Long Covid
Long Covid is a serious and sometimes disabling condition affecting millions. Despite a $1 billion Congressional allocation, research into its incidence, causes and treatments has been achingly slow. The Biden Administration must appoint a long Covid point person who can corral agencies to accelerate studies already begun, launch new ones and address gaps in the health and social service support system for current and future patients.

### Fatigue, Brain Fog, and Curtailed Work Schedules

Over the past two years, vaccines, treatments, and increased immunity have blunted the short-term risk of hospitalization and death from Covid. But as the pandemic transitions to endemic, the nation remains unequipped to address Covid’s long-term health impacts, which are formally known as Post-Acute Covid Syndrome and informally as long Covid.

The CDC defines long Covid as “a wide range of new, returning, or ongoing health problems people can experience four or more weeks after first being infected” by SARS-CoV-2. Long Covid has been linked to over 200 symptoms, from fatigue, brain fog to shortness of breath. It seems to manifest in organ systems ranging from the heart to the lungs and gastrointestinal tract.

Although the reported frequency of long Covid in early studies of Covid patients varied from 5% to 60%, working estimates suggest the syndrome affects 1 in 3 infected patients. Even if this is an over-estimate, the numbers are daunting. For example, if only 1 in 20 progresses to long Covid the US is facing the prospect of more than 4 million people with long Covid. Importantly, patients who have asymptomatic or mild infections can still be affected by long Covid. Evidence to date clearly illustrates that long Covid’s distribution reflects the same health inequities characterizing Covid infections and deaths, with studies indicating that people of color and low socioeconomic status are at greater risk of developing long Covid. While estimates have primarily relied on data from adult patients,

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infected children are also at risk of developing long Covid. Estimates in early studies of children have found incidence rates of 1% to 27%60,61. At the moment, there is no specific treatment for long Covid. But preliminary data suggests that vaccination can reduce the risk of long-term health effects after infection.62

The symptoms of long Covid can persist for months with major impacts on people’s lives, social interactions, and the larger economy. Nearly half of long Covid patients have cut back on their work schedules63 and nearly a quarter have stopped working entirely.64 Long Covid within the US military creates new national defense risks.65 If Covid becomes endemic, then there is a risk that many more Americans will experience long Covid, creating huge and lasting health impacts that may rival the pandemic itself.

Long Covid was first identified as a problem in May 202066, with the National Institutes of Health (NIH) launching its first study on long Covid in June 2020.67 As the pandemic progressed, reports of the disease’s frequency and severity mounted, and in December 2020, Congress allocated over $1 billion to long Covid research.68

Despite the large numbers of infected patients and generous government funding, much of the progress so far can be attributed to patient advocacy and non-NIH funded research.69,70 The return on federal investments has been poor, and knowledge about long Covid remains limited.

Long Covid’s causes, incidence, risk factors and most effective prophylactics and treatments are still mysteries.

Multiple challenges have contributed to the failure to understand this important disease. Research done so far has been siloed, with barriers to sharing resources and data. Initiation of critical cohort studies has been slow, inhibiting the generation of longitudinal, population-level data.

Current long Covid research lacks a long-term focus, which risks creating further delays for therapy development. Most importantly, there is no urgency to get rapid answers to basic questions to guide public health and patient care decisions.

There were over 200 long Covid studies registered on ClinicalTrials.gov as of February 2022, but only 8 are

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funded by the NIH. Even though millions if not tens of millions of Americans suffer from long Covid, 74% of all studies — including 7 of the 8 NIH-funded studies — are either in the “recruiting” or “not yet recruiting” stage. Worse, the proposed completion date for many studies is at least 2 years away. The NIH is in the process of developing a national long Covid study platform: Researching Covid to Enhance Recovery (RECOVER). Despite a nearly $500 million dollar allocation to the study, recruitment for RECOVER is only just beginning, and no information about the more than 200 proposed clinical sites was available. Finally, people suffering from long Covid are having a hard time navigating the system to get the health and supportive services they need. To be sure, some progress has been made. An ICD-10 code has been established permitting medical billing for treating patients with long Covid. In addition, guidance has been issued clarifying non-discrimination protections for long Covid patients under the Americans with Disabilities Act. But thousands if not millions are still having difficulty navigating the health care and disability systems. Consequently, long Covid needs to be elevated to a national priority on par with vaccines and antiviral therapeutics.

A point person is needed. President Biden should designate a senior health official, such as the HHS Secretary or the US Surgeon General, to chair a long Covid task force, drive interagency coordination, and lead external engagement and public health messaging related to long Covid. The long Covid task force should be separate from the White House Covid task force, as the latter is focused on the acute public health responses to Covid while the former is focused on a chronic, long-term problem facing American society.

This task force needs the authority to coordinate a whole-of-government response, from research activities at the NIH to disability guidance from the Social Security Administration (SSA).

This group must issue clear priorities, with performance metrics and timelines. It must hold agencies accountable. The task force should hold its first convening within 30 days of its creation, and it should commit to providing monthly progress updates until the major issues related to long Covid are addressed.

The task force’s top two priorities should first be conducting a review of all long Covid policies, projects, and programs, and second to accelerate ongoing research initiatives. The task force must ensure that research is focused on characterizing long Covid’s incidence, causes, risk and mitigating factors, and potential therapeutic targets.

There are several research short cuts that should be quickly taken to get rapid answers to crucial questions. First, the CDC already has a long COVID study in the field at sites across the country, and this could rapidly be expanded and used as a key surveillance and research system — and a biorepository could be added. In addition, existing general population research cohorts including the All of Us Research Program, employment-based population cohorts such as the military’s Millennium Cohort Study.

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condition-specific cohorts such as the Jackson Heart Study\textsuperscript{75}, and subgroup specific cohorts such as the Black Women’s Health Study should be used.\textsuperscript{76} Research is especially needed to quantify the risk factors and impact of long Covid on children, communities of color and those with low socioeconomic status. Drawing from existing cohort studies such as Environmental Influences on Child Health Outcomes (ECHO), in addition to prospective enrollment of children will be critical.\textsuperscript{77}

The extensive health data from these studies, combined with targeted collection of Covid information, should facilitate rapid answers to urgent questions about long Covid’s prevalence and incidence, risk factors, patient experience, and the impact of vaccination status. In addition to these efforts, new prospective cohort studies like RECOVER will be needed to improve characterization of the disease. These prospective studies should also collect data on relevant sociodemographic information to help identify and mitigate long Covid disparities.

The Longer Needs of Long Covid

To coordinate this work, the long Covid task force should immediately direct the NIH to stand up a team for long Covid population health science that is responsible for reviewing and partnering with all existing cohort studies for long Covid in the United States. Within 90 days, it should launch a unified, open-access platform that integrates data from all existing long Covid cohort studies.

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Second, the government should rapidly accelerate long Covid research, including driving progress on the NIH’s RECOVER initiative, expanding and strengthening the CDC’s INSPIRE study, and supporting other meritorious research projects and programs. INSPIRE, a CDC-funded long Covid study being conducted in partnership with 8 leading academic health centers, is already using a cloud-based technology platform for these purposes and could offer best practices to other government-funded studies.

To enroll participants in these studies and others, the long Covid task force should work to engender trust in research. Within 90 days, the government should launch a national messaging campaign to meet the RECOVER and INSPIRE enrollment targets and ensure study participants are representative across age, sex, race, ethnicity, disability, and socioeconomic strata. There is also an opportunity to engage partners from previous pandemic-related clinical research endeavors, such as the studies for convalescent plasma and Covid vaccines. ACTIV, the NIH’s platform study for Covid therapeutics development, is an example of an existing clinical trial network that could be used to recruit for long Covid. At least quarterly updates should be published on a public-facing website for accountability and public transparency. Moreover, these studies should be producing data reports at regular intervals leveraging preprint servers, not just using traditional peer-review channels for results communication. When research is published through the peer-review process, these publications should be required to be open access as opposed to held behind firewalls; a policy many journals have adopted for Covid and should be the norm for scientific research beyond the pandemic.


Third, to maximize the impact of RECOVER and other related initiatives, the task force should take steps to ground all long Covid-related research in open science principles. Building on the strong open science precedent set by the $1 billion Cancer Moonshot initiative launched in 2016 by then-Vice President Biden, the long Covid research agenda should emphasize open data to rapidly improve clinical and biospecimen data sharing, foster collaboration and accelerate scientific discovery. For example, the purpose-built data and biospecimen repository cores for the RECOVER study should be opened to integrate data from other efforts to study long Covid, from patient-led initiatives such as Body Politic and Survivor Corps to cohort studies such as the CDC’s INSPIRE and the National Covid Cohort Collaborative. Consolidating all data reporting into a single, publicly accessible platform would not only amplify the impact of research but also improve the ease of rapid-cycle analyses by external scientists. The goal of every federally funded research project should be to produce strong science and to generate data for others to leverage. Moreover, there should be no grace period — as soon as data are available to be shared, they should be shared — not after a period where some investigators get preferential access. The government can support the infrastructure for sharing. In addition, the data and biospecimen resources, which would be fully deidentified, should also link with socioeconomic data to address long Covid health equity issues.

To promote accountability for research investments, in the next 90 days, the task force should direct HHS to launch a public database of federally funded long Covid projects modeled off of the TAGGS platform for general Covid initiatives, and it should issue a set of milestones and key performance indicators for which progress reports are posted at regular intervals. As the Biden Administration helps jumpstart the long Covid research enterprise, it has a rare opportunity to initiate long-term shifts in the culture and practice of biomedical R&D.

Fourth, to streamline the development of medical products for long Covid, the task force should work with the FDA to issue guidance about expectations for authorization and approval of long Covid diagnostics and treatments. Just as the FDA issued prospective guidance about clinical trials for Covid therapies and vaccines, so too should it release guidance addressing evidence standards for long Covid. Key questions include clarifying the applicability of surrogate markers versus clinical endpoints and the use of patient-reported outcome measures. Long Covid cohorts and registries should align data collection and analysis with this guidance to ensure the evidence generated from those studies is optimized to inform therapeutic development. Furthermore, the FDA will need to issue guidance as to whether long Covid products will still be eligible for Emergency Use Authorization even if the formal public health emergency declaration has expired. In parallel, CMS should be tasked with initiating a process to streamline decisions about coverage, coding, and payment processes for long Covid.

Fifth, the long Covid task force should ensure that evaluating care delivery interventions for long Covid receives as much financial support as potential pharmacological interventions. The task force should direct the NIH to begin identifying potential study sites for multi-center care delivery trials and draw from investigators’ experience conducting randomized controlled trials for related conditions, such as Post-ICU Syndrome.
Ensuring Good Care for Survivors

In addition to supporting research for the future, the task force will need to improve clinical care for long Covid patients in the present. As of February 2022, 66 hospitals have launched long Covid-specific clinics. Nevertheless, many patients still struggle to access resources, have their symptoms acknowledged and validated, or receive timely and responsive care. To improve care for these patients, the long Covid task force should in the next 90 days designate an independent entity, such as the National Academy of Medicine, to develop standardized, consensus-based guidelines for managing long Covid. These guidelines should identify best practices for clinicians at each level of the health system, from primary care practices and mental health providers to hospitals and multidisciplinary centers. The review process could be informed by existing resources from the American Academy of Physical Medicine and Rehabilitation, Long Covid Physio, and the burgeoning network of Post-Covid Care Centers.

Beyond clinical management, the task force should ensure policies for disability status and insurance coverage to ensure parity between benefits and services for long Covid and other disabilities. For example, the Social Security Administration could issue guidance to establish long Covid as a medically determinable impairment. The federal government needs to ensure there is capacity and infrastructure to manage the need, including home and community-based services.

With long Covid affecting nearly a third of all infected patients, disability programs are likely to experience unprecedented demand, and processes need to be set up to streamline the application and adjudication process. To this end, the long Covid task force should in the next 90 days commit to setting up a hotline and website that provides easy-to-understand information to the lay public about how to assess whether they are eligible for disability status due to long Covid, and if so, identify the necessary process and requisite documentation for applications.

Lastly, as long Covid becomes part of the next normal, patients and caregivers will need to be supported. Modeled on the Ryan White HIV/AIDS Program, local programs need to be established to provide patient-centered, community-level outreach, support, and care coordination. Mental health should be a particular focal point given both the prevalence of neurological sequelae and the effects of long Covid on the ability to work or conduct the activities of daily life. Disability infrastructure including Centers for Independent Living, Aging and Disability Resource Centers, Parent Training and Information Centers, should all be bolstered and prepared to meet long-Covid survivors across the lifespan and prepared to support them in advocacy and systems navigation. Every part of the health care system — hospitals, nursing homes, rehab facilities, primary and specialty practices — should be analyzed to ensure there is adequate workforce and care delivery infrastructure to meet the needs of long Covid patients. These delivery system investments should be implemented with an eye towards applications for conditions related to long Covid, such as ME/CFS and post-ICU syndrome.

Local programs need to be established to provide patient-centered, community-level outreach, support, and care coordination.

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Long Covid Strategic Goals

1. Establish a long Covid Task Force to coordinate interagency activities for addressing long Covid.
   a. Establish a long Covid task force, chaired by the Surgeon General to coordinate interagency activities for long Covid, create a central node of accountability across the government for Long COVID, and to engage the public.
   b. Complete a first convening of the task force within 30 days, and issue monthly progress on milestones for each of the long Covid priorities below: scientific research, clinical care, and disability and health services.

2. Create a unified scientific and regulatory response for definitively characterizing the incidence, causes, and therapies of long Covid.
   a. Direct HHS, DOD, and the VA to leverage all ongoing US-based cohort and cross-sectional studies for long Covid research. The NIH should coordinate across these departments, and within 90 days issue a public report indicating number of participants with applicable data and outlining key operational steps for rapid answers to questions about incidence, risk factors, and identifying biological causes of long Covid.
   b. Establish a platform within 90 days for integrating long Covid data from all existing and new studies into a single system to enable data and biospecimen sharing, in alignment with patient consent.
   c. Ensure any long Covid studies or registries collect and report relevant sociodemographic data, with detailed information on race and ethnicity, to assess health disparities associated with the syndrome.
   d. Direct the CDC to create an official counter of long Covid patients, analogous to reporting for Covid infections, that is updated at regular intervals and incorporates data from preexisting and new cohort studies. The counter should be updated to include morbidity estimates as data becomes available.
   e. Execute a national public relations campaign to drive enrollment for long Covid cohort studies within 90 days.
   f. Create a public database of all federally-funded long Covid projects and provide quarterly status updates for public accountability.
   g. Require the FDA and CMS to issue guidance on expected evidentiary standards for long Covid in the next 90 days.
   h. Direct the NIH to issue a public plan for multi-center experimental pharmacological and care delivery interventions for long Covid in the next 90 days.

3. Develop consensus-based guidelines and interdisciplinary care models for clinical management of long Covid that are frequently updated.
   a. Direct an independent entity, such as the National Academy of Medicine, to convene patients, clinical leaders, and professional societies to issue and continuously update guidelines for long Covid. An initial set of guidelines should be published within 90 days, and all guidelines should be communicated to both clinical and lay audiences.
   b. Request the US Surgeon General issue a public advisory on long Covid after guidelines are published and initial data from cohort studies becomes available.

4. Ensure adequate health and social support for long Covid patients.
   a. Establish a dedicated hotline and website providing information about disability eligibility and health insurance coverage requirements for long Covid patients in the next 90 days.
   b. Require SSA to issue guidance establishing long Covid as a medically determinable impairment.
   c. Establish parity between insurance coverage for long Covid and for already recognized disabilities.
   d. Analogous to the “Ryan White Act” for HIV/AIDS, propose legislation investing in local support systems for long Covid emphasizing rehabilitation, caregiving, and mental health, and care delivery workforce and infrastructure.