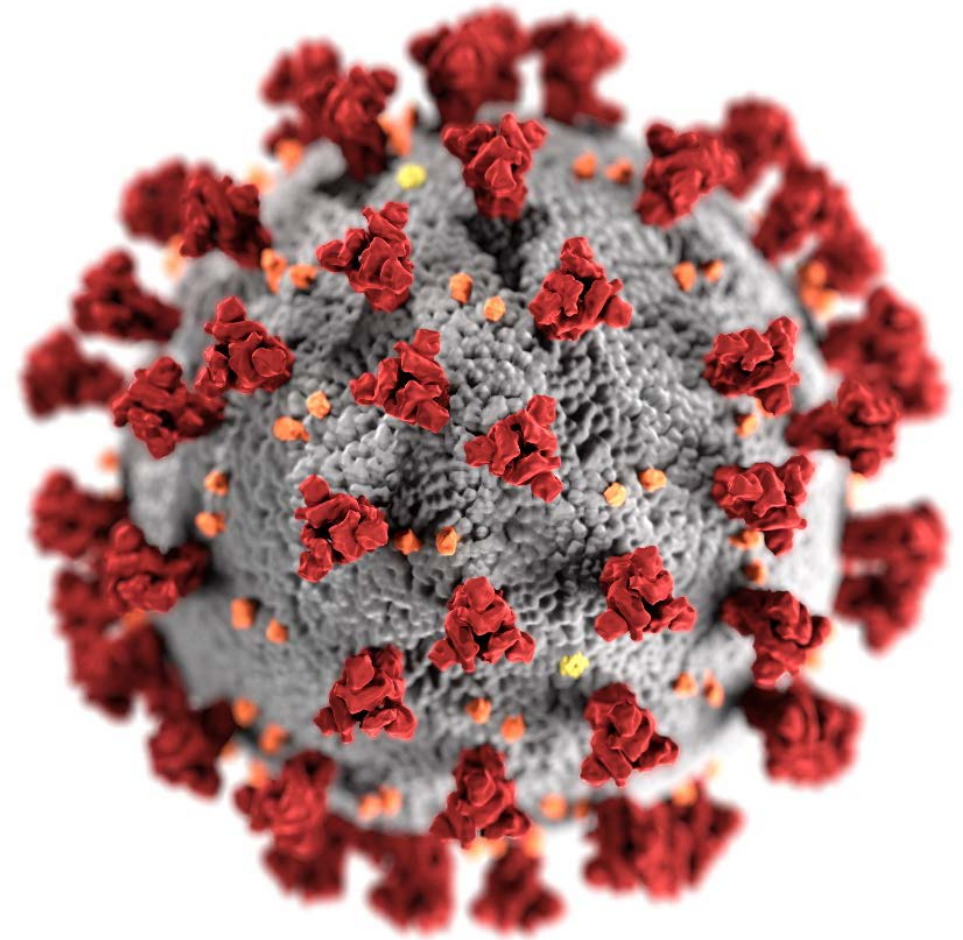# Understanding Long COVID: CDC Current Projects & Collaborations

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COVID Response, Epidemiology Task Force, Natural History Team

Division of Viral Diseases, Respiratory Viruses Branch, Natural History Team

cdc.gov/coronavirus

Overview of CDC's work to understand Long COVID-19

CDC has invested $46 million to understand the long-term health effects of COVID-19

**Examples of CDC's current work includes:**

1. Partnering with clinicians to understand:

- Clinical needs for patients after acute infection

- Type and frequency of late symptoms

- Characteristics of persons most likely to experience late symptoms

2. Analyzing electronic health data including medical records, laboratory data and administrative claims data

- To rapidly describe health outcomes several months after COVID-19 diagnosis
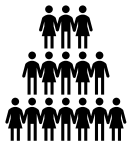
3. Establishing studies with external partners

- To understand the duration of COVID-19 illness, and risks for complications.

Research Questions

- What are the clinical symptoms or signs associated with prolonged illness or new persistent symptoms following SARS-CoV-2 infection?

- How often are symptoms caused by acute infection?

- In patients with persistent symptoms and without other medical explanations, do the symptom profiles match ME/CFS symptom profiles?

- What factors increase the risk of long-term symptoms?

- What is the extent of long-term symptoms in the population?

- What are the mechanisms of viral infection leading to symptoms of potential long term organ damage?

Approach

- Enroll cohorts of patients with and without SARS-CoV-2 infection

- Assess baseline health of the participants

- Monitor participants over time and for multiple years

- Assess risk factors and outcomes of interest including:

  - Symptom profiles

  - Long-term immunologic response

  - Cardiovascular, respiratory, renal, neurological outcomes

  - Mental and physical functioning

Projects funded to assess natural history and outcomes of COVID-19

CDC issued three Broad Agency Announcements (BAAs) on this topic

- **March 25, 2020**

- **June 24, 2020**

- **December 23, 2020**

- Studies are designed to further understand:
  - Household transmission
  - Virus shedding
  - Immune response
  - Clinical course and complications
  - Long term outcomes
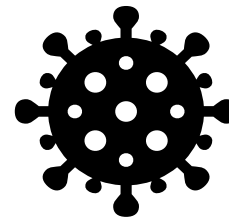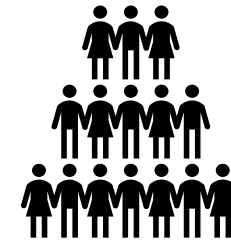
Longitudinal Studies on Persistent Symptoms: COVID-Understanding the Post-Viral Phase (COVID-UPP)

Objective:
- Describe the nature of persisting symptoms, their frequency, severity, and overlap with ME/CFS

Design:
- 4-year longitudinal study of post-acute COVID sequelae
- Participants who test positive for SARS-CoV-2 through their local health department or community health center, with persistent or resolved symptoms
- Phase 1: self-reported health assessed every 3 months
- Phase 2: physical examination on a subset of participants
- Comparison of individuals with persistent and resolved symptoms

Partner: NOVA Southeastern

Status: Launching Spring 2021

Longitudinal Studies on Persistent Symptoms: Innovative Support for Patients with SARS-CoV-2 Infections Registry: INSPIRE Cohort

Objective:

- Characterize clinical course, health care utilization, medications, clinical outcomes
  - Assess outcomes every 3 months and up to 18 months post SARS-CoV-2 test
  - Examine the associations between participants socio-demographic, clinical, and psychosocial characteristics with outcomes

Design:

- Longitudinal multi-center observational cohort of patients testing positive and negative for SARS-CoV-2 to collect clinical and self-reported data, including ME/CFS common data elements

Partners: Rush University, University of Washington, Yale, UTHealth, UTSouthwestern, UCLA, UCSF, Jefferson Medical

Status: Currently enrolling

Longitudinal Studies on Persistent Symptoms: Immune Response to SARS-CoV-2

Objective:

- Risk of morbidity and mortality in Louisiana
- Temporal comparison of viral shedding (multiple sites), cytokine production, sequencing, antibody response
- Long term complications

Design:

- Enroll 500 participants from an inpatient cohort and 500 from a convalescent cohort
- Laboratory studies to assess viral shedding and immunity following SARS-CoV-2 infection
- Identify risk factors for morbidity and mortality in this population included screening for ME/CFS symptoms with follow-up at 3, 6 and 12 months.

Partner: Tulane University

Status: On-going enrollment and follow-up

Longitudinal Studies on Persistent Symptoms: COVID-19 within High-Risk American Indian Communities in the Southwest United States

Objective:
- Determine the transmission dynamics within households
- Assess clinical complications, long-term sequelae and risk factors associated with sequelae
- Antibody persistence following infection

Design:
- Enroll individuals from the Navajo and White Mountain Apache communities SARS-CoV-2 positive and their household members
- Follow for 12 months to assess household transmission of SARS-CoV-2 infection, development and duration of symptoms or complications, and the antibody response.
- Follow-up includes screening for ME/CFS symptoms

Partners: Johns Hopkins University Center for American Indian Health

Status: Enrolling

Population-level measures of Long COVID

- Provide estimates of extent of long-term impact
  - Incidence and prevalence of post-acute COVID conditions
  - ME/CFS diagnosis and association with COVID-19 illness

- Understand the distribution in the population

  - Overall
  - By demographic characteristics including age, sex, race/ethnicity
  - By geographic differences
  - By socio-economic differences
  - By risk factors

Methods to measure Long COVID at the population-level

Use of federal health surveys to measure self-report of COVID-19 illness and ME/CFS

- National Health Interview Survey
  - Nationally representative of the noninstitutionalized U.S. population
- Behavioral Risk Factor Surveillance System
  - Provides state-based estimates

Sentinel surveillance

- Establish detailed surveillance at specific sites throughout the country

Electronic health records

- Analysis of diagnosis and health care utilization

Future directions

- Ongoing research to characterize post COVID condition and understand how it relates to ME/CFS
  - Characterize risk factors and clinical course
  - Identify potential treatments
  - Address potential health inequities and diverse populations
- Surveillance to estimate:
  - Magnitude in the population including incidence and prevalence
  - Current and anticipated health care needs and utilization
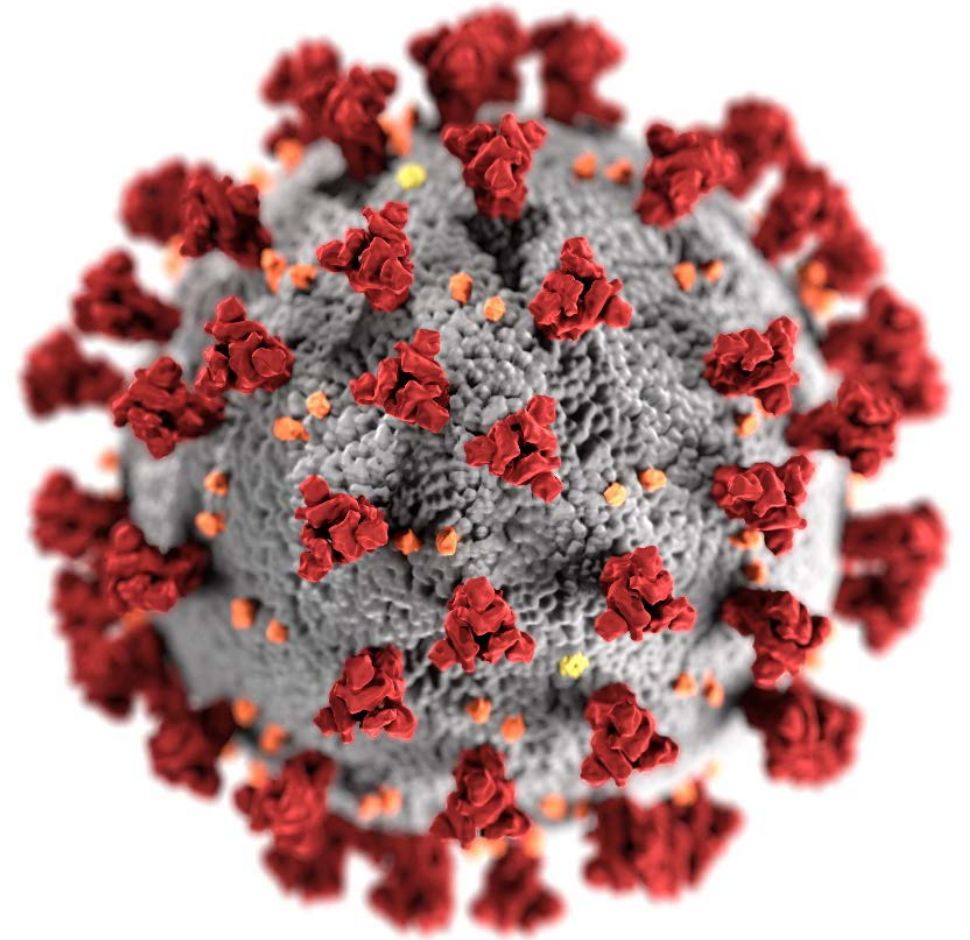
Thank you

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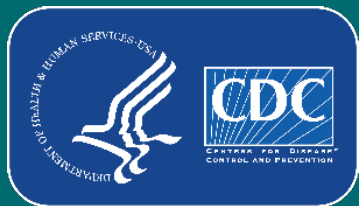
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