer, and convenience sampling.

EXPOSURE SARS-CoV-2 infection.

MAIN OUTCOMES AND MEASURES PASC and 44 participant-reported symptoms (with severity thresholds).

RESULTS A total of 9764 participants (89% SARS-CoV-2 infected; 71% female; 16% Hispanic/Latino; 15% non-Hispanic Black; median age, 47 years [IQR, 35-60]) met selection criteria. Adjusted odds ratios were 1.5 or greater (infected vs uninfected participants) for 37 symptoms. Symptoms contributing to PASC score included postexertional malaise, fatigue, brain fog, dizziness, gastrointestinal symptoms, palpitations, changes in sexual desire or capacity, loss of or change in smell or taste, thirst, chronic cough, chest pain, and abnormal movements. Among 2231 participants first infected on or after December 1, 2021, and enrolled within 30 days of infection, 224 (10% [95% CI, 8.8%-11%]) were PASC positive at 6 months.

CONCLUSIONS AND RELEVANCE A definition of PASC was developed based on symptoms in a prospective cohort study. As a first step to providing a framework for other investigations, iterative refinement that further incorporates other clinical features is needed to support actionable definitions of PASC.

~JN

Publications

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HOME | WHAT IS LONG COVID? | RESEARCH | NEWS & EVENTS | ABOUT THE INITIATIVE

RESEARCH › RECOVER PUBLICATIONS

Sharing science to find answers

Find RECOVER Publications

Researchers within the RECOVER Initiative are learning more about the long-term effects of COVID and they're sharing their progress through research publications. Follow the latest science from RECOVER as we discover more about how COVID affects people and what we can do to predict, treat, and prevent Long COVID. Visit the **Research Summaries** page to learn about the latest science from RECOVER in a format that is easy to understand.

Last updated: August 14, 2023

~JN

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Resources

- Long COVID is complicated and there is still a lot to learn
- To understand why Long COVID develops, RECOVER is gearing up to do molecular analysis on samples that have been collected, and merge it with clinical data from your exams
- RECOVER has a YouTube channel with videos that have some more information about the study

QR Code for RECOVER YouTube channel

~JN

~SP

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LOOKING FOR PARTICIPANTS 18 AND OLDER

Arizona Residents

WE ARE CONDUCTING MULTIPLE SURVEYS TO IMPROVE OUR UNDERSTANDING OF YOUR EXPERIECES & KNOWNLEDGE OF:

- **HEALTH INFORMATION AND TRUST**
- **COVID-19**
- **LONG TERM ILLNESS**
- **LINGERING SYMPTOMS OF COVID INFECTION**
- **SOCIETAL FACTORS INFLUENCING HEALTH**

IF YOU ARE INTERESTED OR WANT TO KNOW MORE, TEXT "JOIN" OR "ENROLL TO (844) 844 - 3004

COMMUNITY ENGAGEMENT ALLIANCE

An Institutional Review Board responsible for human subjects research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Next Steps

Clinical Trials & Continuing Research

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RECOVER VITAL

What is the study about?

RECOVER-VITAL is studying a possible treatment for people who have Long COVID. We want to learn if a study drug can reduce ongoing symptoms from the virus that causes COVID.

With your help, we can better understand why and how Long COVID affects people in different ways.

Am I a good fit for the study?

- You are an adult who had COVID
- You do not have an active COVID infection
- You still have 1 or more of these symptoms:
  - Exhaustion or low energy that interferes with daily activities
  - Trouble thinking clearly or brain fog
  - Dizziness, fast heart rate, shortness of breath, upset stomach, or other changes in body functions that happen automatically

~SP
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RECOVER
VITAL

Viral persistence and reactivation, and immune dysregulation

No health insurance is required.

Learn more at trials.recovercovid.org/vital

RECOVER NEURO

What is the study about?

RECOVER-NEURO is studying possible treatments for adults who have cognitive dysfunction symptoms related to Long COVID. We want to learn if brain training may improve those symptoms.

With your help, we can better understand why and how Long COVID affects people in different ways.

Am I a good fit for the study?

- You are an adult who had COVID
- You do not have an active COVID infection
- You have 1 or more of these symptoms:
  – Brain fog or trouble thinking clearly
  – Trouble paying attention or remembering things

RECOVER NEURO

No health insurance is required

Learn more at trials.recovercovid.org/neuro

~JLI
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RECOVER IS NOT ENOUGH……

It was not meant, designed or funded to take care of people with Long COVID

National Centers of Excellence Strategy

To Develop Evidence-Based Standards of Care For Long COVID Patients

- **We are proposing a national Centers of Excellence (CoE) network to diagnose, treat, educate, and train on, Long COVID.**

WHY?

- **Long COVID is the next pandemic, we need money and resources to care for patients**
- **Unified & coordinated network needed to identify and disseminate best practices for Long COVID diagnosis, treatment, and care, implement the care and train the providers to do so.**
- **There is no federal, agency-, university-, or industry-proposed plan to solve this problem**

ACCOMPLISHMENTS AND CURRENT STATE

- **We (the Aegis consortium) are leading RECOVER Adult Site PI's to establish the Centers**
- **Developed a national CoE strategy that was included into the Senate appropriations language for FY24 ($5M).**
- **Now raising awareness and federal & private fundraising, looking for patient partnerships**

THE UNIVERSITY OF ARIZONA HEALTH SCIENCES
Aegis Consortium

Next Steps

- What can we do to make your life better?
- Tell us your priorities, concerns, etc….
- Let’s work and advocate for Long COVID together

Q&A

For more information:

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Phone:

(520) 621-8354

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