Trump Administration Set to Abolish the Office of Long COVID Research and Practice

The termination follows other steps that appear to target and erase federal responses to the long COVID crisis.

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The Trump administration is set to dismantle the federal government's Office of Long COVID Research and Practice (OLC) this week as part of a larger restructuring of health agencies, sources have told The Sick Times.

This news, also reported by POLITICO and the Substack Inside Medicine, represents another blow among several moves this administration has taken to diminish federal resources for studying and supporting people with long COVID.

The federal Department of Health and Human Services (HHS) launched the OLC in summer 2023, fulfilling plans first set in response to a 2022 order from former President Joe Biden. The office offered input on long COVID programs across the federal government and helped to make connections between agencies and with researchers and advocacy groups.

The OLC's intended role was "coordinator of the government's efforts" to address this complex chronic disease, office director Dr. Ian Simon told The Sick Times in an interview shortly after starting his position in February 2024. In addition to Simon, the office has employed one other full-time staffer and contractors.

Office activities have included supporting research at different federal agencies, promoting best practices for clinical care, identifying support programs that could serve people with long COVID, educating people about the disease, and engaging workers across the government, according to a 2024 report from the OLC. The office helped to commission last year's report from the National Academies of Sciences, Engineering, and Medicine defining long COVID, one source told The Sick Times.

"The office served a really important behind-the-scenes coordinating role," said Meighan Stone, executive director of the advocacy group Long COVID Campaign, in an interview. It ensured "that every possible part of the federal government was engaged on accelerating research and access

to care for long COVID patients." However, the Biden administration "did not often" take the OLC's recommendations, Stone added.

"Losing [the OLC] is a devastating blow—not just to the long COVID community, but to public health as a whole," said Karyn Bishof, founder and president of the COVID-19 Longhauler Advocacy Project, in a statement. "They were our strongest allies: deeply empathetic, mission-driven, and true partners in the fight to understand, address, and prevent long COVID."

An anonymous HHS employee involved with long COVID work told POLITICO that the closure wouldn't save the government any money — and could, in fact, cost the U.S. more money over time. Long COVID is estimated to cost the U.S. $3.7 trillion over five years, according to the economist David Cutler.

In an internal HHS email announcing the office's closure, shared by Inside Medicine and on social media, Simon wrote: "Over the last 3+ years, we have built meaningful connections and fruitful collaborations across the federal landscape to support this work. While our office is closing, we hope that the work we have been dedicated to will continue in some form."

The OLC's closure follows similar targeting of other federal offices and programs that focused on specific health issues. For example, last month, the Trump administration shuttered the HHS Office of Climate Change and Health Equity. This office — also established under Biden — had "helped spur the health sector to reduce greenhouse gas emissions," according to POLITICO's E&E News.

It also follows other moves under Trump to strip resources away from long COVID programs. The President commanded HHS to terminate the Secretary's Advisory Committee on Long COVID before this committee had even started meeting, The Sick Times reported. A website affiliated with the Department of Labor took down resources about long COVID as a disability. And long COVID statistics have been targeted among CDC data purges.

Also under threat: a program supporting long COVID clinics and medical education about the disease. The Agency for Healthcare Research and Quality (AHRQ), a small agency within HHS, had provided grants to twelve clinics across the U.S. to expand their work. Now, the Trump administration may target the AHRQ with layoffs and budget cuts, STAT reported last week. One contract that supported patient engagement for the clinics program has already been canceled, a source told The Sick Times.

There are other federal long COVID initiatives, initiated under Biden, that may be canceled before they can even begin, the source said.

The National Institutes of Health's RECOVER program has been unscathed by federal cuts so far, but advocates are concerned this could quickly change. While HHS Secretary Robert F. Kennedy Jr. pledged to support the research effort during his confirmation hearings, the secretary has failed to push back on any threats to long COVID programs over the last month.

The "decision to abandon long COVID efforts that support and improve care for the millions of

Americans suffering from this condition is unacceptable," Sen. Tim Kaine(D-Va.), who has personal experience with long COVID, told POLITICO.

On social media, people with long COVID, advocates, and allies have expressed deep disappointment with the OLC's closure. Ending this office will contribute to prolonged suffering for millions with the disease, commenters wrote.

"Millions of Americans are suffering, experiencing disability from long COVID," wrote leading researcher Eric Topol on Bluesky. "This abandonment of a key HHS office, despite assurances otherwise, sends a message that will not be forgotten."

The Patient-Led Research Collaborative wrote in a statement that the closure, combined with the Advisory Committee's elimination last month, "raises many questions about the Administration's commitment to progress against this debilitating and complex chronic illness that affects 1 in 19 Americans and keeps millions out of work." These actions also contradict statements made by both RFK Jr. and NIH Director nominee Jay Bhattacharya during their confirmation hearings, PLRC said.

"This would be a devastating time to slow down or stop research for patients who've been waiting over five years for our first steps to get approved drugs," Stone said. In response to the closure, she encouraged people with long COVID and allies to call their representatives and highlight the need for continued federal funding, particularly for the AHRQ clinics program and RECOVER.

Bishof echoed this disappointment, noting that her organization's advocacy had contributed to the office's formation and other important federal government efforts. "To now witness five years of tremendously hard work, progress, and hope unravel in a matter of months is devastating," she wrote. "Without immediate intervention, the U.S. is poised to abandon tens of millions affected by long COVID in the U.S. and as a 'global health leader,' hundreds of millions more."

Closing the OLC is "an all-too-familiar slap in the face for members of the disability community," wrote members of the Long COVID Collective community group in a statement. They called for support from allies: "Out of necessity, those with long COVID, and other sick and disabled folks, have always been committed to supporting each other, but we cannot – and should not – continue to do this alone."

The Long COVID Campaign has made a tool available for people to send calls and emails, while C19LAP has set up a letter to the Trump administration on Action Network. This is "a critical time to reach out and be heard," Stone said.

The Sick Times will continue following long COVID-related news from the Trump administration. Send us tips at editors@thesicktimes.org, or reach out to Betsy on Signal @betsyladyhets.25.

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