



**Cover Note:**

Dear Mr. Secretary,

The Patient-Led Research Collaborative (PLRC) appreciates the clear and strong commitment to addressing the Long COVID crisis that you expressed during your confirmation hearings. Your [exchange with Senator Young](#) outlined a productive path forward, highlighting the expertise of patient-led groups, and recognizing the need to:

- Prioritize Long COVID research and integrate it into broader health care priorities, especially prevention of chronic diseases.
- Collaborate with providers, researchers, and affected communities to mitigate the impacts of Long COVID.
- Work with Congress to accelerate Long COVID research, while centering the expertise of patient groups and in their experiences with RECOVER.
- Place greater emphasis on establishing efficient drug-based clinical trials and pursuing novel research directions (instead of replicating existing research) towards treatments and cures for Long COVID.
- Invest in innovation in public health, including federal policy supporting telehealth.

PLRC would welcome the opportunity to work with you and your team to pursue these priorities and, in doing so, provide a foundation for preventing and addressing complex chronic conditions more broadly. Toward this end, we have identified a number of ongoing activities within HHS that we believe would be essential to this effort. These are described below. These include important investments in drug-based drug-based clinical trials at the National Institutes of Health (NIH), the development of innovative models of care at the Agency for Healthcare Research and Quality (AHRQ), key analytic and policy efforts at the Centers for Disease Control and Prevention (CDC) as well as the Food and Drug Administration (FDA), and essential mechanisms for leadership and coordination across HHS, notably the Office of Long COVID Research and Practice (OLCRP) under the Assistant Secretary for Health.

We would be happy to discuss this in greater detail with you and your staff.

Sincerely,

The Patient-Led Research Collaborative  
team@patientledresearch.com

## **Long COVID Public Health Priorities Department of Health and Human Services**

**National Institutes of Health:** NIH launched the [RECOVER-TLC program](#) in September 2024, and it has been working in close collaboration with patients and providers. TLC is motivated by the fact that there are no approved treatments for Long COVID, which has left millions of patients suffering and waiting for answers, many for five years or longer. **Continued funding for RECOVER-TLC** will help to identify effective treatments for people whose lives have been upended by Long COVID.

The NIH RECOVER initiative, which began in 2021, has provided a valuable foundation of research findings, but given the uncertainty surrounding the continuity of federal funding for Long COVID research and clinical trials, efforts under RECOVER-TLC that focus on drug-based trials should be prioritized. Patient-led groups and patient-advocates have been instrumental to the NIH RECOVER initiative and the development of RECOVER-TLC, and continued patient-engagement will remain essential. Going forward, it will be important for RECOVER to sharpen its focus on longitudinal research and to ensure the findings and resources it has developed are as robust and accessible as possible. To achieve that, engaging with patient advocates and centering patient expertise will be essential.

**HHS Office of Long COVID Research and Practice: OLCRP provides invaluable leadership for the whole-of-government response to the Long COVID crisis.** It helps to ensure effective coordination across agencies, and it leads public-private sector convenings, issues reports on Long COVID, conducts widespread clinician education, holds workshops, and, by doing so, helps to accelerate the overall U.S. Government response. In addition, the OLCRP helps facilitate the Long COVID Coordination Council and meets regularly to share information across 14 federal agencies and with patient organizations, thus maximizing productivity. The Council supports topic-specific workgroups that meet monthly to promote collaboration and communication to tackle tough cross-cutting Long COVID issues. OLCRP's role could be further strengthened by the **reestablishment of the Secretary's Advisory Committee on Long COVID.**

**Agency for Healthcare Research and Quality:** The [AHRO Long COVID Care Network](#) supports the Long COVID Centers of Excellence (LCCoEs) and is vital to expanding access to care for people with Long COVID and to implementing new care delivery models and evaluating their effectiveness. These multidisciplinary Long COVID clinics reach across the US and advance clinical care and Long COVID education, and they foster and replicate best practices for Long COVID care across Centers and for all healthcare workers. As we are involved as External Contributors to the Network and serve on advisory committees for centers, we have seen firsthand the value of the Network and Centers, and how important it will be for improving patient outcomes and the overall efficiency of patient care.

**Food and Drug Administration:** The **FDA's CURE ID initiative** focuses on the potential efficacy of repurposed pharmaceuticals as treatments for Long COVID and other illnesses. Continued support for the CURE ID platform – with greater support from other HHS organizations – would provide a robust and highly effective mechanism for gathering information from patients and healthcare providers on their real-world experiences in treating Long COVID with repurposed drugs. Supporting research studies using CURE-ID data can accelerate the path to selecting drugs to trial, accelerating and improving the effectiveness of Long COVID clinical trials. Supporting research studies using CURE-ID data can accelerate the path to selecting drugs to trial, accelerating and improving the effectiveness of Long COVID clinical trials.

**Centers for Disease Control and Prevention:** A range of efforts at the CDC help to strengthen public education and awareness about the risk and characteristics of Long COVID, foster clinician education about Long COVID and other IACCs, help to fund state and local health departments, and provide invaluable surveillance and analysis, with data made publicly available and easily visualized via a dashboard. A specific priority is the **Long COVID data collected through the Household Trends and Outlook Pulse Survey**. A partnership between the Census Bureau and the National Center for Health Statistics (NCHS), the HTOPS is a shortshort online survey designed to provide rapid information about the impact of social and economic issues on households in the United States. Since June 1, 2022, the survey has included questions about the presence of symptoms of COVID-19 that lasted three months or longer and the extent to which these symptoms cause activity limitations. This provides critical information on the percentage of U.S. adults who have ever experienced or are currently experiencing post-COVID conditions (Long COVID), as well as the impact of Long COVID on quality of life and productivity. Long term data on the number of Americans affected by Long COVID and its impact are essential to an effective response coordination.

**Other HHS Organizations:** The HHS response to the Long COVID crises also includes important activities at other HHS organizations, including support for people disabled by Long COVID at the Administration for Community Living, focused efforts at the Substance Abuse and Mental Health Service Administration, key studies of the impact of Long COVID at the Centers for Medicare and Medicaid Services and the Social Security Administration, outreach and guidance from the HHS Office of Civil Rights, to name but a few.

### **About PLRC**

Patient-Led Research Collaborative (PLRC) is a fiscally-sponsored research nonprofit whose members are people with Long COVID and infection-associated chronic conditions who come from a diverse range of professional backgrounds. Our mission is to improve the breadth, depth, and speed of global research into Long COVID and associated conditions, and to advocate for

policies that improve the quality of life for Long COVID patients worldwide. We have published over 30 papers on Long COVID and We have published over 30 papers on Long COVID and our work impacts patients and the general public; health care professionals; researchers in academia, government and industry; policy makers in several governmental sectors, including public health agencies and drug regulation; and pharmaceutical and biotechnology companies.

### **Key Facts about Long COVID:**

- **Prevalence:** In the United States alone, at least [6% of American adults](#) and [millions of children](#) are experiencing Long COVID. By the end of 2023, [at least 400 million people worldwide](#) had Long COVID.
- **Severity:** One-fourth of adults with Long COVID report that their symptoms are so severe that [they must significantly limit their daily activities.](#)
- **Recovery from Long COVID:** Recovery rates after the first year are low; studies show only [7–9%](#) are fully recovered after two years, and [6%](#) after three years.
- **Lack of Adequate Care:** Few physicians report being confident [diagnosing and treating Long COVID](#). Only 7% reported being confident diagnosing Long COVID, and even fewer (4%) reported being confident treating it.
- **Economic Impact:** Long COVID results in [an estimated annual global economic cost of \\$1 trillion, with significant impacts to the workforce](#). The workforce impacts result in more material hardship – people with Long COVID are [nearly twice as likely to report housing insecurity](#), [25% report very low food security](#), and [23% have difficulty paying utility bills](#).
- **Military Impact:** [A quarter of Marines](#) who had COVID developed Long COVID, and these Marines showed evidence of long-term decrease in functional performance.