Mobilizing State, Local, and Territorial Health Departments to Confront Long COVID Amid the Public Health Consequences of Federal Abandonment and the Erasure of Programs Serving Millions

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C19 LAP — Long COVID & Associated Conditions

COVID-19 LONGHAULER ADVOCACY PROJECT

longhauler-advocacy.org

Disclosures

I have no personal financial relationships to disclose.

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Personal and Organizational Bio

Karyn Bishof, B.S., Founder C19LAP

I am a person with Long COVID, which I developed from a March 2020 COVID-19 infection while working as a firefighter/ paramedic. Prior to becoming a firefigher/ paramedic I was a K-12 educator, coach, and director of athletics. I hold a B.S. in Exercise Science and Health Promotion and I am a single mom with a mixed-indigenous background. I utilize my lived-experience, community connections, and my clinical and educational experience to fight for the tens of millions of people with Long COVID in the U.S. and hundreds of millions globally.

- I founded the COVID-19 Longhauler Advocacy Project in June 2020, which became a nonprofit organization in December 2021.
- I served on the National Academies of Sciences, Engineering, and Medicines committee that developed the Consensus U.S. definition for Long COVID, since adopted across HHS.
- I serve on the NIH RECOVER Initiatives Ancillary Studies committee.
- I have been involved with Long COVID initiatives through AHRQ, NIH, CDC, and CMSS amongst others.
- Publications: The 2024 National Academies of Sciences, Engineering, and Medicine Long COVID Definition: What Clinicians Need to Know | Journal of General Internal Medicine, Long Covid Defined | New England Journal of Medicine, A Long COVID Definition: A Chronic, Systemic Disease State with Profound Consequences | The National Academies Press, and The Kids Are Not Alright: A Preliminary Report of Post-COVID Syndrome in University Students - PubMed

COVID-19 Longhauler Advocacy Project, Inc

The COVID-19 Longhauler Advocacy Project (C19LAP) is a grassroots, patient-led, volunteer 501(c)(3) nonprofit organization founded in June 2020 to advance the understanding of Long COVID and its associated conditions and expedite solutions and assistance to Longhaulers and their families through advocacy, education, research, resource development, and support.

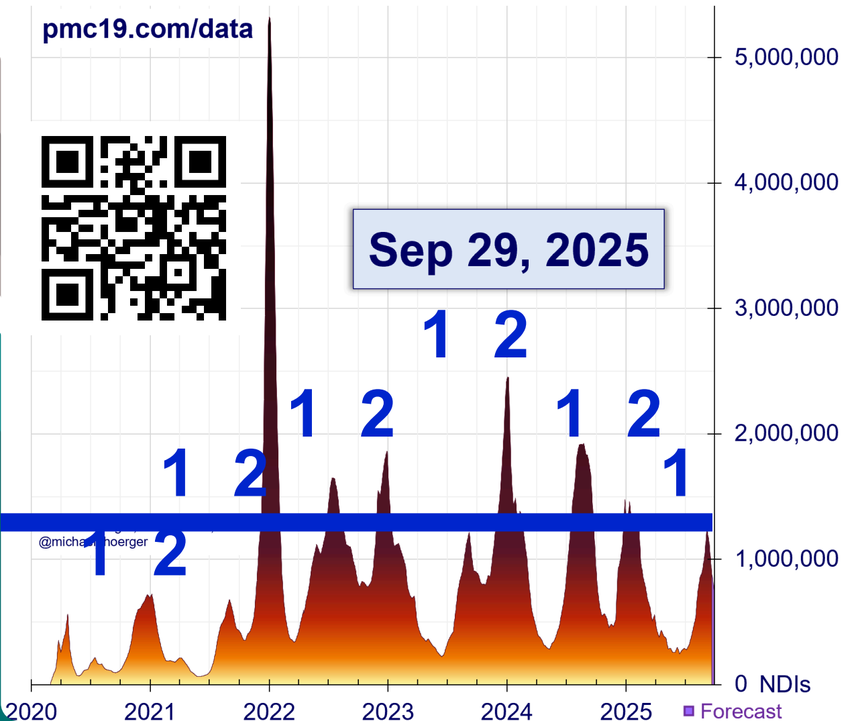
- What began as a single Facebook group has grown into a nationwide network with over 60 state, territorial, and community-based chapters. Today, C19LAP is the longest-standing patient-led Long COVID nonprofit organization in the country and uniquely positioned to lead this initiative as a trusted resource across government, academia, and clinical communities, with formal leadership roles across past and present federal efforts and other key Long COVID initiatives.
- C19LAP believes that education is the foundation of all meaningful progress in the Long COVID space. Our work prioritizes education and resource development, drawing on the collective lived experience of patients and caregivers, as well as deep cross-sector collaboration.

The Data Says the Pandemic Never Ended

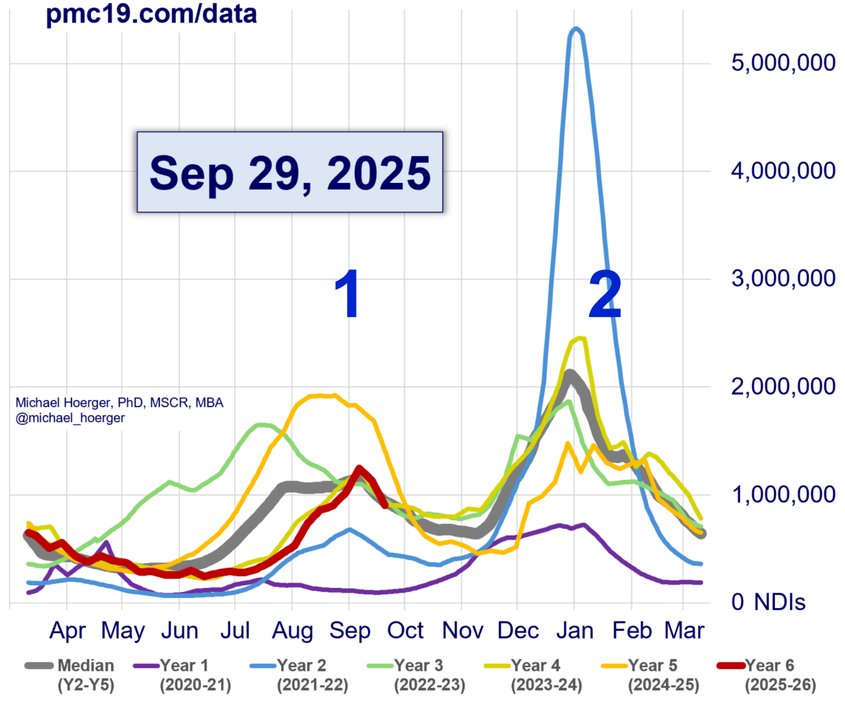
From the very start of the COVID-19 Pandemic, the U.S. failed to adequately respond. While many Long COVID efforts were underway and being stood up, public messaging began pushing the narrative that the pandemic was over and it was under control. This led to premature and costly policy rollbacks and mitigation complacency.

Despite messaging that the pandemic is over, the data proves otherwise. Despite the claim that COVID-19 cases are going down (which they are not), messaging has falsely indicated that the incidence of Long COVID is decreasing. The reality is, COVID-19 cases are higher now than they were in 2020, when we took precautions and treated COVID-19 with the respect that it deserves. Long COVID cases continue to rise, both due to new infections, and due to reinfections which prove to increase the chance of developing, and therefore the prevalence, of Long COVID.

SARS-CoV-2 New Daily Infections, Wastewater-Derived Estimates (U.S.)



SARS-CoV-2 Year-Over-Year Estimates of Transmission (U.S.)



National COVID-19 Estimates (U.S.)

	Sep 29, 2025	pmc19.com/data
Infections		
Proportion Actively Infectious	1 in 66 (1.5%)	
New Daily Infections	743,000	
Infections the Past Week	5,540,000	
Infections in 2025	185,000,000	
Cumulative Infections per Person	4.68	
Long COVID		
Long COVID Cases Resulting from New Daily Infections	37,000 to 149,000	
Long COVID Cases Resulting from New Weekly Infections	277,000 to 1,110,000	
Excess Deaths		
Excess Deaths Resulting from New Daily Infections	210 to 350	
Excess Deaths Resulting from New Weekly Infections	1,600 to 2,600	

Long COVID Definition

The Consensus Long COVID Definition
N.A.S.E.M 2024, Adopted by HHS

Long COVID (LC) is an infection-associated chronic condition (IACC) that occurs after SARS-CoV-2 infection and is present for at least three months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems. LC can affect children and adults, regardless of health, disability, or socioeconomic status, age, gender, sexual orientation, race, ethnicity, or geographic location. LC can follow asymptomatic, mild, or severe SARS-CoV-2 infection and can be continuous from the time of acute SARS-CoV-2 infection or can be delayed in onset for weeks or months following what had appeared to be full recovery from acute infection. LC can impact every organ system. It can last months to years to life, ranging from mild to severe and can present as singular or multiple symptoms and/or conditions.

Why?

NASEM was tasked by OASH and ASPR to develop a consensus definition for Long COVID. There were too many definitions and criteria being used in both research and clinical care, **to be able to make meaningful and accurate use of the data**. The goal was to develop a consensus definition for use to expedite education, research, clinical care, avoid waste, and more. **The definition was adopted.**

- LC can impair individuals' ability to work, attend school, take care of family, and care for themselves. It can have a profound emotional and physical impact on patients and their families and caregivers.
- LC can range from mild to severe. It can resolve over a period of months or can persist for months or years.
- LC can exacerbate pre-existing health conditions or present as new conditions.
- LC can be diagnosed on clinical grounds. No biomarker currently available demonstrates conclusively the presence of LC
- LC can follow asymptomatic, mild, or severe SARS-CoV-2 infection. Previous infections may have been recognized or unrecognized.
- LC can be continuous from the time of acute SARS-CoV-2 infection or can be delayed in onset for weeks or months following what had appeared to be full recovery from acute infection.
- LC can affect children and adults, regardless of health, disability, or socioeconomic status, age, sex, gender, sexual orientation, race, ethnicity, or geographic location.

The Disease State of Long COVID

An Infection-Associated Chronic Condition (IACC)

Acute SARS-COV-2 Infection

Infection (recognized or unrecognized) may be asymptomatic, mild, or severe

Common Symptoms

Can be mild to severe

- Post-Exertional Malaise
- Persistent Fatigue
- Difficulty Concentrating
- Memory Changes
- Recurring Headaches
- Lightheadedness/ Fast Heart Rate
- Sleep Disturbance
- Shortness of Breath/Cough
- Problems with Taste
- Problems with Smell
- Bloating/Constipation/Diarrhea

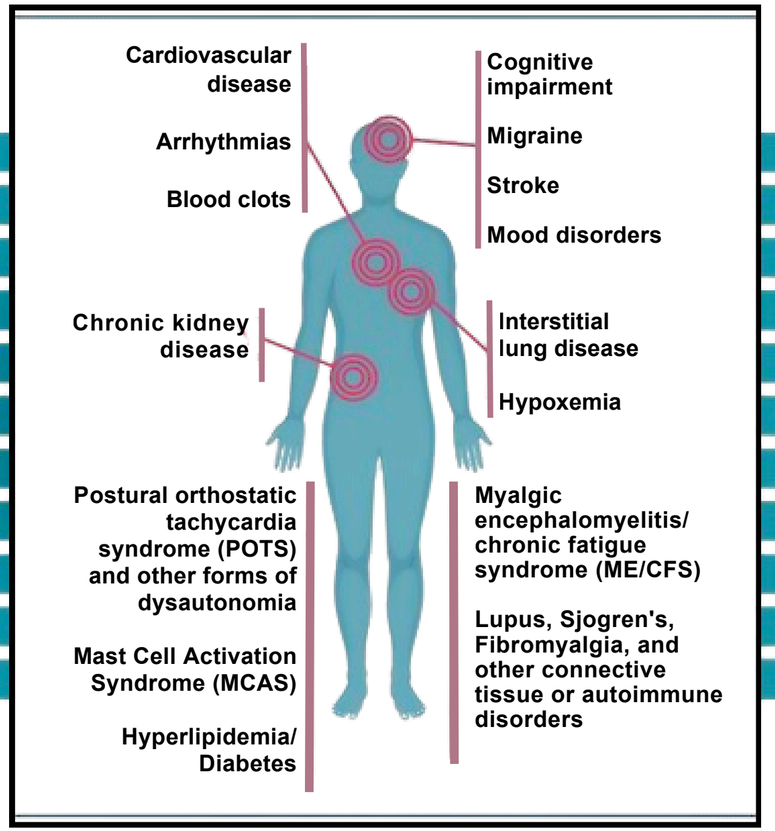
Many other symptoms have been observed.

Can be **continuous** from acute infection or **delayed in onset**

Pathobiology of Long COVID

Diagnosable Conditions

New or worsening of preexisting conditions



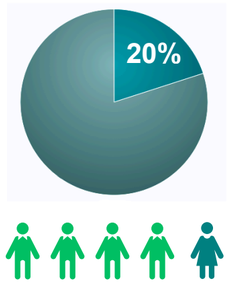
Important Features

- Long COVID can affect children and adults, regardless of health, disability, socioeconomic status, age, sex, gender, sexual orientation, race, ethnicity, or geographic location
- Long COVID can resolve over a period of months or can persist for months or years
- Long COVID can be diagnosed on clinical grounds. No biomarker currently available demonstrates conclusively the presence of Long COVID
- Long COVID can impair affected individual's ability to work, attend school and care for themselves and have a profound emotional and physical impact on patients, families, and caregivers.

Diagnosable when symptoms/conditions are intermittently or continuously present for at least 3 months

The Impacts of Long COVID

U.S. General Public



20% of people who get COVID-19 develop Long COVID. Recent global estimates rise as high as 36%. C19LAP believes this is a **significant undercount** due to a lack of testing, leading to documentation that informs public health policy.

At a rate of 1 in 5 developing Long COVID (off first infection, reinfections increase risk), **nearly 70 million people in the U.S. have Long COVID, while presentation, duration, and severity may vary** (assuming nearly everyone has had COVID-19 at this point.) In fall 2023, the CDC noted that the prevalence of Long COVID was 1 in 5 and that 75% of the U.S. population had already had a COVID-19 infection. **With reinfections, prevalence is likely higher.**

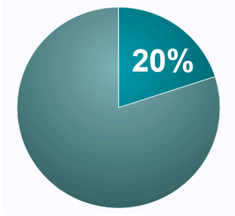
Reinfections Increase the Chance of Developing Long COVID

2 Infections
2.1X

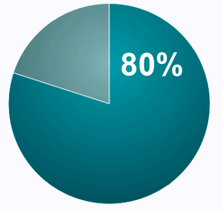
3 Infections
3.75X

U.S. Pediatrics

A study from the NIH RECOVER Initiative found that **20% of infected school-age children and 14% of adolescents met the threshold for probable Long COVID**.



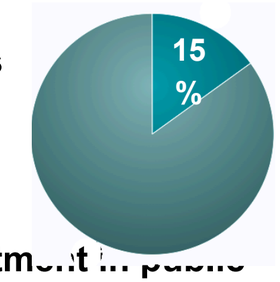
According to a publication from the CDC in JAMA Pediatrics, **80% of children with Long COVID reported activity limitation.**



In the U.S. it is estimated that **6 million children have Long COVID. C19LAP fears this number is a significant undercount** given children often struggle to verbalize what they are experiencing, are dependent on an adult acting upon their complaints, and other variables.

U.S. Clinicians

An AHRQ study found that only 15% of providers felt equipped to identify Long COVID.



We need Long COVID education initiatives now.

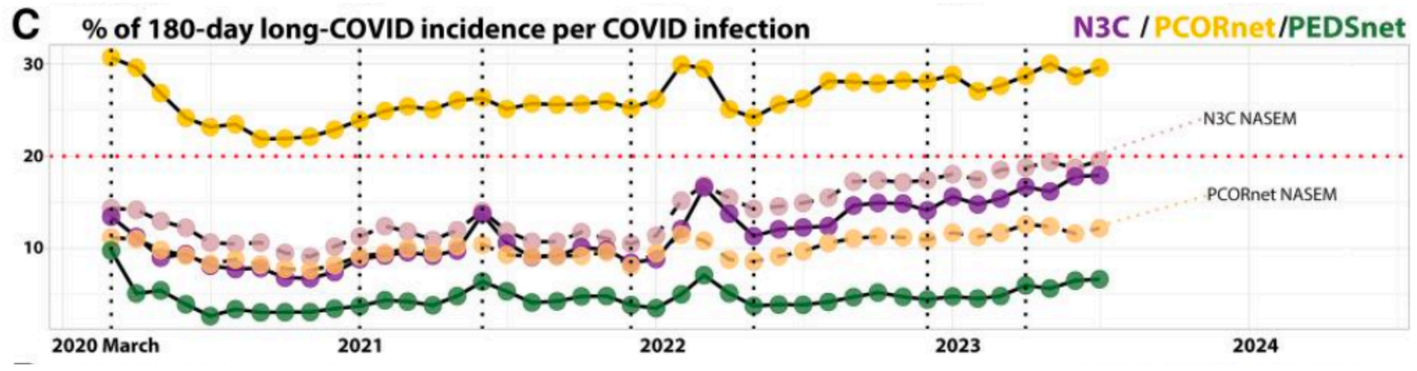
Long COVID is a public health emergency. Investment in public awareness and education, clinician training, and proper funding and resources are needed to address and meet this issue at scale.

A recent EHR study out of NIH RECOVER shows the prevalence of Long COVID is increasing, not decreasing.

The U.S. Bureau of Labor Statistics via FRED shows a dramatic rise in the U.S. population with a disability following the onset of the COVID-19 pandemic. From 2020 onward, the disabled population increased sharply from 29 to over 35 million by mid-2024, representing a **more than 20% increase in just four years.**

Interestingly, **this number mirrors the estimated prevalence of Long COVID, which is 1 in 5, or 20%.** This increase also represents delay or lack of access to care, not having the finances or health to seek care, compounding chronic illnesses and progressive disease, and other barriers faced, including social determinants of health.

In April 2024, Economist Impact published An Incomplete Picture: Understanding the Burden of Long COVID. The report estimated that Long COVID could drive over 1.5 billion lost work hours in 2024, costing more than $152.6 billion, with experts placing **the annual U.S. impact as high as $230 billion, about 1% of GDP.** One cited study projected $43–172 billion in annual medical costs and $101–430 billion in lost income, underscoring the crisis.



Medical $47-172 Billion

Lost Income $101-430 Billion

Lost Work Hours $1.5 Billion

Total Economic Cost $230 Billion or 1% of the U.S. Global GDP

Impacts to Long COVID Programs in 2025

- **Closure of the HHS Office for Long COVID Research and Practice** erased the only government-wide coordinating body before it could fully operate, halting unified national action.
- **Termination of the HHS Secretary's Advisory Committee on Long COVID** eliminated the sole cross-agency policy group guiding research, disability rights, and healthcare strategy.
- **Removal of Long COVID resources from government websites** destroyed access to trusted, science-based guidance—fueling misinformation and medical errors.
- **AHRQ Long COVID Care Network contract cancellations ended patient-informed clinician education** and will cut site funding by 80–90%, crippling care quality efforts.
- **Closure of SAMHSA and DOL Long COVID programs** halted planned mental health and employment supports for millions affected.
- **Censorship of Long COVID organizations on media and social platforms** blocks education and organizing tools vital for disabled communities.
- **Defunding and demoralization of patient-led Long COVID organizations** threaten the entire ecosystem of education, advocacy, and care coordination.
- **DOD and VA Long COVID research programs persist but face internal funding threats.**
- **NIH RECOVER Initiative remains the only active federal Long COVID research program**—temporarily reinstated but still at risk.
- **Termination of agency leaders who partnered with the patient community** severs institutional continuity and trust.
- **Rescission of $11 billion in federal COVID-19 and public health funds** dismantled infrastructure while the virus still kills ~1,000 Americans weekly and drives 100,000 new Long COVID cases.
- **Elimination of public comment opportunities at HHS** silences patients and advocates, excluding lived expertise from federal decision-making.
- **Disbandment of the CMS Health Equity Advisory Committee** jeopardizes Medicaid and Medicare protections, risking coverage loss and rising ER costs.
- **Rollback of DEIA programs** weakens protections in healthcare, education, and employment—forcing more disabled Americans into poverty.
- **Halting disability rights investigations** leaves children with Long COVID unprotected, increasing discrimination and educational harm.
- **Defunding of NIH research** stalls critical treatment development, prolonging disability and economic losses.

A New Direction for Long COVID?

On September 18, 2025, HHS Secretary Robert F. Kennedy, Jr. convened a roundtable of Long COVID stakeholders.

During this roundtable, Secretary Kennedy, along with FDA Commissioner Makary, NIH Director Bhattacharya, Senator Young, Senator Marshall, and Congressmen Bergman discussed their commitments to Long COVID.

HHS announced new actions aimed at improving care for Long COVID:

- Public Awareness and Education Campaign: A forthcoming national campaign will provide patients, families, and employers with accurate, science-based information about Long COVID, its symptoms, and available resources.
- Open-Source Medical Resource Platform: HHS will launch a new online hub where physicians, researchers, and health systems can share best practices and clinical insights for diagnosing and treating Long COVID.
- Agency for Healthcare Research and Quality (AHRQ) Report: “Sources of Health Insurance among Adults with Long COVID: Estimates from the Medical Expenditure Panel Survey” was released during the same day.

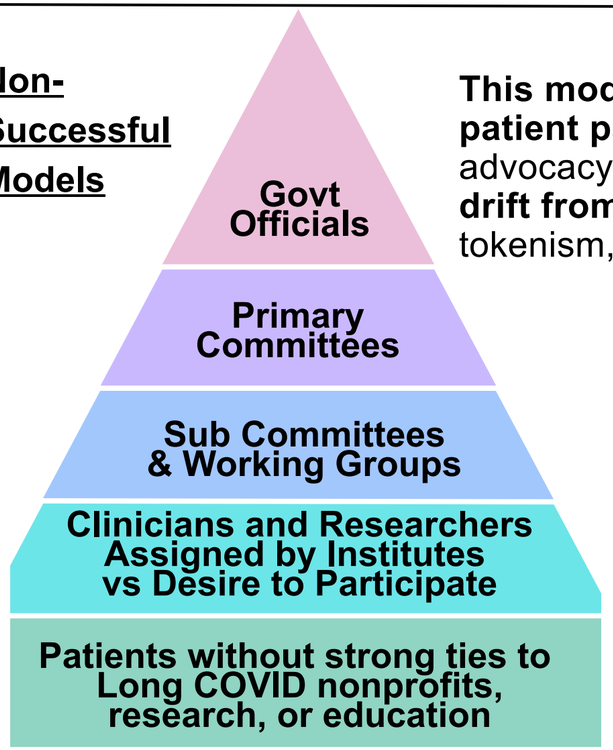
We are optimistic about many of the topics discussed at the roundtable:

- We welcome the renewed national focus on Long COVID after recent cuts to COVID-19 and Long COVID initiatives across the government and industry.
- We’re encouraged by opportunities for real collaboration, diversified approaches, and a patient-up model.
- We’re excited about public and clinician education initiatives, a top priority for C19LAP over the years and central to our work.
- We appreciate the bipartisan momentum signaled by leaders such as Senator Young, Senator Marshall, and Congressman Bergman.
- We support data sharing among researchers, paired with strong safeguards to protect patients and data integrity, is essential to progress.

We are requesting our public health partners to urgently get involved or re-involved in the Long COVID space with this renewed signaling of support.

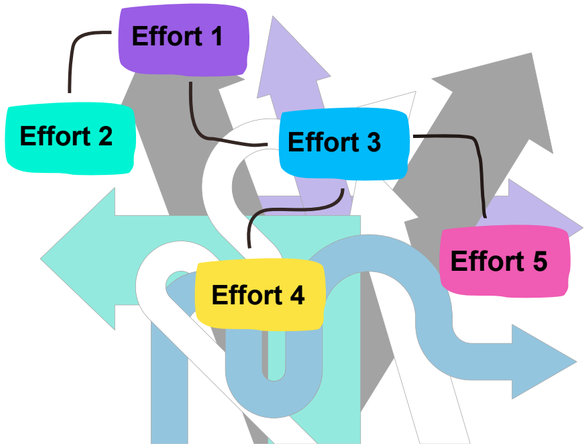
Non-Successful Long COVID Response Models

Non-Successful Models

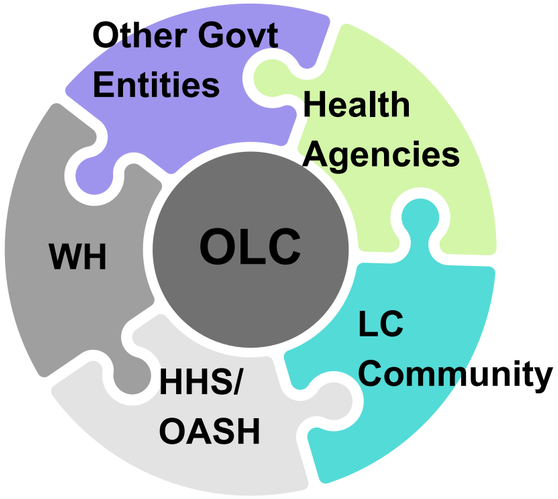


This model relies on a steep, multi-tiered structure with numerous committees but fails to truly center patient partnership. While patients are formally included, key roles often go to those without strong ties to advocacy, research, or education. **Without the expertise of patient-led Long COVID organizations, decisions drift from community priorities, delaying action.** Opaque and unaccountable decision-making leads to tokenism, bias, and stalled execution, where lived experience is absent, priorities distort and progress falters.

Across the country, efforts like state Long COVID offices, university programs, and CIL **initiatives fill local gaps but remain disconnected, uncoordinated, and unsustainable.** Lacking collaboration with patient organizations that understand the full Long COVID landscape, **they duplicate work, miss systemic needs, and fail to scale.** Real progress requires linking these isolated efforts under a unified, patient-led framework.



Previous Semi-Successful Model



The most effective model to date was the Office for Long COVID (OLC), which coordinated a whole-of-government, patient-centered approach before being cut in 2025. While promising, the OLC fell short as **coordination often stopped at discussion, communications remained siloed, and patients had limited direct access to agencies**, with the OLC serving mainly as an intermediary.

What Went Wrong In Current and Past Long COVID Response Efforts?

Meaningful Long COVID patient engagement must be integrated into every stage of solution-building—*from brainstorming and planning, to recruitment, outreach, facilitation, analysis, dissemination, and long-term follow-through*.

The lived experiences of patients are not just perspectives, but essential data points that ground research, policy, and clinical practice in real-world impact. As our community often says, “Nothing About Us, Without Us.”

By collaborating with patients as equal partners, stakeholders can design efforts that are better informed, more efficient, and more responsive to actual needs. This approach reduces wasted time and resources, accelerates the development of effective solutions, and ensures gaps in care or research are closed. Most importantly, it helps prevent the progression of disease, disability, and death, turning collective knowledge into collective progress.

Stages of Patient Partnership for Successful Long COVID Initiatives

Brainstorming

Plannning

Recruiting

Advertising

Facilitation

Analysis

Dissemination

Longitudinal Follow Through

Nothing About Us, Without Us!

With Patients

- **Patients with Long COVID and disabilities identify system failures early,** delayed diagnosis, poor coordination, stigma, inaccessibility, grounding priorities in reality and building trust.
- **Patient-shaped plans are practical and sustainable**, addressing fatigue, air quality, transportation, and caregiving needs while reducing ER visits and disability claims.
- **Patient-led recruitment ensures accessibility, compensation, and inclusion** in hardest-hit communities, yielding more representative and equitable data.
- **Patients craft plain-language, culturally sensitive, stigma-aware messaging** that drives care-seeking, research participation, and prevention.
- **Patient facilitators bring empathy and trust, creating safe, respectful spaces** that improve engagement and data quality.
- **Patients contextualize data, focusing on outcomes that matter,** fatigue, cognition, function, return to work, leading to actionable insights and equity.
- **Patients ensure findings reach all audiences**, speeding best-practice adoption and reducing stigma.
- **Patients sustain accountability**, ensuring programs adapt, endure, and strengthen long-term public health infrastructure.

Without Patients

- Brainstorming without patients leads to **misaligned goals, ableist assumptions, and projects with little real impact—** wasting funds and eroding trust.
- **Programs often fail under real-world pressure** when designed without accessibility, causing dropouts, inequity, and worsening illness.
- **Recruitment skews toward healthier, wealthier participants,** excluding those most affected and reinforcing disparities.
- Messaging that is dismissive or inaccessible **alienates communities, spreads misinformation, and weakens public trust.**
- **Discussions become tokenistic** when lived experience is absent, leading to disengagement and loss of credibility.
- **Research defaults to metrics that ignore real-life function**, overlooking harm signals and producing ineffective interventions.
- **Results remain siloed in journals instead of reaching those who need them**, delaying adoption and fueling confusion.
- **Programs collapse when funding ends, deepening mistrust, wasting resources, and perpetuating preventable disability and costs.**

Establishing a National Long COVID Public Health Network

Long COVID is not a niche condition, it is a mass disabling event and an ongoing public health crisis. Tens of millions of Americans are affected, driving workforce losses, school disruptions, inequities, and record disability claims. Delayed care and clinician shortages compound the crisis, while public trust in institutions continues to erode.

Whether this moment becomes a turning point or a prolonged national failure depends on coordinated, cross-sector action with patients and caregivers at the center. Public health professionals hold the power to transform advocacy into infrastructure and build a sustainable, equitable response.

The Landscape

- **2020–2024: Early federal programs established Long COVID research networks, clinics, and education pilots — many shaped by patient advocacy.**
- **2025: Funding cuts dismantled much of that progress, leaving care fragmented and public health infrastructure weakened.**
- **Now: Bipartisan and cross-government support is re-emerging. The path forward requires rebuilding durable systems — led collaboratively by patients, public health agencies, and state Departments of Health (DOHs) as coordinating entities.**

What we need:

Development of a National Long COVID Public Health Network by developing an Office for Long COVID within each State/Territory/Tribal Department of Health.

However, the model we need, while similar, differs and expands beyond what the Federal Office for Long COVID looked like.

Desired Long COVID Response Model & How It Restores Trust in Public health

Trust in public health eroded because systems acted on communities, not with them. This model restores it by making public health responsive, participatory, and transparent, transforming it from an institution people endure into a partnership they believe in. It replaces top-down control with shared governance between patients and cross-sector leaders, rebuilding credibility through collaboration and measurable impact.

- **Lived experience leads:** Patients and caregivers co-design programs, policies, and research priorities. Their lived knowledge shapes every stage, from planning to evaluation, ensuring that public health reflects real-world needs.
- **Long-term partnership, not consultation:** Patient and community representatives hold standing, compensated roles within agencies, advisory boards, and oversight structures. They remain engaged beyond crises, providing continuity, accountability, and perspective that evolve with time.
- **Information everyone can see:** Transparent dashboards, open data, and plain-language updates make progress visible and measurable. Communities can track results and hold institutions accountable.
- **Action, not promises:** Clean-air standards, telehealth expansion, and equitable care pathways demonstrate protection in practice, not rhetoric. When people see change in their settings, confidence follows.
- **Every sector shows up:** Government, healthcare, education, employers, and community organizations coordinate under a shared strategy. This consistency turns fragmented systems into a network people can rely on.
- **Trust through honesty:** Public health acknowledges uncertainty, learns from mistakes, and adjusts visibly proving integrity is rooted in transparency, not perfection.

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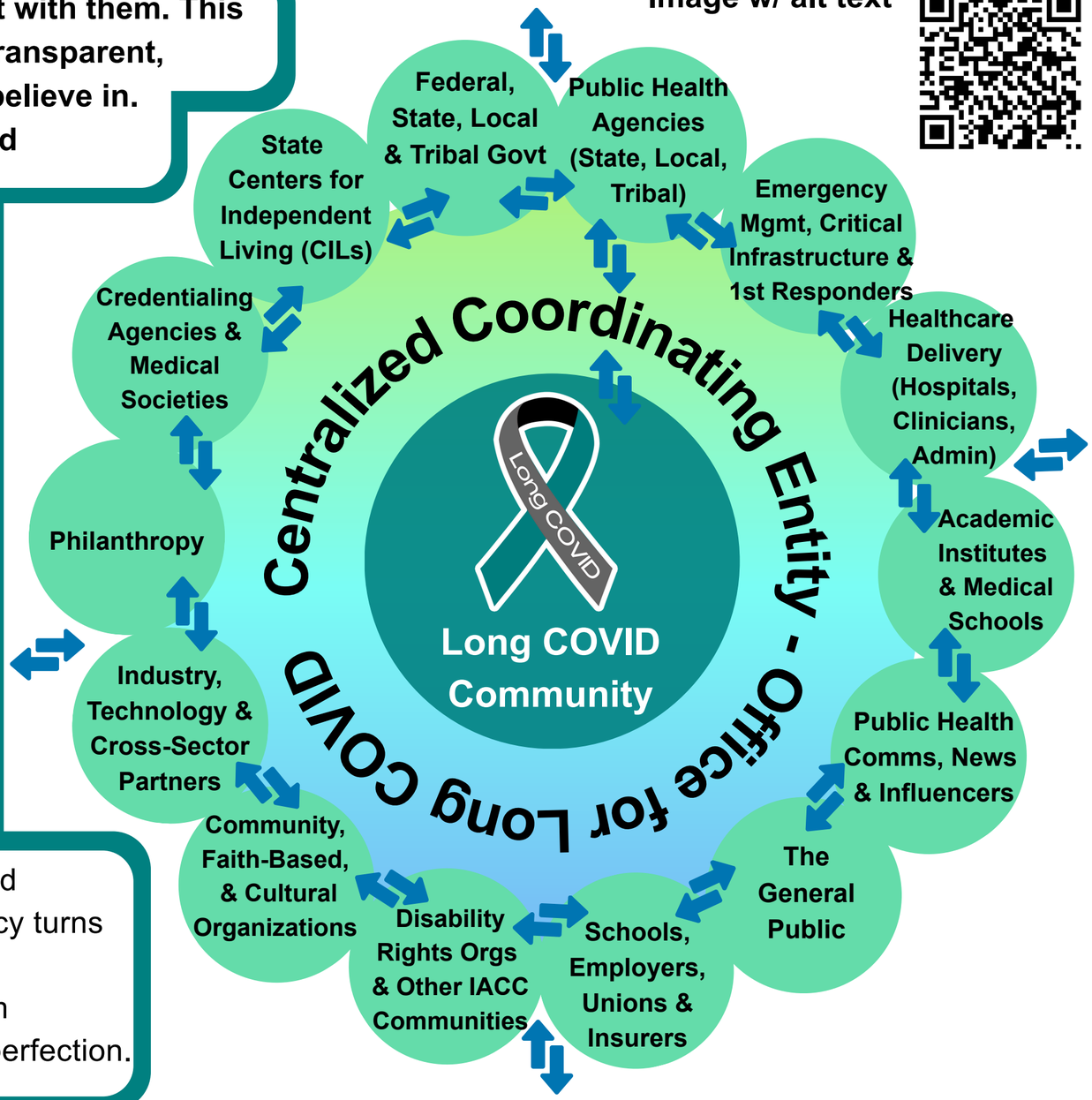

Sectors Involved

We Need You!

Read Our Cross-Sector Guidance for a National Long COVID Public Health Response.

- **Patient & Caregiver Community** – The foundation of the Long COVID response; identifies emerging symptoms, care gaps, and systemic failures in real time.
- **Federal, State, Local & Tribal Government** – Controls policy, funding, infrastructure, and protections.
- **Public Health Agencies (CDC, NIH, HRSA, FDA; State/Local/Tribal Health Departments)** – Lead surveillance, prevention, and coordination of the Long COVID response.
- **Emergency Management & First Responders** – Maintain operational continuity and protect essential services.
- **Healthcare Delivery (Hospitals, Clinics, Clinicians, Administrators)** – The first point of contact; determine whether patients are believed, diagnosed, and treated.
- **Academia & Medical Schools** – Educate the workforce and produce the evidence base for care.
- **Credentialing Agencies & Medical Societies** – Define clinical standards and competencies across specialties.
- **Schools, Employers, Unions & Insurers** – Gatekeepers of inclusion, accommodations, and benefits.
- **Community, Faith-Based & Cultural Organizations** – Trusted anchors connecting institutions and marginalized communities.
- **Industry, Technology & Cross-Sector Partners** – Drive innovation, data infrastructure, and therapeutics.
- **Public Health Communication & Media** – Shape public understanding, trust, and behavior.
- **Philanthropy & Funding Partners** – Provide rapid, flexible, and sustaining resources for innovation and equity.
- **Disability Rights & Centers for Independent Living (CILs)** – Enforce access, accommodations, and protections under disability law.
- **General Public** – The engine of prevention, accountability, and culture.

C19LAP bridges lived experience and institutional response, transforming insight into action, advocacy into infrastructure, and community resilience into national strength.

When any sector fails to act, patients fall through the cracks, inequities deepen, and the nation's infrastructure weakens. But when all sectors engage, guided by patient leadership, we can build equitable, accessible care and prevention systems, reduce disability, restore workforce participation, and rebuild trust in science and public health. The cost of inaction is staggering; the benefits of action are generational.

Together, we can make Long COVID visible, actionable, and solvable
laying the foundation for a healthier, more prepared, and more equitable future.

In collaboration with our public health and cross-sector partners, we aim to:

- Sustain cross-sector collaboration that transforms advocacy into measurable systems change, serving as a Central Coordinating Entity (CCE) in partnership with a co–Coordinating Entity, such as a state-based Office for Long COVID housed within a Department of Health (DOH), to align initiatives and coordinate efforts across sectors.

- Develop and advance legislation establishing state-based Offices for Long COVID (OLCs) within DOHs to serve as CCEs responsible for integrating public health, education, clinical care, research, and cross-sector systems. C19LAP will drive the strategy and mission, ensuring patient leadership, equal voting authority, and lived experience are embedded at every stage. This framework will deliver unified education, data, and communication systems; secure sustainable, bipartisan funding; and translate advocacy into measurable, lasting systems change.

- Expedite solutions for those living with Long COVID while strengthening public health preparedness and response across systems, ensuring lessons learned today build a more resilient, future-ready health infrastructure for all.

References

Centers for Disease Control and Prevention (CDC).
Tracking Long COVID. CDC collects and analyzes data from several public health surveys to monitor the prevalence of Long COVID and symptoms among children and adults.
https://www.cdc.gov/long-covid/php/surveillance/index.html

National Academies of Sciences, Engineering, and Medicine.
A Long COVID Definition: A Chronic, Systemic Disease State with Profound Consequences. Washington, DC: The National Academies Press. 2024.
https://nap.nationalacademies.org/catalog/27768/a-long-covid-definition-a-chronic-systemic-disease-state-with

Agency for Healthcare Research and Quality (AHRQ).
Prevalence of Long COVID Among Adults Who Have Ever Had COVID-19, by Selected Demographic and Socioeconomic Characteristics, U.S. Civilian Noninstitutionalized Population, Spring 2023.
https://meps.ahrq.gov/data_files/publications/st557/stat557.shtml

JAMA Network.
Evidence Mounts That About 7% of US Adults Have Had Long COVID. JAMA. 2024;332(1):5–6.
https://jamanetwork.com/journals/jama/fullarticle/2819957

Economist Impact.
An incomplete picture: understanding the burden of long Covid. Economist Impact. April 28, 2024.
https://impact.economist.com/health/incomplete-picture-understanding-burden-long-covid

Nature Medicine.
Al-Aly, Z., Davis, H., McCorkell, L., et al. Long COVID science, research and policy. Nature Medicine. 2024.
https://longcovidtheanswers.com/wp-content/uploads/2024/09/s41591-024-03173-6.pdf

Yale Medicine.
Cheng, K. Long COVID Keeps People Out of Work and Hurts the Economy. Yale Medicine. December 23, 2024.
https://www.yalemedicine.org/news/long-covid-keeps-people-out-of-work-and-hurts-the-economy

References

Harvard University.
Cutler, D. M. The Economic Cost of Long COVID: An Update. Scholars at Harvard.
https://scholar.harvard.edu/files/cutler/files/long_covid_update_7-22.pdf

U.S. Bureau of Labor Statistics.
COVID-19 and employment outcomes of people with disabilities. Monthly Labor Review. April 2023.
https://www.bls.gov/opub/mlr/2023/beyond-bls/covid-19-and-employment-outcomes-of-people-with-disabilities.htm

Centers for Disease Control and Prevention (CDC).
Long COVID in Children: United States, 2022. NCHS Data Brief, Number 479, September 2023.
https://www.cdc.gov/nchs/data/databriefs/db479.pdf

JAMA Pediatrics.
Ford, N. D., Vahratian, A., Pratt, C. Q., et al. Long COVID Prevalence and Associated Activity Limitation in US Children. JAMA Pediatrics. 2025;179(4):471–473.
https://jamanetwork.com/journals/jamapediatrics/fullarticle/2829880

RECOVER COVID Initiative (NIH).
Home | RECOVER COVID Initiative.
https://recovercovid.org/

U.S. Department of Health and Human Services (HHS).
HHS Advances Fight Against Long COVID with Patient Roundtables and New National Efforts. Press Release, September 18, 2025.
https://www.hhs.gov/press-room/hhs-secretary-kennedy-long-covid-roundtables-action.html

InsideHealthPolicy.com.
HHS Launches Long Covid Consortium, CDC To Create Treatment Tracking Website. September 18, 2025.
https://insidehealthpolicy.com/daily-news/hhs-launches-long-covid-consortium-cdc-create-treatment-tracking-website

We Need You!
Learn How Your Sector Can Help.

Read Our Cross-Sector Guidance for a National Long COVID Public Health Response.

- **20% of people who get COVID-19 develop Long COVID (adults and children).**
- **70 million people in the United States have a form of Long COVID. Hundreds of millions more globally have Long COVID.**
- **COVID-19/ Long COVID has surpassed asthma as the most common chronic health problem affecting children.**
- **80% of children with Long COVID report impacts to their activities of daily living.**
- **The rate of disability in the U.S. has increased 20% since the start of the COVID-19 Pandemic.**
- **COVID-19 rates in the community are higher now than they were at the beginning of the pandemic when things were taken seriously.**
- **The rate of Long COVID is increasing due to both new COVID-19 infections and reinfections.**

- **In 2025, nearly all Long COVID programs and initiatives were shut down**, one's patients fought for and spent years building. Some hope has been reignited around Federal Long COVID efforts with the recent hosting of an HHS Long COVID roundtable with indication of a possible Long COVID consortium. The FDA, ARPA-H, NIH, and HSS, along with three members on congress, participated in this roundtable and indicated their continued involvement in the space.
- Given the current fragility of public health systems and the speed at which federal programs can be dismantled, **it is imperative to build both national and state networks that operate independently of federal funding and oversight, ensuring consistent, reliable support for those in need.** At the same time, these programs must be designed for scalability at the federal level, creating a framework that can expand seamlessly to meet national demand when stability and support return.

C19 LAP — Long COVID & Associated Conditions

COVID-19 LONGHAULER ADVOCACY PROJECT

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