

Implementation of the Government-wide Response to

# LONG COVID

An update from the Office of Long COVID  
Research and Practice | February 2024



Office of the  
Assistant Secretary  
for Health

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# LETTER FROM THE SECRETARY OF HEALTH AND HUMAN SERVICES

Thank you, President Biden, for the opportunity to coordinate a U.S. government-wide effort to address the longer-term impacts of COVID-19.

The U.S. government has been working on Long COVID since 2020. In January 2021, White House Executive Order 13995 established the COVID-19 Health Equity Task Force. In October 2021, the Task Force published recommendations, many of which pertained to Long COVID. The *Memorandum on Addressing the Long-Term Effects of COVID-19* in April of 2022 highlighted the Administration's commitment to harness the full potential of the federal government and to coordinate with public- and private-sector partners to respond fully and effectively to the longer-term effects of COVID-19, including Long COVID and associated conditions. Although the COVID-19 Public Health Emergency ended in May 2023, addressing Long COVID remains a priority for HHS. People continue to get COVID-19 and in turn some develop Long COVID and must deal with other lasting ramifications of the pandemic. It continues to be our responsibility to help them to get the information and services they need to recover and return to their daily lives.

Long COVID does not just affect an individual's health, but all aspects of their life including their ability to go to work or school, their financial stability, and their relationships. That's why it is critical that we are coordinating across 14 federal departments and agencies and with numerous external stakeholders to conduct the work laid out in this report. We are having hard conversations and working with a broad base of stakeholder groups to fully understand and address the longer-term impacts of COVID-19.

A person with Long COVID asked at a recent meeting, "Who do we see as being worthy of socioeconomic stability?" The answer must be everyone. Disparities seen in the COVID-19 pandemic, which has disproportionately impacted Black, Hispanic, American Indian, and Alaska Native populations and people with disabilities and pre-existing chronic illnesses, may likely continue with Long COVID. The challenges associated with COVID-19 exacerbated existing health inequities in our country, highlighting social and racial injustices that impede equitable health outcomes.

There is much that we still do not know about Long COVID. Doing the work of learning is slow and sometimes frustrating, but we know that in the end it will change lives. Even as we endeavor to learn more about Long COVID, we already understand that the best prevention remains to avoid infection and reinfection by following basic prevention interventions such as staying up to date on vaccinations, improving ventilation indoors, wearing a mask in high-risk settings, avoiding crowds or increasing distancing, and handwashing.

I want to thank the professionals in the 14 departments and agencies who worked diligently to prepare this Report. I also want to thank the Assistant Secretary for Health for her leadership in conceptualizing and driving the production of this report. Finally, I want to express my sincere gratitude to numerous organizations and individuals who contributed their time, resources, contacts, and invaluable conversations with us. This collaboration remains critically important in making progress on Long COVID. Those with lived experiences are central to our efforts. A lot of work lies ahead of us, but I invite you to take a moment to celebrate what we have achieved together so far.

Sincerely,  
Xavier Becerra  
Secretary of Health and Human Services

# EXECUTIVE SUMMARY

Long COVID is a patient-created term [broadly defined](#) as signs, symptoms, and conditions that continue or develop after initial SARS-CoV-2 infection or re-infection. Since the pandemic began, there have been over 140 million cases of COVID-19 in the United States. From this high number of cases, [an estimated 11%](#)<sup>1</sup> of adults in the United States who have ever had COVID-19 are currently experiencing Long COVID with symptoms that have lasted three months or longer, which suggests millions of people could be affected in the United States. Long COVID symptoms vary greatly, encompassing an array of approximately 200 different symptoms. People currently experiencing Long COVID have increased healthcare needs and could be considered an individual with a disability under federal disability rights law if the condition or its symptoms substantially limits one or more major life activities. Individuals with disabilities may need reasonable accommodations to participate in the workforce. Based on early estimates taking into account increased healthcare costs, reduced earnings, and reduced community participation, Long COVID could cost the United States [as much as \\$3.7 trillion](#).<sup>2</sup>



**An estimated 11% of adults in the United States are currently experiencing Long COVID.**

Beyond the monetary costs of Long COVID, the impact on lives can be devastating. We hear from patients regularly sharing their struggles.

*"I have buzzing in my head and am constantly dizzy."*

*"I am unable to work because of it. I need help."*

*"I am still having trouble breathing. I am concerned with my health."*

*"My spouse has had Long COVID for 3 years. I have to stay home to take care of him and can no longer work."*

## What do we know about Long COVID today?

- Anyone can experience Long COVID, including children.<sup>3</sup>
- There are over 200 symptoms associated with Long COVID, including respiratory, nervous system, mental health, cardiovascular, and gastrointestinal symptoms.<sup>4,5</sup>
- Some of the most common symptoms of Long COVID include post-exertional malaise, fatigue, brain fog, dizziness, gastrointestinal complications, and heart palpitations.<sup>6</sup>
- About 25% of people with Long COVID experience significant activity limitations.<sup>7</sup>
- Some people who experience Long COVID symptoms get better in a few months, while others report having symptoms lasting much longer.<sup>8,9</sup>
- There are disparities in who experiences Long COVID. For example, women<sup>10</sup>, some racial and ethnic minority groups<sup>11</sup>, people with preexisting conditions<sup>12,13,14</sup>, and people between 45 and 65 years old<sup>15</sup> are more likely to experience Long COVID.
- Research indicates that people who are vaccinated against COVID-19 may have a lower risk of developing Long COVID.<sup>16,17</sup>
- Long COVID can be a disability under [disability rights laws](#).



About **25%**  
of people  
with Long COVID  
experience significant  
activity limitations.

## Background

Long COVID was first identified as a serious health issue by patients, caught the attention of advocacy groups, and spurred many around the world in healthcare, academia, and government to respond. The Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), and other federal government agencies started to investigate Long COVID in 2020. In January 2021, White House Executive Order 13995 established the [COVID-19 Health Equity Task Force](#). In October 2021, the Task Force published [recommendations](#), many of which pertained to Long COVID. On April 5, 2022, President Biden issued the [Memorandum on Addressing the Long-Term Effects of COVID-19](#) outlining actions needed to address the longer-term effects of COVID-19, including Long COVID, mental health and substance use challenges, and bereavement. The memo called for two reports: a [National Research Action Plan on Long COVID](#) and the [Services and Supports for Longer-Term Impacts of COVID-19](#), both published on August 3, 2022. On the one-year anniversary of the memorandum, HHS published a [fact sheet](#) outlining federal progress. While the declared public health emergency for COVID-19 ended in May 2023, the impacts of the pandemic, including Long COVID, continue, and therefore, so does the federal response.

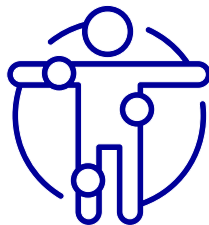


**Long COVID was first identified as a serious health issue by patients, caught the attention of advocacy groups, and spurred many around the world in healthcare, academia, and government to respond.**



Long COVID and associated conditions are examples of infection-associated chronic illnesses. A better understanding of Long COVID will likely benefit and inform our understanding of other associated conditions, such as dysautonomia, fibromyalgia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and chronic conditions following Lyme disease and other vector-borne illness. In addition, developing effective integrated person-centered models of care can help improve care delivery for complex conditions and multimorbidity more broadly. It is also a reminder that the risk of long-term health impacts of infectious diseases needs to figure prominently in pandemic preparedness planning and response.

**Long COVID and associated conditions are examples of infection-associated chronic illnesses.**



## Long COVID Interim Definition

Long COVID is a patient created term broadly defined as signs, symptoms, and conditions that continue or develop after initial SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.\*



## Strategic Response

This report reflects the Office of Long COVID Research and Practice's current perspectives on Long COVID, and the activities the federal government is undertaking to meet the goals and objectives laid out in this report. The federal government continues to play a critical role in this work but will require robust partnerships with patients, advocates, clinicians, researchers, and industry to solve this challenge.

<https://www.covid.gov/be-informed/longcovid/about#term>



**Partnerships with patients, advocates, clinicians, researchers and industry are vital to solve this challenge.**

A logic model in Appendix E provides the conceptual framework that guides our response, drawing connections from inputs, to activities, to outcomes, to impacts. The government-wide response to Long COVID is directed by the two reports published in August 2022 and is organized into five activity domains (research, clinical practice, services and supports, public education, and coordination), each with specific objectives. The Implementation section tracks our progress towards each of these objectives.

\* Note: This interim federal working definition was developed by the U.S. Department of Health and Human Services in collaboration with other federal departments and subject matter experts in 2022. The National Academy of Medicine is currently gathering broad input to examine the definition, with a report expected in summer 2024.

# STRATEGIC RESPONSE

Long COVID is a complex problem that requires multidisciplinary solutions. We must think strategically about the federal actions and mechanisms that will help us to achieve the overall goal of reducing the impacts of Long COVID on people in the United States. The logic model (Appendix E) and goals and objectives build on all of our work up to now, including the previous reports, conversations with stakeholders, and our ongoing efforts. These goals and objectives will help guide and structure the federal government's response to Long COVID and track our implementation of planned activities.

To reduce the impacts of Long COVID and associated conditions, we need to reduce the number of people who are infected and re-infected with SARS-CoV-2 virus and develop Long COVID, help people with Long COVID to recover faster and live better, and improve Long COVID-related health equity. Our work is organized into five domains: research, clinical practice, services and supports, public education, and coordination.



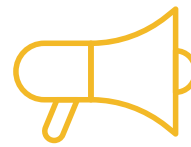
**RESEARCH**



**CLINICAL PRACTICE**



**SERVICES AND SUPPORTS**



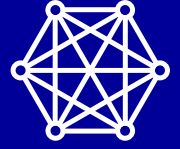
**PUBLIC EDUCATION**



**COORDINATION**

Each of those domains will help contribute to the short- and long-term outcomes that will guide us towards our desired impacts. For example, in the clinical practice domain, activities such as the Agency for Healthcare Research and Quality (AHRQ) funding of [comprehensive, person-centered, multidisciplinary Long COVID clinics](#), the Health Resources and Services Administration (HRSA) [telehealth technology-enabled learning program](#), and CDC-supported [Project ECHO clinician trainings](#) will help lead to more people with Long COVID receiving a timely diagnosis and having access to high-quality, person-centered care. Public education campaigns like [“We Can Do This”](#) have helped to increase people's awareness of Long COVID, which in turn helps them to both take actions to prevent infection with SARS-CoV-2 and to seek needed care if they or someone they know has Long COVID. The Office of the Assistant Secretary for Health (OASH) facilitates and supports all the other activities and outcomes through their coordination efforts.

**Long COVID is a complex problem that requires multidisciplinary solutions.**



## Health Equity

Health equity is the state in which everyone has a fair and just opportunity to attain their highest level of health. Achieving this requires focused and ongoing societal efforts to address historical and contemporary injustices; overcome economic, social, and other obstacles to health and healthcare; and eliminate preventable health disparities.

Multifaceted systemic barriers affect who has access to Long COVID information, diagnosis, care and treatment, and support services. Data on disparities related to Long COVID are limited, but indicate that women, some racial and ethnic minority groups, bisexual and transgender individuals, people with preexisting conditions, and people between 45 and 65 years old are more likely to experience Long COVID.

Long COVID cases are likely underdiagnosed as a whole, but particularly in communities with limited access to testing and care or who experience stigma in the healthcare system – many of which are the same communities hit hardest by COVID-19. Some patients may also experience stigma from providers who don't believe their symptoms or think that Long COVID and associated conditions are not real.<sup>18</sup>



**Health equity is the state in which everyone has a fair and just opportunity to attain their highest level of health.**



**Some patients may experience stigma from providers who don't believe their symptoms or think that Long COVID and associated conditions are not real.**

It is expected that all federal Long COVID research, programs, and services and supports are designed and implemented purposefully to promote health equity. In line with the [recommendations](#) of the Presidential COVID-19 Health Equity Taskforce, OASH is committed to achieving this by elevating community expertise and effective communication; centering health equity in all processes, practices, and policies; ensuring data accurately represents all populations and their experiences; and working towards equitable access to high quality care for everyone.

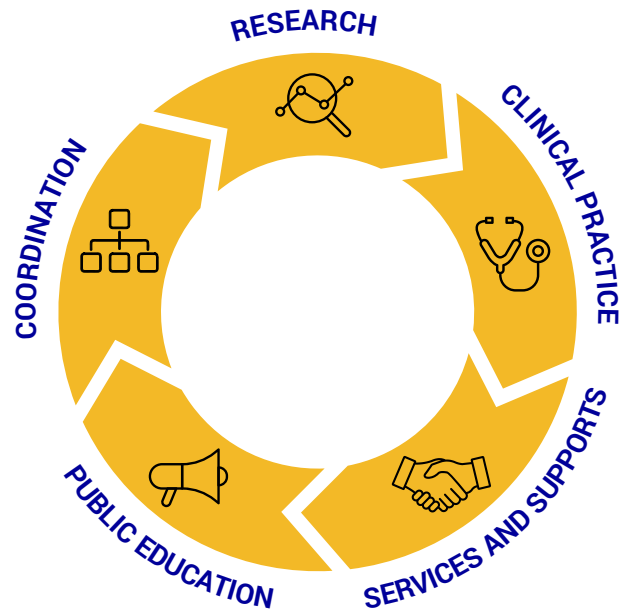
Some examples of how we are working to [reduce health disparities](#) in Long COVID include:

- Ensuring groups most impacted by COVID-19 are included in research studies and patient engagement.
- Increasing access to services.
- Reducing barriers to health care in rural areas and those harder hit by the pandemic.
- Providing culturally appropriate educational materials in multiple languages.
- The NIH Community Engagement Alliance Against COVID-19 Disparities (CEAL) initiative leverages existing community-engaged research efforts to address misinformation, foster trust in science, and ensure inclusive participation of ethnic and racial minority communities disproportionately affected by the COVID-19 pandemic.



# Goal and Objectives

The overarching goal of our work is to reduce the impacts of Long COVID and associated conditions on individuals, families, caregivers, and communities. President Biden’s Memorandum, dated April 5, 2022, and subsequent partner and stakeholder engagement identified targeted impacts: fewer people get SARS-CoV-2 and develop Long COVID; people with Long COVID get better faster and have improved well-being; there is less disparity in Long COVID occurrence, care, and health outcomes; and the federal government has increased capacity and capability to meet emerging public health service needs. To achieve these outcomes, we have organized the objectives into five domains: research, clinical practice, services and supports, public education, and coordination.



The research objectives are pulled directly from the National Research Action Plan on Long COVID. Over the last year, through our ongoing work and conversations with stakeholders, we have identified objectives under the Supports and Services domain, as well as three new domains. We see these five domains as critical areas in which the government can play a role in reducing the impacts of Long COVID and associated conditions. Individually, each domain is important; by working on them together, we can achieve a much greater impact. The domains and objectives may continue to evolve as this is an emerging issue and the landscape is changing rapidly.



**Goal: To reduce the impacts of Long COVID and associated conditions.**

## Domain 1 | Research

Support research to better understand the clinical spectrum, trajectory, underlying causes, prevention, diagnosis, and treatment of Long COVID.



- 1.1 Diagnosis:** Based on understanding of the full clinical spectrum of Long COVID, identify effective diagnostic strategies including development of effective diagnostics devices.
- 1.2 Pathophysiology:** Understand the pathophysiology of Long COVID from molecular to systems levels, including within the broader context of post-infectious chronic illnesses.

- 1.3 Surveillance and Epidemiology:** Engage in coordinated and enhanced surveillance to assess the prevalence, potential health impacts, risk and protective factors, and overall disease burden of Long COVID across demographic groups, taking into account survivor bias, and as the landscape changes (e.g., new variants, new treatments).
- 1.4 Well-Being:** Understand the impacts of Long COVID on overall well-being, including educational outcomes, physical health, behavioral health, education, employment, disability, and family and caregiver well-being.\*
- 1.5 Treatments and Health Interventions:** Identify effective treatments and interventions to prevent Long COVID, improve the health and well-being of people living with Long COVID, and to cure Long COVID.\*\*
- 1.6 Human Services and Supports:** Identify and evaluate optimal person-centered models of support to ensure individuals living with Long COVID and associated conditions can fully participate in their communities.
- 1.7 Health Services and Health Economics Research:** Develop, implement, and evaluate models of health care delivery that reduce barriers to effective care for Long COVID and associated conditions; and expand understanding of the economic costs of Long COVID.

## Domain 2 | Clinical Practice

Promote tools and resources to enable preventive measures, promote reliable and timely diagnosis, and expand access to high-quality, effective care and treatment for people with Long COVID and associated conditions across the country.



- 2.1 Models of Care:** Promote person-centered, multidisciplinary, coordinated models of care, including telehealth.
- 2.2 Clinical Guidance:** Facilitate development and dissemination of comprehensive and equitable Long COVID diagnosis, care, and treatment guidance.
- 2.3 Clinician Education:** Promote accurate information and accelerate and disseminate clinical support and best practices to promote coordinated, integrated care models.
- 2.4 Expanded Access:** Expand access to high-quality Long COVID care for impacted populations.
- 2.5 Payment and Reimbursement:** Promote payment and reimbursement models that support complex, coordinated, person-centered care.

\* Note: In the [National Research Action Plan](#) this was framed as quality of life, but in ongoing patient and partner engagement we have broadened the concept to overall well-being

\*\* Note: In the NRAP this was referred to as “therapeutics”; we opted to change to treatment as it is more inclusive and more plain language.

## Domain 3 | Services and Supports

Support people living with Long COVID and associated conditions, particularly in communities most impacted by the pandemic.



- 3.1 Access to Services:** Increase knowledge of available services and supports and reduce barriers to accessing them to support all aspects of daily life.
- 3.2 Behavioral Health:** Support the mental and behavioral health needs of individuals, families, and caregivers affected by Long COVID.
- 3.3 Disability Rights Protections:** Promote disability rights protections, including reasonable modifications and accommodations, for qualified individuals with disabilities affected by Long COVID.

## Domain 4 | Public Education

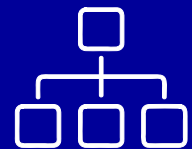
Disseminate up-to-date information about Long COVID and associated conditions to educate the public.



- 4.1 Public Health Communications:** Communicate the risks of Long COVID, how to protect yourself and others, and how to access care and treatment.
- 4.2 Partnerships:** Work together to broaden the reach of public education messages.

## Domain 5 | Coordination

Support a coordinated whole-of-government response to Long COVID and associated conditions in order to increase efficiency, facilitate knowledge sharing, and leverage available resources.



- 5.1 Federal Infrastructure:** Develop a structure to engage federal stakeholders in national efforts to address Long COVID prevention, treatment, supports, and research.
- 5.2 External Partnerships:** Develop partnerships and ongoing communication, including with researchers, professional associations, state, local, and tribal governments, advocacy organizations, community-based organizations, and relevant industries.
- 5.3 Definitions:** Coordinate the development and dissemination of updated working definitions for Long COVID to harmonize work across different entities.
- 5.4 Data Sharing:** Coordinate data sharing across federal agencies.

# IMPLEMENTATION

Below are federal actions that have been, or will be, taken to work towards the goals and objectives outlined above. Many activities contribute to multiple goals and fulfill more than one objective; we list most activities only once. Note that some previously planned activities were canceled due to the Fiscal Responsibility Act.

## Research

As Long COVID is a newly emerging set of conditions, there are many unanswered research questions that are important to understand in order to help individuals with Long COVID. Many of these unanswered questions were laid out in the [National Research Action Plan](#) on Long COVID (NRAP), and efforts to answer these questions have involved government research projects, collaborations with academia and the private sector (including industry), funding for academic research, and sharing of government data that has allowed private groups to perform research, improve clinical models of care, and participate in public health action. Overall, there is substantial progress to answering these questions, an expansive portfolio of research efforts is underway, and additional research will be required to have a full understanding.

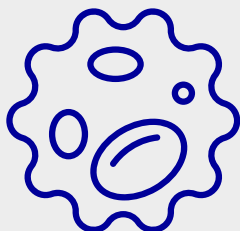
Many of the currently published studies have used epidemiologic data from surveys and electronic health records (EHR) as well as other real-world data to understand the associations between population characteristics and preventive measures on the rate of Long COVID. These types of studies can be completed relatively quickly, which has affected the types of questions that have been answered to date. Many of the analyses focused on questions related to symptoms, the clinical course of infection, and the populations that are affected by Long COVID. These results provide important information regarding the full clinical spectrum of Long COVID, including the type, severity, and frequency of symptoms, as well as risk factors for developing Long COVID. This information is critical to inform the design of clinical trials to test interventions for the treatment of this infection-associated chronic illness and these results provide estimates on the percentage of people impacted by Long COVID.

**As Long COVID is a newly emerging set of conditions, there are many unanswered research questions that are important to understand in order to help individuals with Long COVID.**



**Many published studies have focused on questions related to symptoms, the clinical course of infection, and the populations that are affected by Long COVID.**

Another major gap pertains to health services research and how patients with Long COVID can be best supported. Most completed surveys have focused on understanding the rates of Long COVID and few have focused on individuals' needs or the identification of gaps in clinical care. However, health services research efforts are underway and AHRQ has commissioned an evidence review to summarize and describe what is known about existing models of care for Long COVID, and has started [initiatives](#) to investigate how to best deliver comprehensive, coordinated, person-centered care for people living with Long COVID.



The research community is building on efforts to understand other infection-associated chronic conditions that also impact the body in complex, hard to understand, and likely related ways. Researchers have spent decades learning more about conditions like ME/CFS and mast cell activation syndrome, and some of what we have been able to quickly learn about Long COVID is thanks to that work. By building on that foundation, we hope that Long COVID research and future treatments may also provide help to people who have been living with other infection-associated chronic conditions.

The research below highlights the intergovernmental collaboration and partnerships that have taken place related to Long COVID research. Major publications have been released from the NIH, CDC, Department of Defense (DoD), and Department of Veterans Affairs (VA) that contribute substantively to answering the questions raised in the NRAP. Government researchers have been authors on multiple publications written in collaboration with academic researchers. In addition, information from government conducted surveys has been the backbone to many different publications, especially publications that investigate the economic impacts of Long COVID. And it is the nature of science that answers, in turn, generate more questions. Coordination drives convergence on discovery and implementation of feasible solutions.

## Research Areas

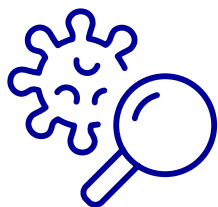
Below, we summarize the status of research addressing the seven research areas delineated by the NRAP. This is not a comprehensive summary but rather highlights efforts of the U.S. government to address priority Long COVID research questions. Research conducted outside of the United States is important yet beyond the scope of this review. Supporting publications for this review are available in Appendix D.

### 1. Characterizing the Full Clinical Spectrum of Long COVID and Diagnostic Strategies

There has been substantial progress on the first of seven research areas identified in the NRAP. The NIH RECOVER Initiative has studies of electronic health records and observational cohort studies that describe the clinical spectrum and natural history of Long COVID in a variety of populations. The RECOVER Initiative has been able to identify a variety of subtypes of Long COVID, although the precise subtypes are still not well defined. These efforts are complemented by studies from the VA and CDC that have identified the preventive impact of vaccines on Long COVID. The next steps will be leveraging the data on the clinical spectrum of Long COVID to understand how the condition can be diagnosed, as there is currently limited research on this need.



One major gap in this research is the development and assessment of diagnostic tests and protocols for Long COVID. For diagnostic-related questions to be answered, first the pathobiology and biological mechanisms of the set of conditions that define Long COVID need to be understood better. As biomarkers of Long COVID are identified, there may be a pathway for diagnostic test development, and then their effectiveness can be assessed on identified cohorts of people with Long COVID that have been developed as part of other research efforts.



**For diagnostic-related questions to be answered, first the pathobiology and biological mechanisms of the set of conditions that define Long COVID need to be understood better.**

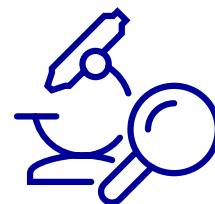


Example publication: Richard SA, Pollett SD, Fries AC, et al. **Persistent COVID-19 symptoms at 6 months after onset and the role of vaccination before or after SARS-CoV-2 infection.** [published correction appears in *JAMA Netw Open.* 2023 Feb 1;6(2):e230734]. *JAMA Netw Open.* 2023;6(1):e2251360. Published 2023 Jan 3. doi:10.1001/jamanetworkopen.2022.51360

## 2. Pathophysiology

Research into the pathophysiology, or the underlying biologic cause, of Long COVID is critical to advancing research related to diagnostics, treatment, and clinical care. While there have been a variety of publications with small sample sizes that have generated hypotheses of the pathophysiologic mechanisms of Long COVID, there have only been a handful of manuscripts that provide strong evidence to support hypotheses. These research efforts have been funded predominantly by NIH grants and have been conducted by multiple academic groups. A major aim of the RECOVER Initiative is to understand the biological underpinnings of Long COVID, and research questions related to pathophysiology will be answered using large cohorts of patients and advanced methodologies. Current literature suggests that there are at least five main mechanisms for the underlying causes of

**Research into the pathophysiology, the underlying biologic cause, of Long COVID**



**is critical to advancing research related to diagnostics, treatment, and clinical care.**

Long COVID: viral persistence and reactivation, immune dysregulation/autoimmunity, dysbiosis of the microbiome, the presence of microclots, and dysfunctional neurological signaling. RECOVER has funded more than 42 studies investigating the pathophysiology of Long COVID and this work is underway.



Example publication: Frere JJ, Serafini RA, Pryce KD et al. (2023) **SARS-CoV-2 infection in hamsters and humans results in lasting and unique systemic perturbations post recovery.** *Sci Transl Med.* 2022;14(664):eabq3059. doi:10.1126/scitranslmed.abq3059


### 3. Surveillance and Epidemiology

The main surveillance efforts have been conducted by CDC. Multiple approaches are used to monitor the occurrence of Long COVID across the population. Using epidemiologic monitoring, modeling, and survey data, multiple estimates of incidence and prevalence have been produced to understand the impact of Long COVID. Electronic health records and observational cohort studies by NIH's RECOVER Initiative and DOD's EPICC study also provide additional insights into the incidence, prevalence, risk and protective factors, duration, and impacts of Long COVID. The Household Pulse Survey, led by the Census Bureau with collaboration from other entities including CDC, is a leading effort that has been able to assess activity limitation, demographic factors, and the impact of Long COVID by state. The Household Pulse Survey data is regularly updated but is not analyzed in depth as it is released. Instead, other groups have used the released data as the backbone of their analysis to answer important questions about Long COVID. Data on Long COVID are also captured in the National Health Interview Survey and the National Health and Nutrition Examination Survey. Both surveys, conducted by CDC's National Center for Health Statistics, include information on symptoms and potential impact of Long COVID and provide these data in the context of other health conditions and healthcare utilization. In addition to CDC surveys, the Centers for Medicare and Medicaid Services (CMS) uses the Medicare Current Beneficiary Survey to further understand the epidemiology of Long COVID.

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**Multiple approaches are used to monitor the occurrence of Long COVID across the population.**

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Example publication: Bull-Otterson L, Baca S, Saydah S, et al. **Post-COVID Conditions Among Adult COVID-19 Survivors Aged 18–64 and ≥65 Years – United States, March 2020–November 2021.** *MMWR Morb Mortal Wkly Rep* 2022;71:713–717. DOI: <http://dx.doi.org/10.15585/mmwr.mm7121e1>

## 4. Long COVID and Overall Well-Being

Few publications have been released related to the overall well-being of individuals with Long COVID. The released studies have been fairly limited in scope and there is a need for a broad effort to understand the needs of people with Long COVID and their caregivers outside of clinical care. One example, the [Health+ Long COVID Report](#), describes narratives from people with Long COVID and what they want and need to live better, healthier lives. In April 2023, the Food and Drug Administration (FDA) held a [patient-focused drug development meeting](#) on Long COVID and the information gathered at that meeting will assist in answering many of these questions when the findings are published.



**There is a need for a broad effort to understand the needs of people with Long COVID and their caregivers outside of clinical care.**

The Administration for Children and Families (ACF) Office of Planning, Research and Evaluation has a number of [research projects and products](#) addressing the impact of the COVID-19 pandemic on children and families, but less focus has been given to the direct impact of Long COVID on educational and developmental outcomes. The pediatric cohort studies within the RECOVER Initiative, which are currently underway, will assist in answering this question. Additionally, HRSA's National Survey of Children's Health Longitudinal Cohort will provide information about the longer-term impacts of the COVID-19 pandemic on educational outcomes, as well as other child and young adult health and well-being outcomes.



Example publication: Admon AJ, Iwashyna TJ, Kamphuis LA, et al. **Assessment of Symptom, Disability, and Financial Trajectories in Patients Hospitalized for COVID-19 at 6 Months.** *JAMA Netw Open.* 2023;6(2):e2255795. Published 2023 Feb 1. doi:10.1001/jamanetworkopen.2022.55795

## 5. Treatments and Other Health Interventions

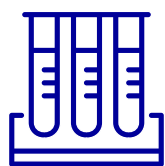
Progress has been made towards identifying interventions that may reduce the rate and severity of Long COVID. A generalized finding is that interventions that reduce the severity of COVID-19 infection may also reduce the risk of later developing Long COVID. For example, publications from the VA, CDC's INSPIRE study, and NIH RECOVER Initiative concluded that vaccination prior to COVID-19 infection reduced the risk and severity of Long COVID. Studies of electronic health records at the VA reported that treatment of acute COVID-19 with nirmatrelvir or molnupiravir prevented a subset of participants from developing Long COVID, but

**In studies from the VA, CDC, and NIH, vaccination prior to COVID-19 infection reduced the risk and severity of Long COVID.**



another study of the same records was inconclusive. These studies are all retrospectively observational in nature, meaning that they are examining existing data, which limits the analysis of a specific intervention on outcomes. Further research is needed, including prospective investigations using blinded randomized controlled trials, to fully understand the ways to prevent Long COVID.

Studies of treatments for Long COVID are underway. The RECOVER Initiative launched clinical trial platforms to test several interventions focused on different aspects of Long COVID that will provide additional information about the effectiveness of treatments. There are also initiatives in the private sector focusing on Long COVID treatment. Additionally, a published study from DoD identified a decrease in Long COVID symptoms following vaccination. This effect was only seen at 6 months post infection in individuals who had not been previously vaccinated, but this study did provide evidence for potential treatment pathways moving forward.



**Further research is needed, including prospective investigations using blinded randomized controlled trials, to fully understand the ways to prevent Long COVID.**

Some people with Long COVID have reported using a variety of alternative treatments, including ones that may not be supported by reliable evidence or may even be contraindicated by future research. Consequently, there is a need to study treatments being used by the public for which there is no scientific evidence base. There has been some work in this field, such as an NIH-supported study that concluded that neither ivermectin nor fluvoxamine treatment during COVID-19 infection had an impact on the rate of Long COVID. Additional research and monitoring will be needed to ensure people are not being harmed by unproven Long COVID treatments.



Example publication: Xie Y, Choi T, Al-Aly Z. **Association of Treatment With Nirmatrelvir and the Risk of Post-COVID-19 Condition.** *JAMA Intern Med.* 2023;183(6):554-564. doi:10.1001/jamainternmed.2023.0743

## 6. Human Services and Supports

There is little published research addressing the services and supports needs of individuals with Long COVID. There is a need to identify gaps in access to services in a quantitative manner to inform the creation of interventions. To support this need, the Administration for Community Living (ACL) National Institute on Disability, Independent Living, and

**There is a need to identify gaps in access to services in a quantitative manner to inform the creation of interventions.**



Rehabilitation Research has funded research to identify methods to allow individuals with cognitive impairments due to Long COVID to return to work and to promote positive employment outcomes.



Report: National Academies of Sciences, Engineering, and Medicine. **Addressing the Long-Term Effects of the COVID-19 Pandemic on Children and Families.** Washington, DC: The National Academies Press 2023. <https://doi.org/10.17226/26809>

## 7. Health Services and Health Economics Research

The research questions posed in the NRAP related to health services and economics cover a wide range of topics. Although some areas have several publications seeking to answer the research questions, there is an overall research gap on this topic. Further research on access to care, especially among diverse populations, will be required to understand how best to deliver Long COVID care.

Early research has highlighted the utility of multidisciplinary care centers for the treatment of patients with Long COVID. AHRQ has commissioned an evidence review summarizing different models of care for managing adults and children with Long COVID. This review will include a review of the literature and input from key informants. In addition, AHRQ is funding an [initiative](#) to expand access to comprehensive, coordinated, and person-centered care for people with Long COVID and to ensure equitable access to care for people that are most impacted by Long COVID. These efforts by AHRQ will support clinicians in caring for persons with Long COVID.



**Research has highlighted the utility of multidisciplinary care centers for the treatment of patients with Long COVID.**

The Household Pulse Survey, mentioned above, has been an essential starting point for studies related to the broader economic impacts of Long COVID. Governmental, academic, and private groups have used Household Pulse data to estimate the overall cost of Long COVID as well as the potential impact of Long COVID on employment rates, although these studies have not been peer reviewed. As the relationship between Long COVID and the ability to work is further understood, future studies will be able to predict the economic impacts of Long COVID more accurately.



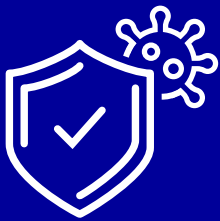
Example publication: Pike J, Kompaniyets L, Lindley MC, Saydah S, Miller G. **Direct Medical Costs Associated With Post-COVID-19 Conditions Among Privately Insured Children and Adults.** *Prev Chronic Dis.* 2023;20:E06. Published 2023 Feb 9. doi:10.5888/pcd20.220292



## Conclusion

The currently published research has laid the groundwork for future discovery of Long COVID causes, prevention, diagnosis, treatment, and outcomes. Understanding who has Long COVID and the clinical presentation of the condition is informing further studies to investigate the underlying mechanisms of disease and providing information that could lead to targeted treatments. There have been highly impactful publications related to preventing Long COVID that implicate the utility of vaccination and antiviral drugs.

The goal of these research efforts is to not only help people who are currently experiencing Long COVID, but also to prevent new cases. While there are still many unanswered questions, work underway at multiple agencies is moving forward with this goal in mind. Upcoming clinical trials and efforts centered on clinical care are likely to have substantial impacts on patient experiences. Additional research on each of the above research questions is required and careful consideration of the current results will be required to ensure productive studies are conducted.



**The goal of these research efforts is to not only help people who are currently experiencing Long COVID, but also to prevent new cases.**

## Health Equity in Research

- Inclusive and diverse participation in Long COVID research helps ensure that the results of the research are applicable to the wide range of populations affected.
- Meaningful patient and community engagement is a guiding principle of RECOVER, which has intentionally engaged patients, caregivers, and individuals from communities most affected by SARS-CoV-2 at nearly all levels of the Initiative. RECOVER includes a National Community Engagement Group and, at the level of enrolling sites, collaborates with the NIH Community Engagement Alliance Against COVID-19 Disparities program.
- Research methods must establish the validity of instruments in diverse populations that are the focus of the studies.
- Ensuring that interventions for Long COVID are effective and accessible for diverse populations enhances future uptake and effectiveness. This includes language access and culturally competent care.

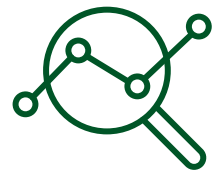


Table 1. Research Activities. This table presents completed, ongoing, and planned Long COVID research activities. Activities are organized under the objectives they support.

**Domain 1 | Research:** Support research to better understand the clinical spectrum, trajectory, underlying causes, prevention, diagnosis, and treatment of Long COVID.

*Obj 1.1 Diagnosis: Based on understanding of the full clinical spectrum of Long COVID, identify effective diagnostic strategies, including development of effective diagnostics devices.*

Activities	Agency
<p>CDC is leveraging the <a href="#">STOP ME/CFS</a> study which conducts ongoing syndromic surveillance of chronic, unexplained fatigue to identify and characterize patients with ME/CFS-like illness following SARS-CoV-2 infection. The COVID-SELECT sub-study will identify and describe patients who have Long COVID symptoms through prospective follow-up. CDC is funding the <a href="#">COVID-UPP</a> study, which assesses participants' health over time using surveys, physical exams and medical tests to compare differences and similarities between Long COVID and ME/CFS.</p>	<p>CDC</p>
<p>DoD is conducting the <a href="#">Epidemiology, Immunology, and Clinical Characteristics of Emerging Infectious Diseases with Pandemic Potential</a> (EPICC) study. This study includes aims described across multiple objectives. Aims include describing the natural history of clinical disease, identifying risk factors for infection and severe clinical course, characterizing the host immune response, and developing and operationally assessing diagnostic and prognostic tools for the study of novel pathogens.</p>	<p>DoD</p>
<p>NIH's <a href="#">RECOVER Initiative</a> aims to improve understanding of and ability to predict, treat, and prevent post-acute sequelae of SARS-CoV-2 infection (PASC). RECOVER includes longitudinal observational studies across the lifespan, EHR studies, pathobiology and tissue pathology studies, a mobile health platform, clinical trials, and a patient registry.</p> <ul style="list-style-type: none"> <li>• Studies analyzing electronic health records have focused on topics including how many people get Long COVID, common symptoms, racial disparities, subphenotypes, and how to identify people with Long COVID from their health records. These studies include more than 60 million health records and 27 manuscripts have been published to date.</li> <li>• The RECOVER Longitudinal Observational Cohort is measuring incidence and prevalence, who gets Long COVID, clinical presentation, and subphenotypes. As of January 2024, &gt;12,000 adults, &gt; 14,000 children, and &gt;2,000 pregnant people are enrolled across approximately 200 study sites. An interim analysis of the adult cohort study has been published, identifying a set of symptoms that are more distinctive for individuals with PASC than for those who don't have PASC.</li> <li>• Pathobiology and tissue pathology studies aim to answer questions about the underlying biological mechanisms, clinical biomarkers, and organ systems involvement of Long COVID, which will help with diagnosis and identify potential therapeutic targets and biomarkers.</li> </ul>	<p>NIH</p>

Activities	Agency
<p>VA is using data from over 700,000 individuals with COVID-19 to learn more about Long COVID. This includes building on already published analyses of EHR data on <a href="#">kidney</a>, <a href="#">cardiovascular</a>, <a href="#">mental health</a>, <a href="#">neurologic</a>, <a href="#">endocrine</a>, and <a href="#">gastrointestinal</a> outcomes in people who had COVID-19. VA studies also <a href="#">evaluated the effectiveness of vaccines in reducing risk of Long COVID</a> and characterized the risks of <a href="#">repeated infections</a> on acute and long-term COVID outcomes. Other VA research findings show <a href="#">vaccine</a> and <a href="#">booster</a> effectiveness against infection and death. Ongoing VA studies seek to evaluate the effectiveness of antivirals in reducing risk of Long COVID.</p>	VA

*Obj 1.2 Pathophysiology: Understand the pathophysiology of Long COVID from molecular to systems levels, including within the broader context of post-infectious chronic illnesses.*

Activities	Agency
<p>CDC is partnering with the National Academies of Science, Engineering, and Medicine (NASEM) to study Long COVID and infection associated chronic illness. A number of chronic illnesses, from persistent Lyme disease to ME/CFS to Long COVID, have been associated with prior infectious disease. However, the link between infection and long-lasting symptoms remains poorly understood, leading to limited treatment options for the often debilitating symptoms of infection-associated chronic illnesses. A <a href="#">June 2023 workshop</a> brought together clinicians, researchers, and other stakeholders, including RECOVER leadership and investigators, to examine common biological and clinical factors associated with these chronic illnesses, discuss potential strategies to treat or prevent disease progression, and increase collaboration among stakeholders to build a community of shared priorities that can enhance patient care.</p>	CDC
<p>The EPICC study includes aims related to understanding the correlation between symptom severity, virologic and microbiologic characteristics, the host immune response, and clinical course and outcomes such as Long COVID.</p>	DoD
<p>The <a href="#">RECOVER Initiative</a> includes pathobiology and tissue pathology studies that aim to answer questions about the underlying biological mechanisms, clinical biomarkers, and organ systems involvement of Long COVID.</p> <p>NIH also plans to award <a href="#">R01</a> and <a href="#">R21</a> studies to understand the neurological effects of COVID-19 and PASC.</p>	NIH

*Obj 1.3 Surveillance and Epidemiology: Engage in coordinated and enhanced surveillance to assess the prevalence, potential health impacts, risk and protective factors, and overall disease burden of Long COVID across demographic groups, taking into account the impact of survivor bias, and as the landscape changes (e.g., new variants, new treatments).*

Activities	Agency
<p>The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is following cohorts of Long COVID Medicare beneficiaries, examining long-term utilization and diagnoses in matched cohorts for each COVID-19 variant.</p> <p>ASPE is analyzing the Household Pulse Survey to understand trends in Long COVID by select sociodemographic categories.</p> <p>ASPE is analyzing the Current Events Tracker to understand knowledge and attitudes towards Long COVID of the U.S. population.</p>	ASPE
<p>CDC is taking a multipronged approach to surveillance. Their work leverages electronic health records to estimate the burden of Long COVID. Questions on Long COVID have been included in several national health surveys including National Health Interview Survey, National Health and Nutrition Examination Survey, Household Pulse Survey, and the Behavioral Risk Factor Surveillance System. CDC has also analyzed Household Pulse <a href="#">data</a> on Long COVID. CDC has published multiple reports on the burden and occurrence of Long COVID in the <a href="#">MMWR</a> to rapidly disseminate information.</p> <p><a href="#">TrackPCC</a> is a multi-year sentinel surveillance project that will investigate the burden and impact of Post-COVID Conditions (PCC) in diverse populations within the United States. TrackPCC entails both passive and active surveillance and long-term follow-up of cohorts in collaboration with public health, academic, and healthcare partners.</p> <p>CDC's <a href="#">INSPIRE</a> study aims to describe the long-term effects of COVID-19 infection. In this entirely virtual study, more than 6,000 participants completed online surveys and shared their medical information over 18 months, leveraging innovation to address the pressing needs for answers.</p> <p>The <a href="#">COVID-RELIEF</a> study tracks electronic health records of adult inpatients and outpatients who test positive and negative for SARS-CoV-2 and documents symptoms and medical conditions for an average of 2 years after infection to investigate risk factors for SARS-CoV-2 infection that is severe or leads to long-term illness.</p>	CDC
<p>The Medicare Current Beneficiary Survey (MCBS) is a continuous, multipurpose survey of a nationally representative sample of the Medicare population conducted by CMS through a contract with NORC at the University of Chicago. The MCBS provides important information on health outcomes and social determinants of health not available in the administrative program data. In 2021, questions relating to Long COVID were added to the survey. Analysis of the collected data will provide insights into the impact of Long COVID on the Medicare population.</p>	CMS

Activities	Agency
<p>DOD’s EPICC study includes aims to identify risk factors, characterize the host immune response and the relationship to the clinical course and outcomes, and establish a database and specimen repository for future studies of novel pathogens.</p> <p>DoD has also established a COVID registry which includes data from over 950,000 individuals with COVID-19 and allows rapid access to electronic health records of DoD beneficiaries with COVID-19. Uniformed Services University has also established the COVID-19 Military Registry Analysis Project (MRAP) study to analyze registry data. As of February 2023, 496,000 individuals with a prior diagnosis of COVID-19 had accessed health care for at least one Long COVID symptom, demonstrating the scale of the challenge and the difficulty of distinguishing Long COVID from common health problems. The DoD also conducted a review of Service Members separated from active duty for Long COVID.</p>	DoD

*Obj 1.4 Well-Being: Understand the impacts of Long COVID on overall well-being, including: educational outcomes, physical health, behavioral health, education, employment, disability, and family and caregiver well-being.*

Activities	Agency
<p>CDC is working with partners to study the impact of Long COVID on workforce and the workplace. This includes tracking long-term COVID-19 impacts using <a href="#">workers' compensation systems</a> and federal surveys (such as the National Health Interview Survey and National Health and Nutrition Examination Survey) that collect employment-related information.</p>	CDC
<p>The National Survey of Children’s Health Longitudinal Cohort is a survey that will provide information about longer-term impacts of the COVID-19 pandemic on educational outcomes, as well as other child and young adult health and well-being outcomes. Public data and linked Medicaid claims data are expected to be available in early 2025.</p>	HRSA
<p>The <a href="#">Health+ Long COVID</a> Report shares findings from qualitative research of patients experiencing Long COVID and associated conditions, caregivers, frontline workers, and those with lived experience. HHS will continue to utilize innovative human-centered design to engage partners to build creative solutions to Long COVID’s toughest challenges.</p>	OASH
<p>The Social Security Administration (SSA) is funding research focused on how Long COVID may affect health, employment, and participation in Social Security programs. SSA has sought insight via <a href="#">forums</a>, workshops, <a href="#">standing committee meetings</a>, and a <a href="#">consensus study committee</a>. Workshops include:</p> <ul style="list-style-type: none"> <li>• <a href="#">The Use of Telehealth for Disability Evaluations in Medicine and Allied Health: A Workshop</a></li> <li>• <a href="#">Long-Term Health Effects Stemming from COVID-19 and Implications for the Social Security Administration: A Workshop</a></li> </ul> <p>In 2022, SSA compiled and published research and statistics detailing the demographic makeup of SSA program populations. In addition, SSA made their <a href="#">Racial Equity Research, Statistics, and Data Resources</a> available to the public.</p>	SSA



*Obj 1.5 Treatments and health intervention: Identify effective therapies and interventions to prevent Long COVID, improve the health and well-being of people living with Long COVID, and cure Long COVID.*

Activities	Agency
<p>A major goal of the EPICC study is to inform Military Health System clinical care and practice guidelines to improve clinical care and management of those with COVID-19 and Long COVID. Study aims also include investigating the efficacy of emergency use authorization and Investigational New Drug (EUA and eIND) therapies and preventions that may be administered to enrolled study participants during the course of clinical care.</p>	DoD
<p>FDA is responsible for assuring the safety, effectiveness, and quality of products intended to treat, diagnose, or prevent Long COVID.</p> <p>FDA has an internal working group that meets regularly to coordinate across centers.</p> <p>They held a <a href="#">Patient-Focused Drug Development for Long COVID</a> meeting to obtain patient input on aspects of Long COVID, including how Long COVID affects their daily life, symptoms that matter most to patients, their current approaches to coping with Long COVID, and what they consider when determining whether to participate in a clinical trial.</p> <p>FDA is working with NIH and external partners to expand the <a href="#">CURE-ID</a> platform to capture data in a patient portal, including treatment of Long COVID, to incorporate person-centered outcomes and reports into CURE-ID. This includes the development of a patient treatment survey on what symptoms people with Long COVID have been experiencing, what drugs they have tried, and what impact they felt the treatments had on their symptoms, if any.</p>	FDA
<p>The RECOVER Initiative has identified five focus areas for clinical trials:</p> <ol style="list-style-type: none"> <li>1) viral persistence/reactivation and immune dysregulation</li> <li>2) autonomic dysfunction</li> <li>3) neurologic and cognitive dysfunction</li> <li>4) exercise intolerance and fatigue</li> <li>5) sleep disturbances</li> </ol> <p>RECOVER is implementing adaptive <a href="#">platform protocols</a> for each focus area to maximize the potential to discover medical breakthroughs. Platform protocols include shared endpoints, regulatory frameworks, and common data elements; shared approach to patient inclusion; ability to rapidly assess target therapeutics; cross-trial analysis; and development of PASC-validated patient-reported outcomes.</p> <p>The first RECOVER clinical trials <a href="#">launched</a> in July 2023, focused on treatment targeting viral persistence and interventions for cognitive dysfunction. Additional trials will launch in the coming months.</p>	NIH

*Obj 1.6 Human Services and Supports: Identify and evaluate optimal person-centered models of support to ensure individuals living with Long COVID and associated conditions can fully participate in their communities.*

Activities	Agency
<p>ACF partnered with NASEM to publish a report on <a href="#">Addressing the Long-Term Impact of the COVID-19 Pandemic on Children and Families</a>, which includes recommendations to recover from the harms of the pandemic and to address the inequities that have made the pandemic’s impact disproportionate. The report also includes recommendations for research.</p>	ACF
<p>ACL is funding three research projects to develop and test interventions aimed at improving cognitive functioning and employment among people with Long COVID. Two of these projects are 3-year efforts: <a href="#">Technique to Enable Return-to-Work by Employees with Long COVID Brain Fog</a> (FY22-FY24) and <a href="#">Intensive Attention Training to Treat Brain Fog in Individuals with Long-COVID</a> (FY23-FY25). The third project <a href="#">awarded by ACL</a> is a 5-year grant, <a href="#">Living and Working with Disabilities &amp; Long COVID</a> (FY23-FY27), for research to understand how individuals with disabilities, particularly those with intersectional identities, are living and working with Long COVID and test an intervention - job crafting - to promote positive work outcomes.</p>	ACL
<p>The Department of Labor (DOL) and Social Security Administration are partnering to test early interventions to help workers stay at work or return to work quickly after experiencing the onset of a work-threatening injury, illness, or disability, like Long COVID, through <a href="#">Retaining Employment and Talent after Injury/Illness Network (RETAIN)</a>.</p>	DOL, SSA

*Obj 1.7 Health Services and Health Economics Research: Develop, implement, and evaluate models of health care delivery that reduce barriers to effective care for Long COVID and associated conditions; and expand understanding of the economic costs of Long COVID.*

Activities	Agency
<p>AHRQ has commissioned an <a href="#">evidence review</a> summarizing different models of care for managing adults and children with Long COVID, with contextualized findings for the U.S. setting. This review will include a review of the literature and input from key informants.</p>	AHRQ
<p>AHRQ and NIH are partnering to develop a standards-based, interoperable, electronic care (e-care) plan designed to facilitate aggregation and sharing of critical person-centered data across home, community, and clinical settings to support research and to improve the care of people living with multiple chronic conditions who are at increased risk for adverse outcomes from COVID and developing Long COVID. The project has identified standardized data elements for Long COVID and incorporated them into the e-care plan. Additional details can be found at <a href="#">Understanding COVID-19 Trajectory and Outcomes in the Context of Multiple Chronic Conditions (MCC) through e-Care Plan Development</a> and <a href="#">Multiple Chronic Conditions e-Care Plan Project</a>.</p>	AHRQ, NIH

Activities	Agency
<p>CDC collected health data through a <a href="#">Multi-site Post-COVID Conditions Study</a> (MPCC) to describe the health and medical care of patients at clinics designed for Post-COVID care to help classify types of Post-COVID health problems and care needed, and highlight unmet needs for care in other medical settings.</p> <p>CDC is conducting a <a href="#">study</a> of a clinician education intervention delivered via the ECHO distance learning platform. The study aims to determine the effectiveness and feasibility of a program focused on multi-specialty case-consultation and peer-to-peer sharing of emerging best practices to support management of complex cases associated with Long COVID, ME/CFS, and other post-infectious fatiguing illnesses.</p>	CDC
<p>VA is launching the Long COVID Practice Based Research Network (LC-PBRN), which will generate more rapid insights into the care and outcomes of VA patients with Long COVID.</p>	VA

# What is RECOVER?



One of the most comprehensive and diverse patient-centered research programs to understand, treat, and prevent Long COVID.



**Over 29,000 participants enrolled**  
(including adults, children, and pregnant people)



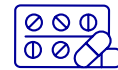
**Over 60 million electronic health records analyzed**



**Over 40 studies of the biological details**  
of Long COVID  
(its pathobiology)



**Comprehensive tissue collection**  
and tissue pathology studies



**Five clinical trial platform protocols**  
to test treatments for Long COVID

## RESEARCH TO...

Understand clinical spectrum/biology underlying disease trajectory over time

Define risk factors, numbers of people getting Long COVID, and if there are specific different types of Long COVID

Study how Long COVID progresses over time and how that may relate to other illnesses

Identify possible treatments for Long COVID

*Continues on next page*

# What is RECOVER? *(continued)*



## Meaningful Patient Engagement

Engage patients, patient groups, and caregivers in the research.

- The **National Community Engagement Group is a forum central to RECOVER** that provides input into RECOVER research, communication activities, and more.
- **Patients, caregivers, and community members are involved at all levels**, including serving on the Executive Committee, Steering Committees, **scientific working groups**, oversight committees, and on local Community Advisory Boards.
- **More than 1,000 patients participated in some way in protocol design, trial application review, and/or symptom survey development.**



## Enrolling Clinical Cohorts

Studying >29,000 adult and pediatric participants from 200+ sites across the country.

- Adult and pediatric observational cohorts are enrolled and in-depth follow-up of participants is being conducted.
- First analysis of interim results published; identified PASC sub-phenotypes and proposed a research tool with specific symptom criteria of PASC.
- Understanding the impact of different COVID-19 variants and vaccination on Long COVID.
- Biomarker testing underway.
- PASC prevalence in adults.



## Long Standing Community-based Cohorts

Leveraging more than 14 existing longitudinal community-based cohorts with 49,000 adults and 12,000 children.

- More than 17,000 sero-surveys (testing of blood serum) performed in adults, with more than 7,680 COVID cases identified.
- Risk factor data analysis underway.
- Incidence and prevalence across variants.



## Leveraging Real World Data

Understand incidence, prevalence, risk factors over time; capture data with minimal participant burden; define sub-phenotypes to inform clinical approaches. From these data, we know...

- **Computable phenotypes of post-COVID symptoms in adults and children.**
- **COVID vaccination reduces risk of Long COVID.**
- Prevalence in children.
- Risk factors for development of Long COVID in adults and children.
- Increased risk of certain new-onset conditions in PASC patients.



## Testing Potential Therapies (Clinical Trials)

Investigating major symptom clusters and their potential causes; and evaluating treatments to improve Long COVID symptoms.

- Integrated **suite of 5 adaptive platform clinical trials** to evaluate multiple treatments across 5 domains: viral persistence/reactivation and immune dysregulation; neurologic/cognitive dysfunction; autonomic dysfunction; sleep disorders; and cardiopulmonary, exercise intolerance, fatigue.
- Testing known and novel interventions across broad range of treatment types (drugs, devices, rehabilitation, etc.).
- Developed 5 adaptive master protocol platforms testing 13 interventions—two trials began enrolling in 2023 (focused on viral persistence/immune dysregulation and neurological/cognitive dysfunction) and the others will open to enrollment in 2024 (focused on autonomic dysfunction, sleep disorders, and cardiopulmonary/exercise intolerance/fatigue).



## Pathobiology and Tissue Pathology Studies

Conducting studies to learn **how the human body is affected by Long COVID**, as well as to enable identification of biomarkers; discovery of therapeutic targets that inform clinical trials; and improved diagnosis, monitoring, and patient stratification.

- **More than 42 pathobiology studies focused on the effects of SARS-CoV-2 infection, including the immune response, inflammation, autoimmunity; epigenetics, multi-omics; and animal models.**
- In-depth tissue pathology studies of multiple tissue types underway.



## Clinical Practice

The federal government provides some direct care to persons with Long COVID through the VA, DoD, and Indian Health Service (IHS). However, most of the activities in this domain are focused on helping providers outside the government access the tools and evidence they need to provide care. This includes educating providers that Long COVID and its symptoms are real, to reduce the stigma that patients may face when seeking care. Many of the challenges faced are part of much larger structural challenges within the U.S. healthcare system. Solutions will not come quickly or easily, but we are committed to grappling with the challenge. [Professional associations and other groups](#) working on clinical guidance also play a vital role.

**Many of the challenges faced are part of much larger structural challenges within the U.S. healthcare system.**



## Health Equity in Clinical Practice

- Everyone should have access to high-quality prevention and care.
- Individuals who are medically underserved and historically marginalized communities include but are not limited to racial and ethnic minority groups, people living in rural areas, people with disabilities, people with limited English proficiency, and LGBTQ+ people. These groups may also be disproportionately impacted by COVID-19 and Long COVID.
- Models of care should consider ways to expand access to care, such as hub-and-spoke models with primary care, and telehealth options.
- Clinician training on Long COVID should include primary care clinicians serving populations in rural and underserved areas, especially those disproportionately impacted by the pandemic.
- Clinician education is needed to reduce stigma around Long COVID and associated conditions.
- Payment models and systems should ensure that high-quality Long COVID care and treatment is accessible for all patients.



Table 2. Clinical Practice Activities. This table presents completed, ongoing, and planned activities related to Long COVID clinical practice. Activities are organized under the objectives they support.

**Domain 2 | Clinical Practice:** Promote tools and resources to enable preventive measures, support reliable and timely diagnosis, and expand access to high-quality, effective care and treatment for people with Long COVID and associated conditions across the country.

*Obj 2.1 Models of care: Promote person-centered, multidisciplinary, coordinated models of care, including telehealth.*

Activities	Agency
<p>AHRQ is funding the <a href="#">“Implementing and Evaluating New Models for Delivering Comprehensive, Coordinated, Person-Centered Care to People with Long COVID”</a> initiative to expand access to comprehensive, coordinated, and person-centered care for people with Long COVID, particularly underserved, rural, and other populations that are disproportionately impacted by the effects of Long COVID. This initiative funds nine multidisciplinary Long COVID clinics to (1) develop and implement new or improved care delivery models, (2) provide services to more people with Long COVID, (3) expand services offered, (4) strengthen care coordination, (5) implement and share best practices for Long COVID management, (6) support the primary care community in Long COVID education and management, (7) evaluate project success, and (8) disseminate project findings.</p>	AHRQ
<p>HRSA is working with community health centers across the country to improve Long COVID care for underserved communities, using telehealth and technical assistance. The <a href="#">Telehealth Technology Enabled Learning Program</a> connects specialists at academic medical centers with primary-care clinicians in rural, frontier, and underserved populations, providing evidence-based training and support to help them treat patients with complex conditions in their communities, including Long COVID.</p>	HRSA
<p>The Indian Health Service (IHS) is working with healthcare providers to support Long COVID care for American Indian and Alaska Native communities using telehealth and technical assistance. The IHS expanded telehealth using technology and providing specialists as resources for primary-care clinicians in rural, and underserved American Indian and Alaska Native populations. Training and support on using the technology and resources is provided to help treat patients with complex conditions, including Long COVID, in their communities.</p>	IHS
<p>VA has identified prevalent models of care in providing Long COVID care to Veterans and across the different modalities (in-person, tele-health, and video visits). Models may range from a dedicated Long COVID program at a specific VA Medical Center, Clinical Resource Hubs which will regionalize the care across a Veteran Integrated Service Network, as well as a Nationally Designated Tele-Health Hub (NDTH) which would provide access to Long COVID care across a range of specialists that would cover national needs across the VHA enterprise. The NDTH will leverage a Digital Population Health Management Solution which would help scale and automate clinical workflows while driving clinical insights driven by analytics on a cloud backend to support digital screen and subsequent clinical care needs.</p>	VA

*Obj 2.2 Clinical Guidance: Facilitate development and dissemination of comprehensive and equitable Long COVID diagnosis, care, and treatment guidance.*

Activities	Agency
<p>VA created the first <a href="#">Whole Health System Approach to Long COVID guide</a> (PDF) in the country. It equips healthcare providers with a patient-centered holistic approach to caring for patients with Long COVID. It includes 10 one-page guides for signs, symptoms, and treatment recommendations to facilitate a patient-centered approach to caring for Veterans with Long COVID. The guide provides helpful information at-a-glance, including links to additional information if desired.</p> <p>Because it was the first of its kind, VA continues to provide Long COVID tools and expertise to federal and state governments and private sector health care partners.</p> <p>VA is deploying a Digital Population Health Management Solution at five of its health systems, offering a digital screening platform by email and text to rapidly identify those with Long COVID to provide clinical intervention and support. The Whole Health approach is integrated in the nature of the screening questions to help clinicians rapidly identify and meet those who need care. The Solution allows clinicians to target Veterans of certain demographics, ethnicity, gender, rurality, as well as clinical qualifiers to ensure equitable Long COVID diagnosis and engagement across the Veteran population.</p>	<p>VA</p>

*Obj 2.3 Clinician Education: Promote accurate information and accelerate and disseminate clinical support and best practices to promote coordinated, integrated care models.*

Activities	Agency
<p>CDC maintains an <a href="#">Information for Healthcare Providers</a> webpage on Long COVID. CDC is working with the American Academy of Physical Medicine and Rehabilitation to improve coordination and dissemination of clinical knowledge of recovery and symptom management of Long COVID. CDC also supports continuous learning through Clinician Outreach and Communication Activity (COCA) <a href="#">webinars</a> on Long COVID and in partnership with <a href="#">Project ECHO</a>.</p>	<p>CDC</p>

*Obj 2.4 Expanded care: Expand access to high-quality Long COVID care for impacted populations.*


Activities	Agency
<p>The IHS is committed to working with federal and tribal partners as well as tribal communities to educate, identify, assist, and treat American Indian and Alaska Native people with Long COVID, according to the best available science.</p>	IHS
<p>OASH is in discussions with primary care professional associations and other government agencies about how to better support primary care clinicians to work with people with Long COVID. Being able to receive Long COVID diagnosis and care at the primary care level will greatly expand access, as many people do not live near Long COVID clinics.</p>	OASH
<p>VA is establishing a Nationally Designated Tele-Health Hub for Longitudinal Care to provide care to Veterans, no matter where they live as well as to support VA Medical Centers who do not have established Long COVID Programs. The VA National Long COVID program is a unified approach to care, support, and services across VHA facilities, with a robust referral and follow-up system. Veterans work with a team of specialists, including neurology, pulmonology, cardiology, psychiatry and mental health, and other wellness modalities to provide the most comprehensive, Whole Health care possible.</p> <p>There are now 25 Long COVID Programs which also serve an additional 16 spoke sites.</p>	VA

*Obj. 2.5 Payment and Reimbursement: Promote payment and reimbursement models that support complex, coordinated, person-centered care.*

Activities	Agency
<p>CMS developed educational materials on using the <a href="#">ICD-10 code for Long COVID</a>.</p>	CMS
<p>OASH is leading discussions across HHS to investigate coverage, payment, and reimbursement models for complex chronic conditions, such as Long COVID.</p>	OASH

## Services and Supports

The federal government provides and funds many services and programs that may be able to support people with Long COVID. These programs were detailed in the [Services and Supports Report](#) released in August 2022. Since then, numerous agencies have continued to add new resources to help people with Long COVID understand what programs they might qualify for and how to access them. They have also issued resources for individuals with Long COVID to help them understand their rights under Federal civil rights laws including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, Section 1557 of the Patient Protection and Affordable Care Act, and other federal laws and requirements that may apply. Substance Abuse and Mental Health Services Administration (SAMHSA) has published two reports on the mental and behavioral health impacts of Long COVID and evidence-based resources for treatment.



**The federal government provides and funds many services and programs that may be able to support people with Long COVID.**

### Health Equity in Services and Supports

- Individuals from underserved populations may experience multifaceted systemic barriers to accessing human services, supports, and interventions for Long COVID.
- People with Long COVID may be protected under disability rights laws, such as the Americans with Disabilities Act.
- Resources are available to help people with Long COVID understand their rights and the protections and accommodations that they may offer.





Table 3. Services and Supports Activities. This table presents completed, ongoing, and planned activities related to Long COVID services and supports. Activities are organized under the objectives they support.

**Domain 3 | Services and Supports:** Support people living with Long COVID and associated conditions, particularly in communities most impacted by the pandemic.

*Obj 3.1 Access to Services: Increase knowledge of available services and supports and reduce barriers to accessing them to support all aspects of daily life.*

Activities	Agency
DOL partnered on a <a href="#">State Scan of Long COVID Responses and resources</a> .	DOL
OASH is leading discussions across the U.S. government to improve how we communicate available <a href="#">services and supports</a> .	OASH
SSA published <a href="#">Long COVID: A Guide for Health Professionals on Providing Medical Evidence for Social Security Disability Claims</a> on the SSA website. This guide describes the kinds of medical evidence the SSA needs to evaluate disability claims filed by individuals with Long COVID and can support clinicians and patients in gathering evidence for claims.	SSA

*Obj 3.2 Behavioral Health: Support the mental and behavioral health needs of individuals, families, and caregivers affected by Long COVID.*

Activities	Agency
SAMHSA published two reports on mental health and Long COVID. <a href="#">Overview of the Impacts of Long COVID on Behavioral Health</a> provides a summary of the evidence on Long COVID’s behavioral-health implications, including associated disorders, neuropsychiatric causes, and future research needs. <a href="#">Identification and Management of Mental Health Symptoms and Conditions Associated with Long COVID</a> discusses the epidemiology of mental health symptoms and conditions of Long COVID and provides evidence-based resources for their treatment. SAMHSA has also held two subject matter expert panels focused on establishing the state of mental health assessment and treatment for Long COVID and the promotion of equitable Long COVID community-based care.	SAMHSA

*Obj 3.3 Disability Rights Protections: Promote disability rights protections, including reasonable modifications and accommodations, for qualified individuals with disabilities affected by Long COVID.*

Activities	Agency
<p>ACL launched <a href="#">the DIAL</a>, a call-in service that provides information to people with disabilities, including information related to Long COVID as a disability. They have also hosted <a href="#">webinars</a> on <a href="#">Long COVID and the ADA</a>, and maintain <a href="#">web resources</a> on <a href="#">Long COVID</a>.</p>	ACL
<p>DOJ provides technical assistance for questions related to Long COVID and the ADA through its <a href="#">information line</a>, including how to file a complaint. In the case of a complaint of discrimination against somebody with Long COVID by a business or state or local government, DOJ may investigate and take enforcement action if applicable.</p>	DOJ
<p>DOL is working to provide employers and employees with the tools and information necessary to support continued engagement in the workforce for those impacted by Long COVID. They have published a <a href="#">report</a> with possible solutions to workplace challenges posed by Long COVID as well as a <a href="#">guide for employers</a>, which provides information and resources to help employers support employees with Long COVID so they can maintain employment. They also published a blog on <a href="#">Long COVID and FMLA</a> and maintain several <a href="#">web pages</a> as <a href="#">resources</a>.</p>	DOL
<p>The Department of Education (Ed) provides <a href="#">information</a> about Long COVID as a disability and about schools' and public agencies' responsibilities for the provision of services and reasonable modifications to children and students for whom Long COVID is a cause of disabilities.</p>	Ed
<p>The Equal Employment Opportunity Commission (EEOC) provides detailed information on <a href="#">What You Should Know About COVID-19 and the ADA, the Rehabilitation Act, and Other EEO Laws</a>, including addressing Long COVID. If an employee or applicant at a private company, a federal agency, or a state or local government agency believes they have been discriminated against based on Long COVID or a related condition, they may file a charge or complaint with the relevant agency so that it can be investigated, litigated, or adjudicated, as appropriate.</p>	EEOC
<p>HHS Office of Civil Rights (OCR) and DOJ are working together to protect people with Long COVID from discrimination and educating them on their rights through national webinars. In addition, their <a href="#">Guidance on Long COVID as a Disability under the ADA</a> helps individuals understand their rights.</p>	OCR
<p>SAMHSA and SSA published guidance on <a href="#">developing SSI/SSDI applications for individuals with Long COVID</a>.</p>	SAMSHA
<p>The SSA is partnering with <a href="#">NASEM</a> to understand the impacts of Long COVID on the SSA. Refer to this link for information on <a href="#">How to Apply for Social Security Disability Benefits (ssa.gov)</a>.</p>	SSA

## Public Education

The government's primary message to the public is that Long COVID is real. While we are still learning about why and how it develops, we do know some ways to reduce the risk of developing Long COVID. An important part of the government response is getting this information to the public and updating it as we learn more. This happens through public health information campaigns like We Can Do This, government agency websites including [Covid.gov/LongCOVID](https://www.covid.gov/LongCOVID), and other communications materials that help people to understand what Long COVID is, how they can protect themselves, and what to do if they get it. The government also relies on non-federal partners to help disseminate these messages to target populations.

**The government's primary message to the public is that Long COVID is real.**



### Health Equity in Public Education

- Educational materials should be culturally appropriate and accessible to all, including multiple languages and formats accessible to those with communication disabilities.
- Campaigns should work with communities disproportionately impacted by COVID-19 to design messaging and materials.
- Resources are available to support patients in seeking care for Long COVID.
- The NIH [Community Engagement Alliance](#) (CEAL) works closely with the communities hit hardest by COVID-19 by sharing information and resources so people can be informed and take steps to overcome COVID-19 and its longer-term impacts.

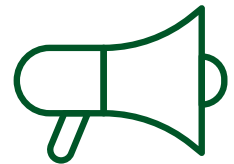


Table 4. Public Education Activities. This table presents completed, ongoing, and planned activities related to public education on Long COVID. Activities are organized under the objectives they support.

**Domain 4 | Public Education:** Disseminate up-to-date information about Long COVID and associated conditions to educate the public.

*Obj 4.1 Public Health Communications: Communicate the risks of Long COVID, how to protect yourself and others, and how to access care and treatment.*

Activities	Agency
<p>The HHS <a href="#">We Can Do This</a> public health education campaign educated the public about the risks of Long COVID and how to best protect yourself and your family. Resources including FAQs, patient stories, messages from experts, and social media posts are available in multiple languages.</p>	ASPA
<p>In addition to providing basic information on Long COVID <a href="#">symptoms, risk factors, and prevention</a>, CDC’s web pages, <a href="#">Patient Tips: Healthcare Provider Appointments for Post-COVID Conditions   CDC</a>, provide assistance with preparing for a Long COVID-related medical visit and information on <a href="#">Caring for People with Post-COVID Conditions   CDC</a>.</p>	CDC
<p><a href="#">Covid.gov/LongCOVID</a> is a repository of timely and accurate information on Long COVID, including links to dozens of federal resources.</p> <p>The Long COVID Communications, Partnerships and Policy Workgroup meets monthly to facilitate clear and consistent communications on Long COVID across federal agencies.</p>	OASH
<p><a href="#">Long COVID: Three Veterans’ Journey video</a> helps veterans recognize Long COVID symptoms and know that they are not alone and that there is hope.</p> <p>The <a href="#">Long COVID Fact Sheet</a> and Symptom Checker is a companion to the clinical guide for veterans, written in plain language. It gives examples of possible symptoms and provides space to write down symptoms to share with health care providers.</p> <p>Additionally, the VA, through the Veterans Experience Office, has designed a series of Long COVID surveys completed by Veterans to better understand the lived journey across COVID and Long COVID. All surveys provide trustworthy educational content, the <a href="#">Veteran Health Library link for Long COVID</a> education on the VA.gov website, as well as links to the informational videos sharing Veterans’ personal journeys through long COVID and their care from the VA. Additionally, the digital screens from the Digital Population Health Management Solution also include those educational assets.</p>	VA

*Obj 4.2 Partnerships: Work together to broaden the reach of public education messages.*

Activities	Agency
The <a href="#">COVID-19 Community Corps</a> is made up of thousands of individuals and organizations dedicated to encouraging their friends, families, and communities to get vaccinated.	ASPA
The NIH <a href="#">Community Engagement Alliance</a> (CEAL) works closely with the communities hit hardest by COVID-19 by sharing information and resources so people can be informed and take steps to overcome COVID-19 and its longer-term impacts.	NIH

## Coordination

With the Presidential Memorandum issued in April 2022, the Office of the Assistant Secretary for Health began coordinating the whole-of-government response to Long COVID. Assistant Secretary for Health, Admiral Rachel Levine, leads the Long COVID Coordination Council, which brings together hundreds of employees from 14 federal agencies to share information and resources, discuss strategies and challenges, and respond to emerging issues. The Council has since stood up five workgroups to tackle specific issues, such as service eligibility and disability rights protections, with two more workgroups expected by the end of 2023.

OASH also coordinates with external partners and other external stakeholders, learning about their work and making connections with the right agencies to move forward together. OASH has held more than 70 partner meetings with organizations ranging from state health departments to patient advocacy groups and has completed a partner mapping process to identify gaps in partner engagement that we are working to fill.

HHS is partnering with [NASEM](#) to examine the [interim federal working definition](#) of Long COVID and associated technical terms for various uses, such as clinical practice, research, surveillance, and public education. The interim federal working definition was published last August in the two reports. NASEM is building from that definition, engaging diverse stakeholders, and reviewing the current literature to help us move forward in our understanding of Long COVID.

### Health Equity in Coordination

- Engagement with diverse stakeholders including people with Long COVID and associated conditions, caregivers, clinicians, and advocates guides OASH in coordinating the federal response to Long COVID.

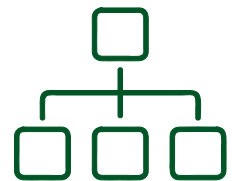




Table 5. Coordination Activities. This table presents completed, ongoing, and planned activities related to coordination of the US federal government response to Long COVID. Activities are organized under the objectives they support.

**Domain 5 | Coordination:** OASH will coordinate the whole-of-government response to Long COVID in order to increase efficiency, facilitate knowledge sharing, and leverage available resources.

*Obj 5.1 Federal infrastructure: Develop a structure to engage federal stakeholders in national efforts to address Long COVID treatment, prevention, and research.*

Activities	Agency
<p>The Office of Long COVID Research and Practice was created within the Office of the Assistant Secretary for Health to respond to the emerging challenges posed by Long COVID and the longer-term impacts of COVID-19.</p> <p>The Assistant Secretary for Health chairs the Long COVID Coordination Council. The Council was created in May 2022 and meets regularly to share information across 14 federal agencies. The Council supports topic-specific workgroups that meet monthly to promote collaboration and communication to tackle tough cross-cutting Long COVID issues, including</p> <ul style="list-style-type: none"> <li>• Communications, Partnerships, and Policy</li> <li>• Service Eligibility and Disability Rights Protections</li> <li>• Data and Surveillance</li> <li>• Research</li> <li>• Coverage, Reimbursement, and Payment</li> <li>• Clinical Practice</li> <li>• Behavioral Health</li> </ul> <p>HHS is working to establish the Secretary’s Advisory Committee on Long COVID to bring perspectives from outside the government to help inform action of the Executive Branch on Long COVID and associated conditions.</p>	<p>OASH</p>

*Obj 5.2 External partnerships: Develop partnerships and ongoing communication with external stakeholders including researchers, professional associations, state, local, and tribal governments, advocacy organizations, community-based organizations, and relevant industries.*

Activities	Agency
<p>The <a href="#">CDC Foundation, in partnership with CDC through a cooperative agreement</a>, is working with patient partner organizations, including community-based organizations, patient advocacy groups, and patient and caregiver groups focused on raising awareness and helping people with Long COVID and other infection-associated chronic conditions. The goal is to build capacity to develop tools and relationships to increase responsiveness of systems and practitioners to the medical and social support needs of individuals affected by these conditions.</p>	<p>CDC</p>
<p>Federal agencies regularly meet with external partners and other external stakeholders to make connections and move forward together. Engagement with external partners is a bedrock of our work. Listening and learning from patients, advocates, clinicians, researchers, and everyone impacted by Long COVID helps us do our job better.</p>	<p>OASH</p>

*Obj 5.3 Definitions: Coordinate the development and dissemination of updated working definitions for Long COVID to harmonize work across different entities.*

Activities	Agency
<p>HHS is partnering with the <a href="#">National Academies of Medicine</a> to examine the <a href="#">interim federal working definition</a> of Long COVID and associated technical terms for various uses, such as clinical practice, research, surveillance, and public education.</p>	<p>ASPR, OASH</p>

*Obj 5.4 Data sharing: Coordinate data sharing across federal agencies.*

Activities	Agency
<p>OASH is leading discussions with 14 U.S. government departments and agencies to facilitate the development of shared metrics around Long COVID.</p>	<p>OASH</p>

# GAPS AND FUTURE DIRECTIONS

## Research

As detailed in the previous sections, the federal government has made investments in Long COVID research, and while much work is underway, until there are validated diagnostic methods and effective ways to prevent and treat Long COVID, there will be outstanding research needs. The current path forward focuses on understanding the underlying biologic mechanisms of Long COVID to allow for the development of diagnostics and treatments. These underlying mechanisms remain poorly understood. Based on observational studies, we have made substantial progress in identifying potential methods to prevent Long COVID. Interventional trials will be important to strengthen supporting evidence. Current NIH RECOVER funding will allow the completion of studies currently underway and in development, but more funds will be needed beginning in 2025 to enable follow-up of longer-term patient outcomes, understanding underlying pathogenesis, and testing of additional candidate interventions in adults and children.



**The current path forward focuses on understanding the underlying biologic mechanisms of Long COVID to allow for the development of diagnostics and treatments.**

Currently standards of care for patients with Long COVID do not have a strong evidence base. Health services research, such as the efforts underway at AHRQ, should develop care models that provide Long COVID patients with high quality care in efficient and sustainable ways. Beyond clinical care, there is little research on how to effectively and efficiently deliver the supports and services people with Long COVID need. Without this research, social service programs are left to guess at the needs of a diverse group of patients. In particular, while we know Long COVID occurs among children, we do not have a full picture of the prevalence or impact on children's education and other development.

Finally, there is a gap in understanding the economic and financial impacts of Long COVID. There are estimated to be millions of Americans currently experiencing Long COVID, yet there are few analyses of the potential cost of the condition. By understanding the magnitude of healthcare and support services needs of people with Long COVID, the federal government and state governments will be better able to plan for the needs of their populations.

**There are estimated to be millions of Americans currently experiencing Long COVID, yet there are few analyses of the potential cost of the condition.**



## Clinical Practice

Patients with Long COVID need help now to manage their symptoms. Patients report difficulty accessing care and long wait times at specialty clinics. In addition, there are some clinicians who don't believe that Long COVID is real, or don't believe patient-reported symptoms, and patients may experience stigma when trying to seek care. This can be compounded by existing inequalities in the healthcare system for women, people with pre-existing conditions, and people of color. Clinician associations have begun to create expert guidance for the treatment of Long COVID (e.g., [AAPM&R](#)), but more evidence is needed. In the meantime, living evidence reviews and guidance that incorporates current knowledge and best practices and adapts with the changing evidence base may be an important intermediate step. We must continue to build clinicians' knowledge and skills, leveraging lessons from Long COVID clinics and other infection-associated chronic conditions. We will also continue to work across HHS to investigate care models that are person-centered, financially sustainable, and support coordinated care across disciplines.



**Difficulty accessing care can be compounded by existing inequalities in the healthcare system for women, people with pre-existing conditions, and people of color.**

## Services and Supports

The [Services and Supports for Longer-Term Impacts of COVID-19](#) report is a comprehensive inventory of benefits that may be available to help those impacted by Long COVID. Yet we have not measured whether people with Long COVID are aware of these services, if they are accessing them, and if they are encountering barriers. A better understanding of service awareness and utilization could improve outreach and education efforts.

Numerous federal agencies are dedicated to serving individuals disabled by Long COVID, yet there seems to be a large gap in knowledge and utilization of accommodations to continue daily life. Simultaneously, employers, education systems, and health and human service providers may be unaware of the rights of people with disabilities including Long COVID and associated conditions.



**Numerous federal agencies are dedicated to serving individuals disabled by Long COVID, yet there seems to be a large gap in knowledge and utilization of accommodations to continue daily life.**

## Public Education

Since the start of the pandemic, there have been massive investments in educating the public about COVID-19. Building on the public education investments for COVID-19 are efforts to increase awareness of Long COVID. Many individuals and even clinicians remain unaware of the potential longer-term impacts of COVID-19. It is particularly important to increase awareness of promising potential preventive measures against Long COVID, including vaccination and treatment for COVID-19.

**It is important to increase awareness of promising potential preventive measures against Long COVID, including vaccination and treatment for COVID-19.**



## Coordination

This work takes time, especially in the current resource constrained environment. Creating new offices, new advisory committees, and new coordinating structures is not fast or easy. Working across funding streams, across agencies, and across cultures is hard work. But it is necessary, and the new Office of Long COVID Research and Practice will help to centralize and emphasize the importance of these efforts. HHS will continue to build and nurture the structures, relationships, and communications necessary to build synergies and avoid redundancies across the federal government and with external partners. Ultimately, this requires dedicated funding and support, both at the federal and state level.

We will continue to listen to people with Long COVID and other stakeholders and work with federal colleagues, Congress, and the private sector to prioritize needs and fill these gaps.



**HHS will continue to build and nurture the structures, relationships, and communications necessary to build synergies and avoid redundancies.**



## APPENDIX A

# REFERENCE DOCUMENTS

[Executive Order 13995](#), Ensuring an Equitable Pandemic Response and Recovery (January 2021)

[FACT SHEET: Biden-Harris Administration Marks Anniversary of Americans with Disabilities Act and Announces Resources to Support Individuals with Long COVID](#) (July 2021)

[Presidents COVID-19 Health Equity Taskforce](#) (October 2021)

[National COVID-19 Preparedness Plan](#) (March 2022)

[Memorandum on Addressing the Long-Term Effects of COVID-19](#) (April 2022)

[FACT SHEET: The Biden Administration Accelerates Whole-of-Government Effort to Prevent, Detect, and Treat Long COVID](#) (April 2022)

[Services and Supports for the Longer-term Impacts of COVID-19](#) (August 2022)

[National Research Action Plan on Long COVID](#) (August 2022)

[Health+ Long COVID Report](#) (November 2022)

[FACT SHEET: Biden-Harris Administration Makes Progress in the Whole-of-Government Response to Long COVID](#) (April 2023)

## APPENDIX B

# REPORT ABBREVIATIONS

ADA	Americans with Disabilities Act
COCA	Clinician Outreach and Community Activity
COVID-19	Coronavirus disease of 2019
EHR	Electronic health records
EPICC	Epidemiology, Immunology, and Clinical Characteristics of Emerging Infectious Diseases with Pandemic Potential
FMLA	Family and Medical Leave Act
ICD-10-CM	10th revision of the International Statistical Classification of Diseases and Related Health Problems
INSPIRE	Innovative Support for Patients with SARS-CoV-2 Infections
ME/CFS	Myalgic encephalomyelitis/chronic fatigue syndrome
MMWR	CDC's Morbidity and Mortality Weekly Report
NASEM	National Academies of Science, Engineering, and Medicine
NRAP	National Research Action Plan on Long COVID
PASC	Post-acute sequelae of SARS-CoV-2 infection
PCC	Post-COVID-19 Conditions
RECOVER	Researching COVID to Enhance Recovery (NIH Initiative)
RETAIN	Retaining Employment and Talent After Illness Injury Network
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2

## APPENDIX C

# CONTRIBUTING U.S. GOVERNMENT ENTITIES

### Departments

Department of Defense (DOD)  
Department of Education (ED)  
Department of Energy (DOE)  
Department of Health and Human Services (HHS)  
Department of Homeland Security (DHS)  
Department of Housing and Urban Development (HUD)  
Department of Justice (DOJ)  
Department of Labor (DOL)  
Department of the Treasury (DOT)  
Department of Veterans Affairs (VA)  
Equal Employment Opportunity Commission (EEOC)  
Federal Emergency Management Agency (FEMA)  
National Council on Disability (NCD)  
Office of Personnel Management (OPM)  
Social Security Administration (SSA)

### HHS Divisions

Administration for Children and Families (ACF)  
Administration for Community Living (ACL)  
Agency for Healthcare Research and Quality (AHRQ)  
Centers for Disease Control and Prevention (CDC)  
Centers for Medicare & Medicaid Services (CMS)  
Food and Drug Administration (FDA)  
Health Resources and Services Administration (HRSA)  
Indian Health Service (IHS)  
National Institutes of Health (NIH)  
Office for Civil Rights (OCR)  
Office of Global Affairs (OGA)  
Office of Intergovernmental and External Affairs (IEA)  
Office of the Assistant Secretary for Administration (ASA)  
Office of the Assistant Secretary for Health (OASH)  
Office of the Assistant Secretary for Planning and Evaluation (ASPE)  
Office of the Assistant Secretary for Preparedness and Response (ASPR)  
Office of the Secretary (IOS)  
Office of the Surgeon General (OSG)  
Substance Abuse and Mental Health Services Administration (SAMHSA)

# SUPPORTING PUBLICATIONS

## 1. Characterizing the Full Clinical Spectrum of Long COVID and Diagnostic Strategies

- Al-Aly Z, Xie Y, Bowe B. High-dimensional characterization of post-acute sequelae of COVID-19. *Nature*. 2021;594(7862):259-264. doi:10.1038/s41586-021-03553-9
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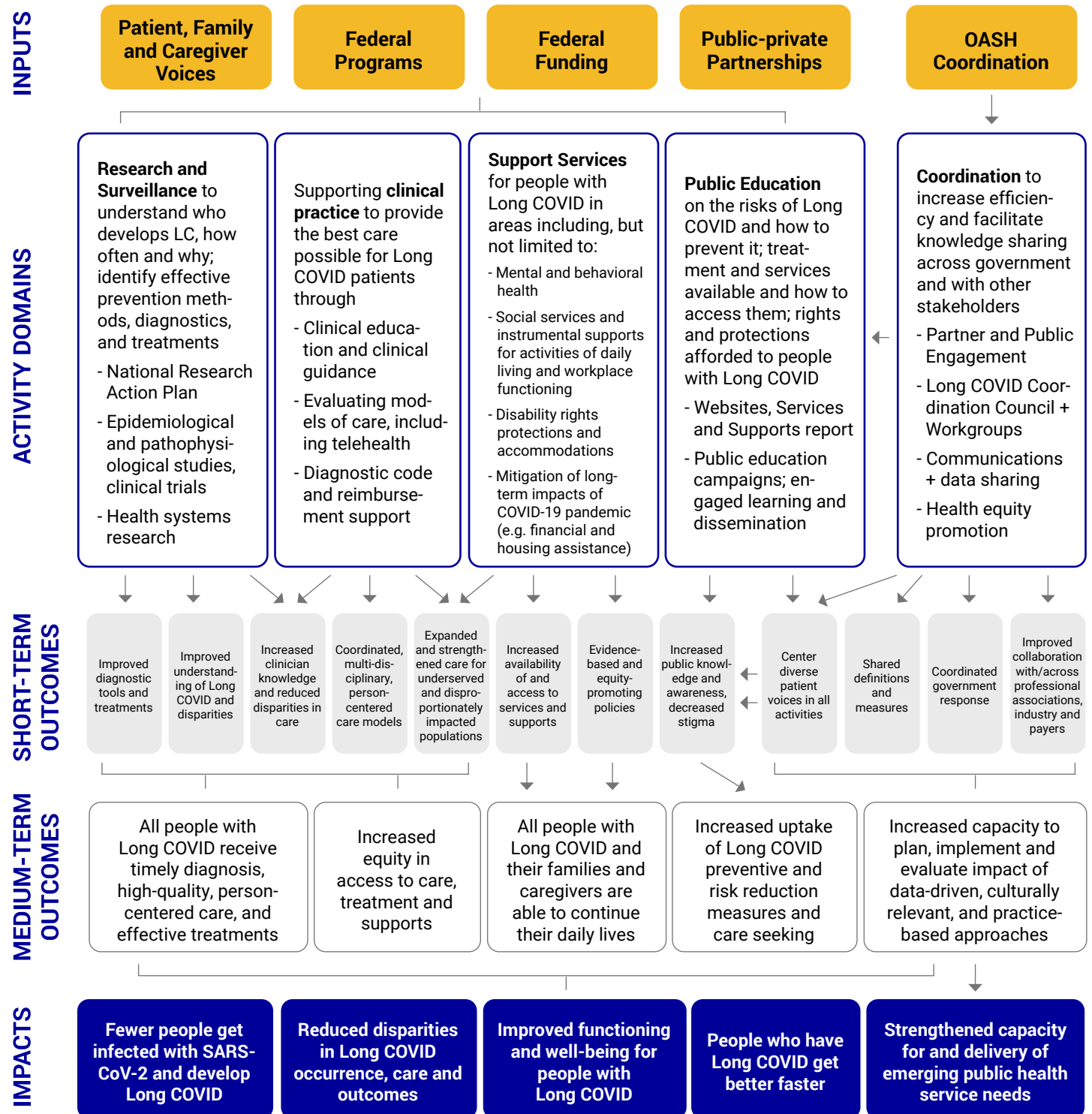
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## APPENDIX E - UNITED STATES GOVERNMENT

# LONG COVID LOGIC MODEL

This U.S. government logic model underpins our federal organizational structure, working with internal and external partners and stakeholders. Health equity is embedded in all the activities, even where not explicitly stated.

**United States Long COVID Logic Model Goal:** To reduce the impacts of Long COVID



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