Long COVID
RECOVER Study

Arizona Participant Town Hall
Wednesday, September 27th
We thank all the participants enrolled in the RECOVER Initiative and their families and caregivers.

This research was funded by the NIH (OTA OT2HL161841, OT2HL161847, and OT2HL156812) as part of the Researching COVID to Enhance Recovery (RECOVER) research program and R01 HL162373.

~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

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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

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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
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.
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?
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
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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)
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
RECOVER Adult Cohort Timeline

**Post-Acute Cohort**
(with infection before enrollment)
Includes pre-Omicron and Omicron variant as well as vaccinated and unvaccinated 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

**Acute Cohort**
(with infection around enrollment)
Almost exclusively Omicron variant and vaccinated participants

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

Protocol developed with input from patients, patient reps, clinicians, and other scientists
Development of a Definition of Postacute Sequelae of SARS-CoV-2 Infection
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

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

~JN
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RECOVER Adult Self-Reported Symptoms

**Metabolic**
- Thirst

**Dermatologic**
- Hair loss
- Skin color
- Skin pain
- Skin rash

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

**Respiratory**
- Chronic cough
- Short breath

**Gastrointestinal**
- Abdominal pain
- GI symptoms
- Throat pain

**Musculoskeletal**
- Back pain
- Foot pain
- Joint pain
- Muscle pain
- Weakness

**Neurologic**
- Abnormal movements
- Loss/change smell/taste
- Numbness/tingling
- Unspecified nerve pain
- Seizures

**Cardiovascular**
- Chest pain
- Palpitations
- Swelling of legs

**Urinary**
- Bladder

**Psychiatric**
- Anxiety
- Depression

**Reproductive**
- Pelvic/genital
- Sexual capacity

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

~JN

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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

~JN
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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
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
¿Ha experimentado anteriormente o continúa experimentando síntomas relacionados con COVID?

PUEDE SER ELEGIBLE PARA PARTICIPAR EN UN ESTUDIO DE INVESTIGACIÓN. DEBE ESTAR DISPUESTO A COMPARTIR SUS EXPERIENCIAS RELACIONADAS CON COVID CON LOS MIEMBROS DE SU COMUNIDAD. SU TIEMPO SERÁ COMPENSADO HASTA $3,120.

LLAMA O MANDA UN MENSAJE DE TEXTO PARA MÁS INFORMACIÓN
520-542-2970

Una Junta de Revisión Institucional responsable de la Investigación con seres humanos en la Universidad de Arizona examinó este proyecto de investigación y encontró que era aceptable, de acuerdo con las disposiciones estatales y federales, así como las políticas universitarias destinadas a proteger los derechos y el bienestar de los participantes en la investigación.
LOOKING FOR PARTICIPANTS
18 AND OLDER

Arizona Residents

WE ARE CONDUCTING MULTIPLE SURVEYS TO IMPROVE OUR
UNDERSTANDING OF YOUR EXPERIENCES & KNOWLEDGE 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

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

RECOVER
Researching COVID to Enhance Recovery
An Initiative Funded by the National Institutes of Health
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

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

JLI
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RECOVER IS NOT ENOUGH……

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