COVID-19 LONGHAULER ADVOCACY PROJECT

The COVID-19 Longhauler Advocacy Project (C19LAP) is a grassroots, patient-led 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, cross-sector collaboration, and peer support.

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.

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 the future of Long COVID 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.

In the absence and loss of Long COVID programs, our leadership role is more important than ever to bridge the gaps in action, barriers faced, and development of new and more successful initiatives driving solutions. C19LAP is consistently educating those on the front lines and helping to inform national policy and research through education and direct collaboration with scientists, public health leaders, policymakers, and most importantly, our community.

Initiatives We Have Participated In

- National Academy of Sciences, Engineering, and Medicine- 2024 Consensus Long COVID Definition, Adopted by HHS
- Our early research led to the Memorandum on Long COVID which led to the NIH RECOVER Initiative, the Office for Long COVID Research and Practice, the Long COVID Coordination Counsil, the Long COVID Federal Advisory Committe, the AHRQ Long COVID Care Network, amongst other federal efforts.
- AHRQ Long COVID Care Network
- NIH RECOVER Initiative Ancillary Studies
- Coordination w/ the Office for Long COVID
- Center for Medical Specialty Societies
- Centers for Disease Control
- Co-founded the Long COVID Alliance
- Co-founded the Infection-Associated Chronic Conditions Initiative
- Members of the Disability Economic Justice Collaborative
- APHA Members and multi-year presenter and exhibitor
- Drafted the Treat Long COVID Act, provided language to several other Long COVID and public health bills
- and many more!

Let's Work Together!

C19 LAP — LONG COVID & ASSOCIATED CONDITIONS

COVID-19 LONGHAULER ADVOCACY PROJECT

What is Long COVID?

The Consensus Long COVID Definition- N.A.S.E.M 2024 Adopted by HHS for Use Across the Whole of Government

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 including the brain, gastrointestinal tract, heart, lungs, and immune 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 such as, but not limited to, persistent fatigue, post-exertional malaise, difficulty concentrating, memory changes, recurring headache, dizziness, fast heart rate, sleep disturbance, migraine, stroke, blood clots, chronic kidney disease, postural orthostatic tachycardia syndrome (POTS), myalgic encephalomyelitis /chronic fatigue syndrome (ME/CFS), mast cell activation syndrome (MCAS), diabetes, and other autoimmune disorders such as lupus, rheumatoid arthritis, and Sjogren's syndrome.

Important Features of Long COVID

- 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)

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

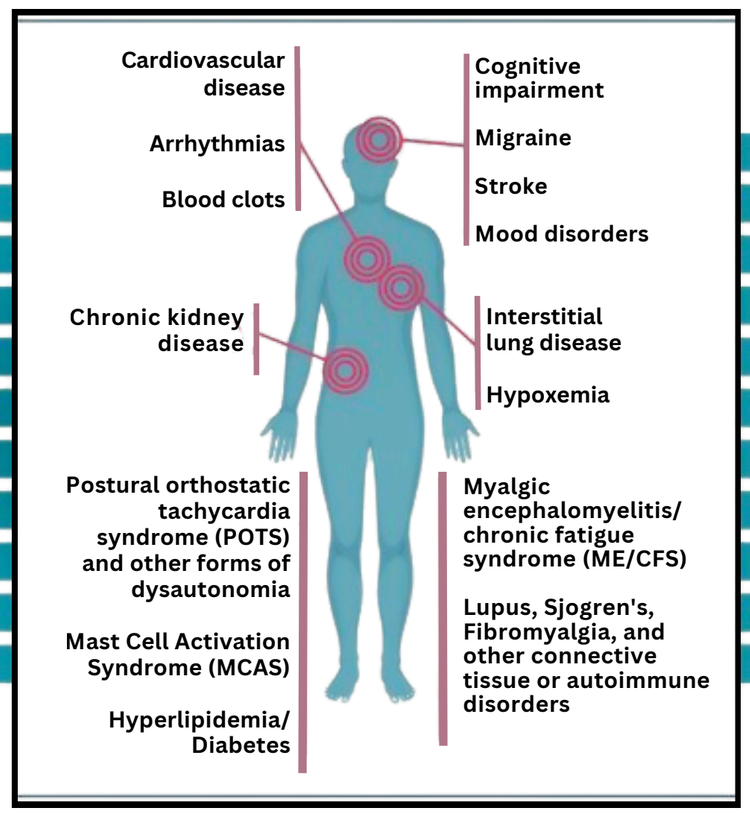
Many other symptoms have been observed.

Acute
SARS-COV-2 Infection

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

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.

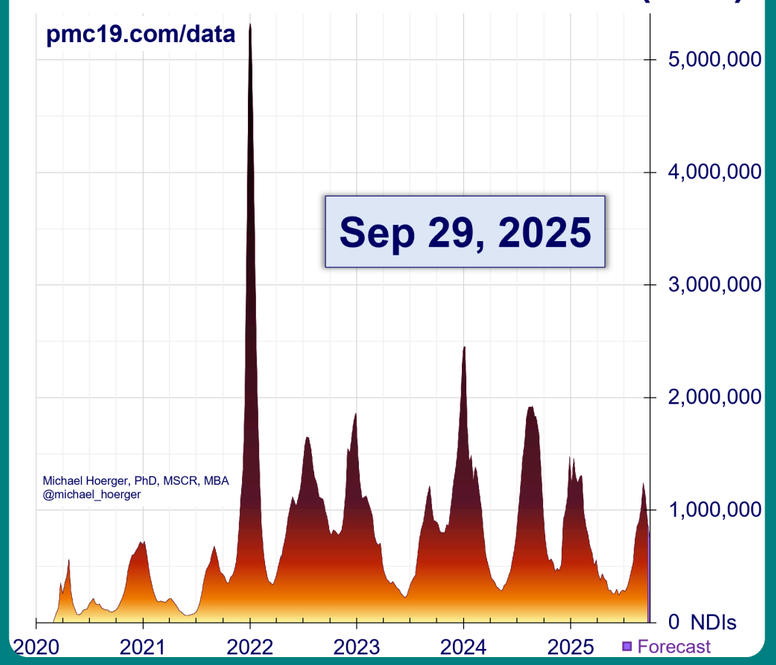
Can be **continuous** from acute infection or **delayed in onset**

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

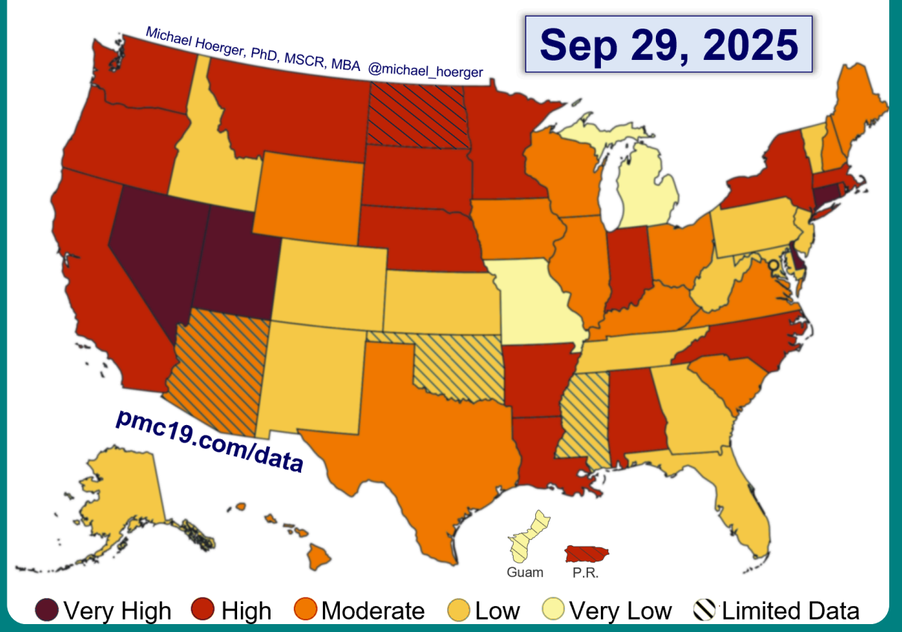
The COVID-19 Pandemic Never Ended

The pandemic never ended. As of September 29, 2025, an estimated 743,000 Americans are being newly infected with COVID-19 each day, fueling more than 5.5 million infections each week and bringing the total for this year alone to 185 million infections. These ongoing waves are not benign—each day's infections are projected to generate 37,000 to 149,000 new cases of Long COVID. The toll on lives remains staggering, with 210 to 350 excess deaths daily. Nearly five years into this crisis, the U.S. population has experienced an average of 4.68 infections per person, underscoring the dangerous myth that the pandemic is "over."

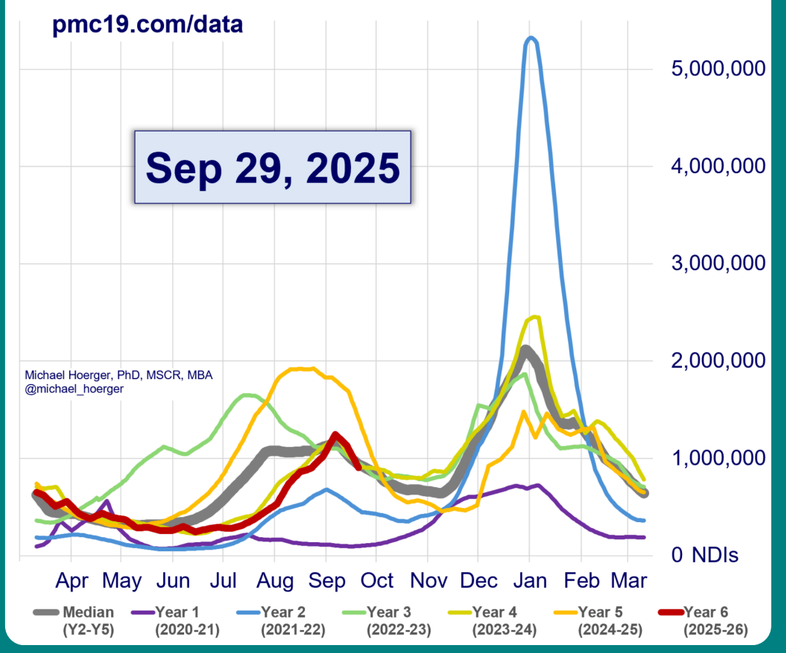
SARS-CoV-2 New Daily Infections, Wastewater-Derived Estimates (U.S.)



COVID-19 Heat Map, Based on CDC Wastewater Data and Levels (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

COVID-19 State Prevalence Estimates

pmc19.com/data — Sep 29, 2025

State	CDC Level	PMC Estimate, % Actively Infectious	Chances anyone is infectious in a room of 10 to 100 people: 10	25	50	100
Alabama	High	1 in 33 (3.0%)	26%	54%	79%	95%
Alaska	Low	1 in 69 (1.5%)	14%	31%	52%	77%
Arizona	Moderate*	1 in 42 (2.4%)	21%	45%	70%	91%
Arkansas	High	1 in 38 (2.7%)	24%	49%	74%	93%
California	High	1 in 36 (2.8%)	24%	50%	75%	94%
Colorado	Low	1 in 69 (1.5%)	14%	31%	52%	77%
Connecticut	Very High	1 in 18 (5.6%)	44%	77%	95%	>99%
Delaware	Very High	1 in 24 (4.1%)	34%	65%	88%	98%
District of Columbia	Low	1 in 81 (1.2%)	12%	27%	46%	71%
Florida	Low	1 in 62 (1.6%)	15%	34%	56%	80%
Georgia	Low	1 in 101 (1.0%)	10%	22%	39%	63%
Guam	Very Low	1 in 130 (0.8%)	7%	18%	32%	54%
Hawaii	Moderate	1 in 53 (1.9%)	17%	38%	61%	85%
Idaho	Low	1 in 62 (1.6%)	15%	33%	55%	80%
Illinois	Moderate	1 in 60 (1.7%)	15%	34%	57%	81%
Indiana	High	1 in 27 (3.8%)	32%	62%	85%	98%
Iowa	Moderate	1 in 58 (1.7%)	16%	35%	58%	82%
Kansas	Low	1 in 78 (1.3%)	12%	28%	48%	73%
Kentucky	Moderate	1 in 39 (2.6%)	23%	48%	73%	93%
Louisiana	High	1 in 36 (2.7%)	24%	50%	75%	94%
Maine	Moderate	1 in 40 (2.5%)	22%	47%	72%	92%
Maryland	Low	1 in 69 (1.4%)	14%	30%	52%	77%
Massachusetts	High	1 in 37 (2.7%)	24%	50%	75%	94%
Michigan	Very Low	1 in 111 (0.9%)	9%	20%	36%	60%
Minnesota	High	1 in 37 (2.7%)	24%	49%	74%	93%
Mississippi	Low*	1 in 70 (1.4%)	13%	30%	51%	76%

* Limited data reporting

COVID-19 State Prevalence Estimates

pmc19.com/data — Sep 29, 2025

State	CDC Level	PMC Estimate, % Actively Infectious	Chances anyone is infectious in a room of 10 to 100 people: 10	25	50	100
Missouri	Very Low	1 in 156 (0.6%)	6%	15%	27%	47%
Montana	High	1 in 37 (2.7%)	24%	50%	75%	94%
Nebraska	High	1 in 27 (3.8%)	32%	62%	85%	98%
Nevada	Very High	1 in 15 (6.6%)	50%	82%	97%	>99%
New Hampshire	Moderate	1 in 59 (1.7%)	16%	35%	58%	82%
New Jersey	Low	1 in 82 (1.2%)	12%	27%	46%	71%
New Mexico	Low	1 in 102 (1.0%)	9%	22%	39%	63%
New York	High	1 in 35 (2.8%)	25%	51%	76%	94%
North Carolina	High	1 in 35 (2.9%)	25%	52%	77%	94%
North Dakota	High*	1 in 34 (3.0%)	26%	53%	78%	95%
Ohio	Moderate	1 in 58 (1.7%)	16%	35%	58%	83%
Oklahoma	Low*	1 in 81 (1.2%)	12%	27%	46%	71%
Oregon	High	1 in 32 (3.1%)	27%	55%	80%	96%
Pennsylvania	Low	1 in 61 (1.6%)	15%	34%	56%	81%
Rhode Island	High	1 in 33 (3.1%)	27%	54%	79%	96%
South Carolina	Moderate	1 in 40 (2.5%)	22%	47%	72%	92%
South Dakota	High	1 in 28 (3.5%)	30%	59%	84%	97%
Tennessee	Low	1 in 75 (1.3%)	13%	28%	49%	74%
Texas	Moderate	1 in 48 (2.1%)	19%	41%	65%	88%
Utah	Very High	1 in 26 (3.8%)	32%	62%	86%	98%
Vermont	Low	1 in 69 (1.5%)	14%	31%	52%	77%
Virginia	Moderate	1 in 45 (2.2%)	20%	43%	67%	89%
Washington	High	1 in 31 (3.2%)	28%	56%	80%	96%
West Virginia	Low	1 in 68 (1.5%)	14%	31%	52%	77%
Wisconsin	Moderate	1 in 52 (1.9%)	18%	39%	62%	86%
Wyoming	Moderate	1 in 47 (2.1%)	19%	41%	66%	88%

* Limited reporting; North Dakota has no data and uses the average of MN, MT, & SD

We Must Adequately Address COVID-19, Long COVID, & Its Systemic Impacts.

Join us as partners to prevent mass disability, death, and erosion of public health.

Used with the permission from:
Michael Hoerger, PhD, MSCR, MBA
Pandemic Mitigation Collaborative
www.pmc19.com (Est. March 2020)

C19 LAP — Long COVID & Associated Conditions

COVID-19 LONGHAULER ADVOCACY PROJECT — Long COVID

2025 Impacts to COVID-19 & Long COVID Programs

Closure of the HHS Office for Long COVID Research and Practice, which was intended to coordinate Long COVID efforts across federal agencies, represents a devastating loss. This office was designed to unify and accelerate government-wide responses, but was shut down before it had the chance to fully launch or impact policy.

Termination of the HHS Secretary's Advisory Committee on Long COVID eliminated a vital policy body that provided cross-agency guidance on research, disability rights, and healthcare strategy. Without this committee, there is no centralized national leadership driving solutions for Long COVID and associated conditions.

Rescission of over $11 billion in federal funds that had been allocated for COVID-19 response and various public health initiatives. The Department of Health and Human Services (HHS) claimed the pandemic was over and that continued funding was unnecessary. However, this decision was dangerously premature. COVID-19 is still killing approximately 1,000 people in the U.S. each week and contributing to over 100,000 new cases of Long COVID weekly, with more than 60 million Americans already living with the condition. Rescinding these funds undermines critical public health infrastructure, including infectious disease surveillance.

Removal of Long COVID resources (ie: JAN Long COVID Guidance) from government websites has erased trusted, science-based information that clinicians, patients, and caregivers relied on. This rollback promotes misinformation, increases misdiagnoses, and leads to avoidable healthcare complications and costs.

The AHRQ Long COVID Care Network had a contract cancelled that allowed patient input into crucial decision making and shaping of clinician care for Long COVID. Additionally, and after the initial contract cuts, sites are now expected to lose 80-90% of their funding in the coming weeks.

Closure of SAMHSA and DOL Long COVID Programs stopped the launch of important mental health and employment initiatives for people living with Long COVID. These programs were essential for addressing the workforce impact and psychological toll of this mass-disabling condition.

Long COVID organizations and initiatives are experiencing extreme censorship both on social media, and in the media, creating major issues for organizing and educating online, which is an essential tool for people with disabilities who cannot participate in in-person events.

Elimination of public comment opportunities at HHS has silenced patients and advocates, excluding them from decisions that directly impact their lives. Without this input, federal agencies risk crafting policies that are disconnected from real-world needs and ineffective in practice.

Disbandment of the CMS Health Equity Advisory Committee threatens essential Medicaid and Medicare protections. This rollback risks coverage loss for millions of disabled and low-income Americans, increases emergency room visits, and drives up uncompensated care costs—ultimately raising national healthcare spending.

Gutting of Diversity, Equity, Inclusion, and Accessibility (DEIA) programs undermines protections in healthcare, employment, and education. These rollbacks disproportionately affect people with Long COVID and other disabilities—further pushing individuals out of the workforce and into poverty.

Halting of disability rights investigations leaves children with disabilities, including Long COVID-related impairments, unprotected in schools. Without enforcement of federal protections, students face increased discrimination, exclusion, and long-term educational and economic harm.

Defunding of NIH research has halted critical scientific progress. These disruptions delay the development of treatments that could help people return to work and reduce federal disability claims. Investing in this research now, would not only improve lives, but also yield long-term economic savings.

DOD and VA programs are still ongoing, but are self-run and at risk of internal funding losses supporting their Long COVID research programs.

The NIH RECOVER Initiative grants were terminated at the end of March, but rapidly reinstated two days later, and it is the only federally funded Long COVID program left standing, and it is still currently at great risk.

The termination of agency directors who have worked closely with the patient-community and on Long COVID initiatives for the past years.

The loss of funding and support for patient-led Long COVID organizations by loss of the above programs and momentum, and the fear others hold about operating in such a targeted space.

New Action & Direction

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.

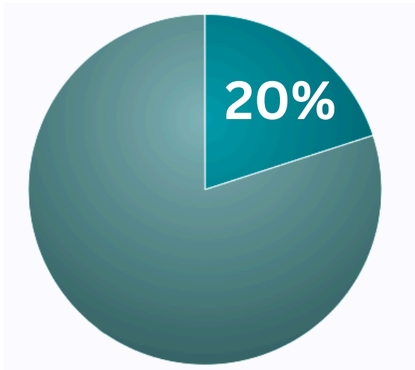
Long COVID Prevalence & Recognition

C19 LAP — COVID-19 Long COVID Associated Conditions

LONGHAULER ADVOCACY PROJECT

learn more at longhauler-advocacy.org

U.S. General Public



20% of people who get COVID-19 develop Long COVID. Recent globally 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.

2025 U.S. Population: ~350,000,000 People

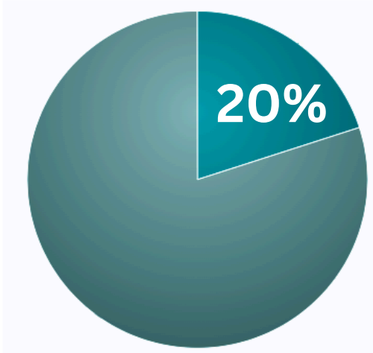
Reinfections Increase the Chance of Developing Long COVID

2 Infections
2.1X

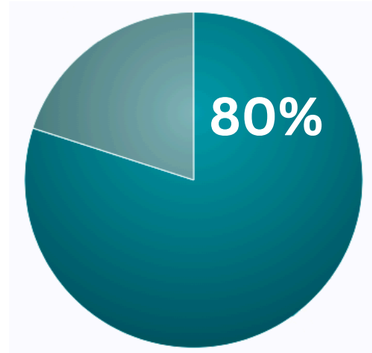
3 Infections
3.75X

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.



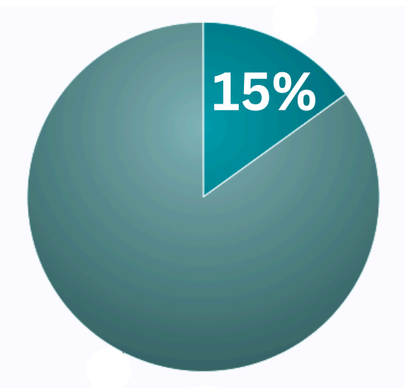
According to a publication from the CDC in JAMA Pediatrics, 80% of children with Long COVID reported activity limitation.



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.

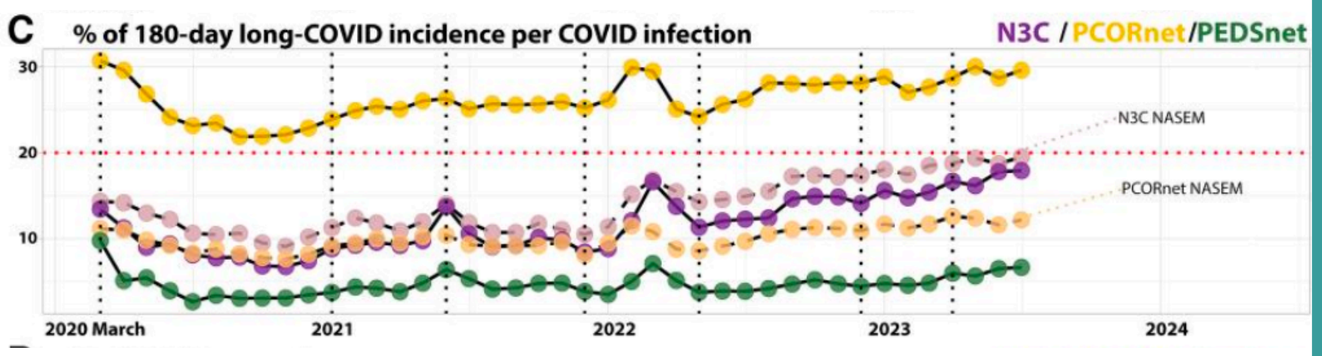
The Costs & Systemic Impacts of Long COVID

C19 LAP — LONGHAULER ADVOCACY PROJECT

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

Long COVID continues to be a neglected public health crisis.

To address Long COVID, we must begin with adequately responding to the virus that causes it, and the factors that lead to infection, such as, but not limited to access to information, healthcare, masks, and testing. Credible public messaging can significantly contribute to addressing Long COVID.



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, just before the release of the National Academies' broader Long COVID definition, 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.

In reality, millions are already out of work—both patients and caregivers, further straining the healthcare system, disability programs, and national infrastructure. And because the report relied on prevalence estimates less than half the now broadly recognized ~20%, the true costs are likely far higher.

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

Responding at Scale:
A National Long COVID Public Health Network

Patient-Centered and Driven with a Central Coordinating Entity, and Cross-Sector Involvement & Collaboration

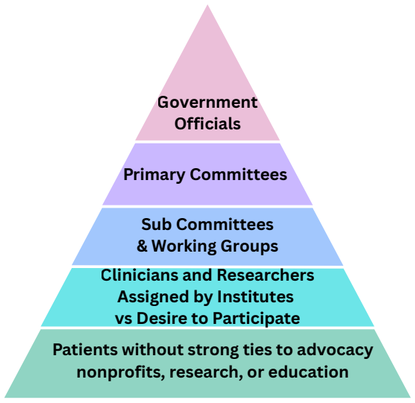
Previous Semi-Successful Model

Our experience to date suggests that the most effective federal model was the Office for Long COVID (OLC), which coordinated a whole-of-government, patient-centered approach. We advised on, helped stand up, and worked toward this structure over several years. Its closure earlier this year eliminated a critical coordinating entity at a pivotal moment.

While we supported the OLC framework, it did not go far enough. Key decisions and funding authority remained internal to the administration, which constrained implementation and often limited patient influence to consultation rather than shared governance. Coordination frequently stopped short of action, and communications were siloed: patients were "at the table," but direct lines to participating agencies were limited, with the OLC functioning as an intermediary.

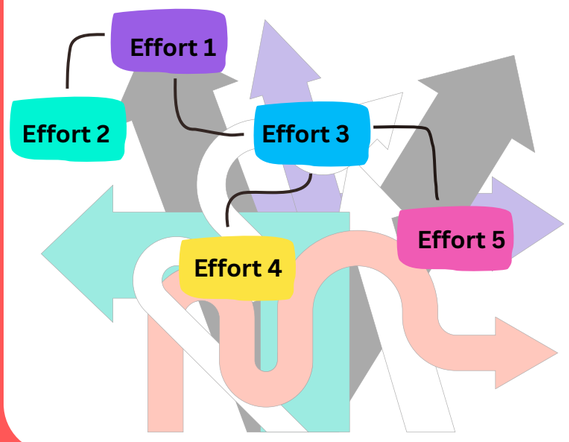
Going forward, we support a broader, actionable model that preserves national coordination while embedding patient leadership with real decision rights, establishes clear funding streams for implementation (not just convening), and creates direct, bidirectional channels among agencies, states, and patient organizations. This evolution would maintain the benefits of centralized strategy while enabling timely execution across programs in clinical care, research, education, and disability supports.

Non-Successful Models



This model is built on a steep, multi-tiered structure with numerous committees and subgroups, yet it fails to meaningfully center patient partnership. While patients are formally included, priority roles often go to individuals without strong ties to advocacy nonprofits, research, or education. These contributions are important, but without the landscape expertise of patient-led LC organizations, decisions can drift from community priorities and systemic needs. Communication pathways are unclear and non-linear—messages pass through multiple layers, get reframed, and lose urgency—slowing decision cycles and delaying action. Decision-making is opaque and largely anonymous, with no clear accountability to the patient community.

The outcome is predictable: tokenistic engagement, prolonged back-and-forth, and slow or stalled execution. With decision-makers removed from lived experience, priorities become distorted and accountability weakens. The structure also invites bias and undue pressure into key choices, increasing the risk of misdirected investments.

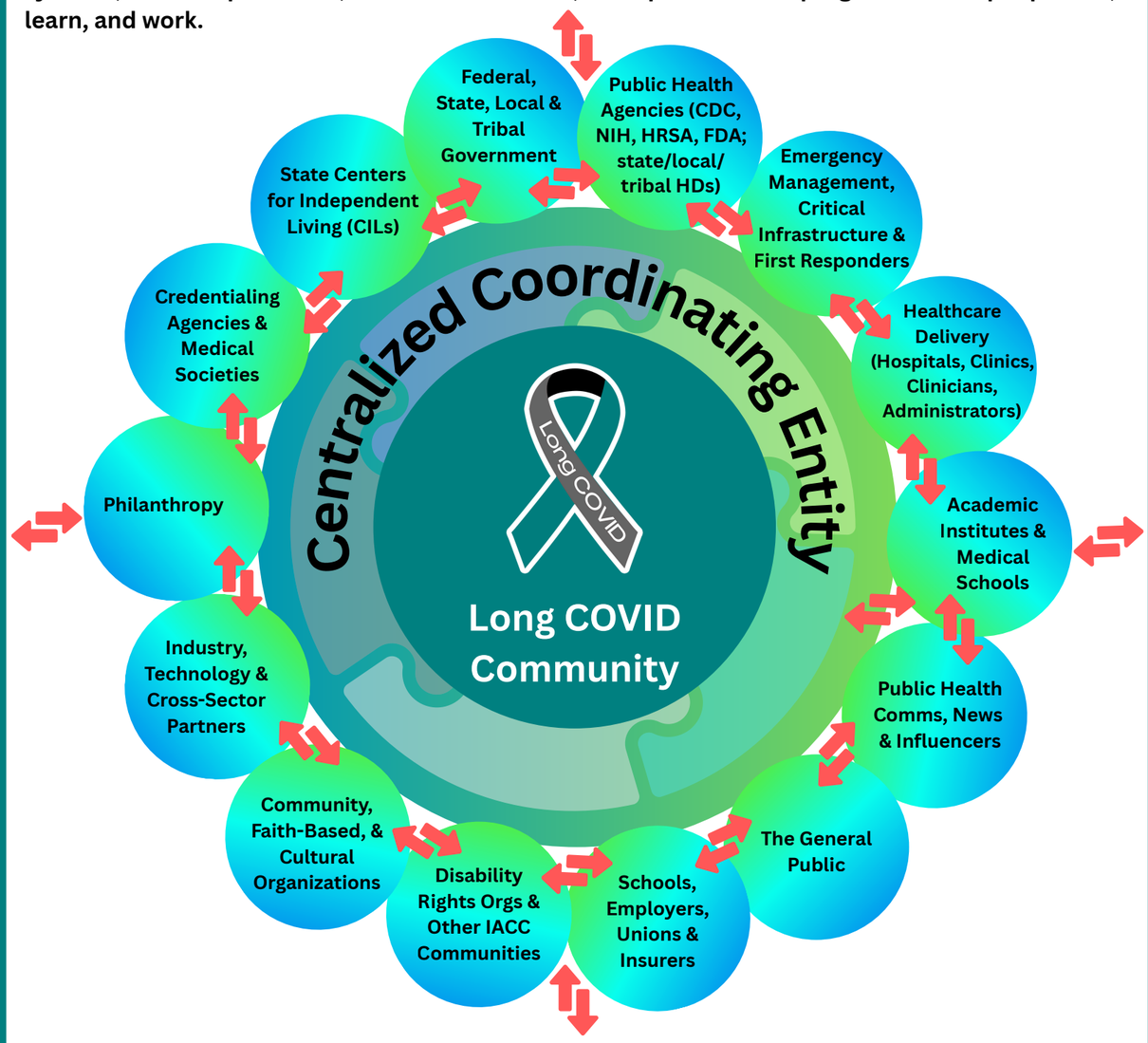


Current one-off efforts may deliver valuable local benefits, but they are moving in different directions, lack coordination, and are difficult to scale. Some include patients meaningfully; others do not. Without a common framework and shared infrastructure, these activities risk duplicating work, diluting impact, and ultimately burning out.

We encourage all Long COVID initiatives, but the most effective will be those coordinated and designed for national—and ultimately global—scalability. Otherwise, even well-intentioned projects function as short-term band-aids rather than durable solutions.

Desired Cross-Sector Model

A patient-led national model places Long COVID organizations not just "at the table," but at the helm—as the architects of the strategy itself. LC patient leaders develop the vision, set priorities, and design the playbooks for education, clinical pathways, navigation, accommodations, research alignment, and policy. A centralized coordinating entity (CCE) then supports that blueprint: standardizing toolkits and templates, building shared data systems and metrics, brokering cross-agency alignment, and providing technical assistance so the patient-authored plan can be executed with consistency and scale. State and territorial hubs adapt the national plan to local systems, train chapter leads, mobilize volunteers, and operationalize programs where people live, learn, and work.



This shifts the role of government, public health agencies, healthcare delivery, credentialing and medical societies, academia, disability rights organizations and CILs, schools and employers, industry and technology partners, community and faith-based organizations, philanthropy, emergency management, media, and the general public: they are implementation partners and force multipliers—resourcing, codifying, and delivering the patient-designed strategy.

By positioning LC patient organizations as the strategists and masterminds—and equipping the CCE and sectors to execute—we replace fragmented efforts with durable infrastructure, faster translation from evidence to practice, credible communication, and equitable access to care and supports. This model delivers timely action for millions with Long COVID and establishes a reusable public-health framework for future crises.

Call to action: With no federal Office for Long COVID, states and territories must act now. *Establish a State/Territorial Office for Long COVID—patient-led and DOH-administered*—to coordinate education, care pathways, benefits, research, and policy. The COVID-19 Longhauler Advocacy Project can coordinate nationally, providing the framework, toolkits, and technical assistance to ensure consistency, equity, and scale.

Nothing About Us, Without Us.

LONGHAULER ADVOCACY PROJECT

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

Brainstorming

Plannning

Recruiting

Advertising

Facilitation

Analysis

Dissemination

Longitudinal Follow Through

With Patients

People living with Long COVID and disability know where the system fails—delayed diagnosis, poor care coordination, stigma, and inaccessible services. Their ideas surface the most urgent gaps early, ensuring priorities are grounded in reality, not theory. This builds trust and creates strategies that reflect actual needs, improving both patient outcomes and public health preparedness.

Plans shaped by patients are practical and sustainable. They anticipate fluctuating symptoms, fatigue, air-quality needs, transportation, and caregiving responsibilities. They focus on outcomes that matter—improved function, return to work or school, independence. This reduces program failure and strengthens health systems by lowering preventable ER visits and disability claims.

Recruitment designed by patients addresses stigma and distrust. It ensures compensation, accessibility, and outreach in diverse communities hardest hit by Long COVID and disability. This yields more representative data and equitable public health interventions.

Patients craft messaging that is credible, plain-language, culturally sensitive, and stigma-aware. It motivates people to recognize symptoms, seek care, and participate in research or programs. This reduces misinformation and improves public health by encouraging prevention and early intervention.

Patient facilitators bring empathy, cultural competence, and lived experience. They build safe spaces where participants feel heard and respected, fostering honest dialogue and stronger engagement. This results in higher-quality data and more effective solutions.

Patients provide context for interpreting data, ensuring measures reflect meaningful outcomes—fatigue reduction, cognitive improvements, daily functioning, return-to-work capacity. Their insights guide subgroup analyses that highlight disparities and prevent one-size-fits-all conclusions. This leads to actionable results for clinicians, policymakers, and communities.

Findings are translated into accessible resources for patients, caregivers, clinicians, schools, employers, and policymakers. Patients ensure knowledge is shared widely, leading to faster adoption of best practices, reduced stigma, and better care.

Patients hold stakeholders accountable, ensuring initiatives adapt, sustain momentum, and avoid being abandoned. This prevents resource waste, builds resilience, and creates durable public health infrastructure to respond to Long COVID and disability long term.

Without Patients

Brainstorming often results in misaligned goals or ableist assumptions. Resources are spent on projects with little community impact, leaving gaps unaddressed. The result: wasted funds, slower progress, and growing mistrust that undermines participation.

Programs collapse under real-world pressure. Patients drop out due to inaccessible timelines or criteria, and policy decisions rely on unrealistic measures. The outcome: wasted investments, inequitable access, and continued progression of illness and disability.

Recruitment skews toward healthier, wealthier participants, producing biased results. Communities most affected remain excluded, reinforcing inequities and leading to ineffective interventions.

Messaging risks being dismissive or inaccessible. It alienates communities, deters participation, spreads confusion, and allows misinformation to thrive —damaging both patient trust and population health.

Discussions risk becoming tokenistic or dominated by professionals unfamiliar with lived challenges. Participants disengage, key insights are missed, and outcomes lose credibility in the community.

Research defaults to surrogate markers that don't translate into real-life improvements. Harm signals in vulnerable groups are overlooked. The result: interventions that look successful on paper but fail patients in practice.

Results stay siloed in journals or inaccessible reports. Communities, frontline providers, and the public remain uninformed, delaying uptake and fueling misinformation.

Programs stall, drift, or collapse when funding cycles end. Mistrust deepens, resources are squandered, and the cycle of inaction perpetuates worsening disability and higher costs.

The Most Comprehensive Patient-Developed Long COVID Resource Developed to Educate Cross-Sector Stakeholders

Now in its second volume (first published in 2021), C19LAP's Comprehensive Guide to Long COVID is the most complete, patient-developed resource for cross-sector stakeholders—patients and caregivers, clinicians, researchers, public-health officials, payers, employers, schools, and community leaders—built on five years of frontline, patient-led work. What sets this guide apart is its end-to-end usability (from bedside to policy), the credibility of lived experience paired with clinical rigor, and a cross-sector design that turns education into operations: documentation drives data, data informs policy, and policy allocates resources. Education is the hub of this entire cycle—without accurate, shared learning, care pathways stall, data quality erodes, and policy fails to meet need.

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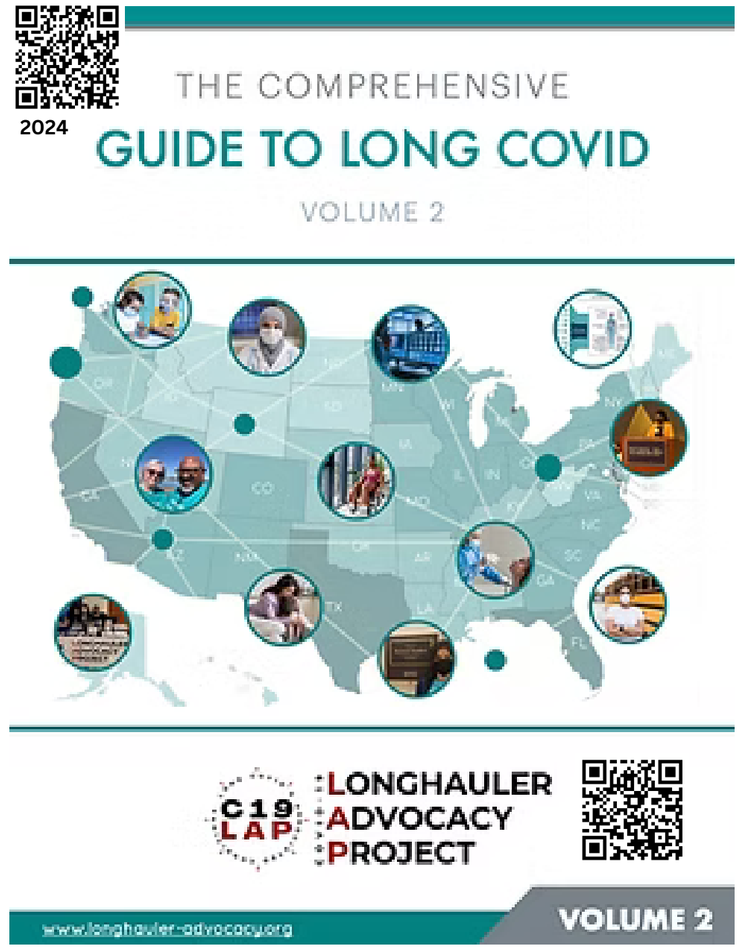

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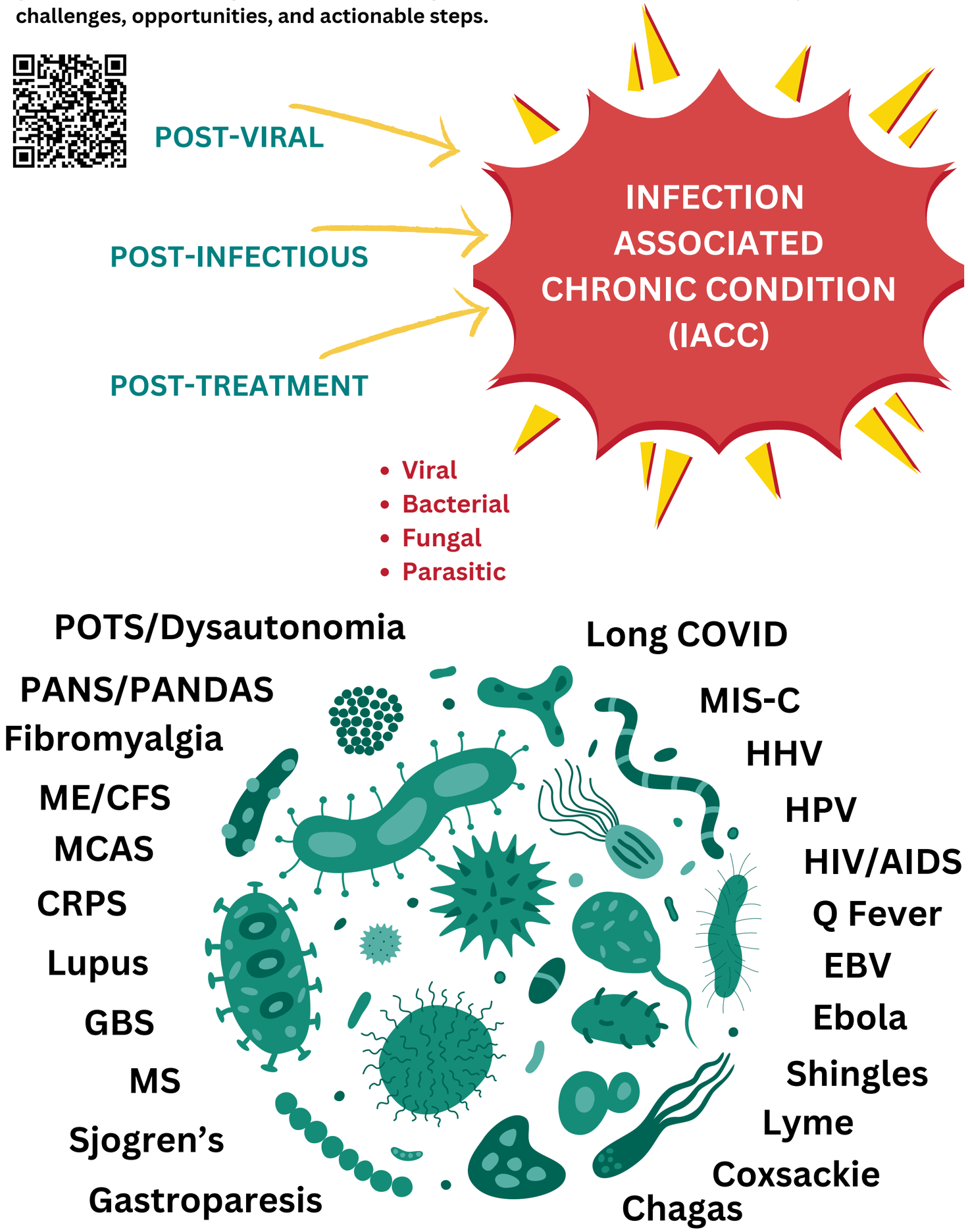
Long COVID is an Infection-Associated Chronic Condition

What is an IACC?

The term "Infection-Associated Chronic Condition" (IACC) applies to a variety of chronic conditions that can be triggered by viruses, bacteria, fungi, or parasites (CDC Foundation, 2024).

Millions of Americans were living with IACCs before the COVID-19 pandemic. The term IACC highlights the ongoing nature of the medical condition and its association with a triggering infection without conveying any unwarranted conclusions about pathobiological mechanisms. Furthermore, the use of this collective term can promote alignment across diverse disease groups and patient organizations—allowing for the identification of common objectives, challenges, opportunities, and actionable steps.



Examples of the Number of People in US w/ IACC Conditions

- **Long COVID: 20,000,000- 56,000,000 (2023-2024) (Long COVID has greatly exacerbated the number of people living with IACCs. For example, nearly 70% of people with Long COVID were found to have moderate to severe forms of autonomic dysfunction (dysautonomia), while nearly 50% met the criteria for an ME/CFS diagnosis.**
- **Postural Orthostatic tachycardia Syndrome: 1,000,000- 3,000,000 (2019)**
- **Sjogren's Disease: 400,000- 3,100,000 (2008)**
- **Persistent Lyme Disease: 1,620,000- 2,300,000 (2020)**
- **Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: 1,500,000 (2020)**

Research and clinical challenges in Infection-Associated Chronic Conditions (IACCs) are significant due to the complex nature of these diseases and limited understanding of their causes. Key challenges include the need for better funding, improved diagnostics, greater awareness and interest in the field, and effective treatments. Collaboration between researchers, clinicians, patient groups, and funders is vital.

- **Complex Etiologies: Infections trigger immune responses that can lead to chronic conditions, though mechanisms are not fully understood, hindering treatment development.**
- **Diagnosis Difficulties: Lack of specific biomarkers often delays diagnosis or leads to misdiagnosis, as symptoms overlap with other conditions.**
- **Limited Research Funding: IACCs like Long COVID, dysautonomia, ME/CFS and post-Lyme disease syndrome are underfunded despite their impact, limiting diagnostic and treatment progress.**
- **Stigmatization: Patients face stigma due to invisible symptoms and lack of medical recognition, affecting treatment and support.**
- **Inadequate Treatment: Many IACCs lack cures, with treatments focusing on symptom management rather than root causes.**
- **Symptom Variability: Diverse symptoms across patients complicate standardized treatments and clinical trials.**
- **Long-Term Research: Long-term studies are needed to understand IACC progression, but securing sustained funding and participation is difficult.**

C19 LAP — LONG COVID & ASSOCIATED CONDITIONS — COVID-19

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SUPPORTING LONG COVID RESEARCH, CARE DELIVERY, & RESOURCES

Investing across the full therapeutics spectrum directly helps patients, providers, and policymakers.

Funding repurposed agents (antivirals, monoclonals, T-cell/other immunotherapies) helps by shortening the path from bench to bedside so clinicians have options now and disability is reduced sooner. Testing rational combination regimens helps by attacking a multi-system disease on multiple fronts, increasing the odds of meaningful gains in activities of daily living, cognition, and orthostatic tolerance. Backing truly novel approaches, including CAR-T, CRISPR, and next-gen targets, helps by building the pipeline for breakthroughs when repurposing isn't enough, creating durable treatments instead of stopgaps, and positioning the U.S. to lead on a mass-disabling condition. We applaud HHS for recently providing ARPA-H funding to bring these kinds of therapies closer to those impacted, and we hope to see this research cross over into and include Long COVID. Starting high-risk/high-reward programs early and at scale helps by preventing another lost decade; every year gained moves candidates into trials faster, cuts long-term costs, and restores people's ability to work, learn, and participate in life. Moving research beyond RECOVER and diversifying investigators and sites, including independent, community, and academic centers, with external funding and strong guardrails helps by bringing fresh ideas, faster iteration, real-world diversity, and greater public trust through transparent, patient-involved governance. Designing trials to measure what matters to patients (ADLs, return-to-work/school, decreased symptom and disease burden) helps by producing results clinicians can act on and outcomes patients can feel, turning investment into tangible recovery.

A sustained commitment to public and clinician education delivers immediate, tangible gains.

Clear, repeated, evidence-based messaging ("Long COVID is real, prevalent, and preventable; vaccination lowers severe disease but doesn't eliminate risk; science evolves with evidence") builds trust, corrects minimization, and separates Long COVID from vaccine injury so policy isn't derailed by conflation. A national, science-driven campaign, on TV, radio, online/print media, social media, podcasts, public transit, and in community venues, clinics, schools, and workplaces, equips people to reduce infections and reinfections, recognize symptoms early, and seek appropriate care, while clinician education on assessment, diagnosis, documentation/coding, and care pathways speeds time-to-diagnosis, improves care coordination, and increases accurate documentation, because documentation informs data which informs policy, which informs resource allocation. Turnkey toolkits for DOHs, CILs, medical schools, health systems, and community groups streamline rollout; misinformation guardrails and rapid myth-busting protect the public conversation; and leaders modeling basic protections translate words into lowered risk. C19LAP's patient-built materials, already field-tested through social campaigns, billboards, guides, webinars, and conference outreach, can be deployed or scaled now, closing knowledge gaps, expanding clinical capacity, unlocking bipartisanship and funding, and ultimately helping millions keep learning, working, and living their lives.

Sustained, bipartisan, cross-sector, patient-driven collaboration is a force multiplier.

It turns cross-sector interest into trials, tools, and care, fast, while fixing a key bottleneck on Capitol Hill. The politicization and stigmatization of COVID-19, led to the same for Long COVID. Bipartisan support has long been absent, yet desperately needed. Reducing mis- and disinformation and giving lawmakers what they need to educate their colleagues and build durable majorities for multi-year funding is a necessity. At the federal level, the table must include HHS and its agencies, NIH, CDC, CMS, HRSA, FDA, alongside VA, DOL, SSA, DOE, and DoD to align science, coverage, workforce, disability benefits, education, and mission readiness. State and local governments, especially Departments of Health, translate that alignment into action. This coordinated, cross-party, cross-agency approach also de-risks participation for industry partners who previously stepped back, re-opens collaboration pathways, and delivers tangible outcomes patients can feel: faster diagnosis, safer schools and clinics, better access to care, and a credible pipeline of therapeutics.

Center people with Long COVID (as a primary diagnosis) at every stage of work. Nothing about us, without us.

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.

LONG COVID & ASSOCIATED CONDITIONS
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learn more at longhauler-advocacy.org

What Do You *Really* Know About *Long COVID*?

- COVID-19, or SARS-CoV-2, is a real and scientifically verified and researched virus that began circulating in fall 2019.
- Long COVID is a real and serious health condition recognized by health organizations worldwide.
- Long COVID is not psychosomatic. Recovery from Long COVID is not simply a matter of willpower or mental determination.
- Long COVID is not a vaccine injury.
- Long COVID, like many chronic conditions, often does not have outwardly visible symptoms.
- Normal results on standard blood tests (CBC, CMP, BMP) do not necessarily rule out Long COVID or other illnesses.
- People with Long COVID are not lazy. They want to work, attend school, and participate in their lives. Long COVID can impair individuals' ability to work, attend school, take care of family, and care for themselves.
- While a balanced diet, regular exercise, and certain supplements may help manage symptoms and improve overall health for some, they are not a cure for Long COVID and may actually harm people.
- It is possible to have had COVID-19 and develop Long COVID without ever having received a positive test result.
- Achieving herd immunity through infection with COVID-19 is unlikely.
- Reinfections significantly increase the risk of developing Long COVID,
- Asymptomatic COVID-19 infections (~40%) are the largest contributors to the spread of COVID-19.
- 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 impacts children just as severely as adults and they face high absenteeism rates and are often academically punished.
- Long COVID, chronic illness, and disability can have a profound emotional and physical impact on patients and their families and caregivers.
- Long COVID can follow asymptomatic, mild, or severe COVID infection which may have been recognized or unrecognized.
- Long COVID can be continuous from the time of acute COVID infection or can be delayed in onset for weeks or months following what had appeared to be full recovery from acute infection.
- Long COVID can range from mild to severe, 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.
- Research indicates that individuals with symptoms lasting at least 3 months have a higher chance of persistent symptoms lasting at least 1 year.
- Reseach highlights several mechanisms that may be involved in Long COVID: immune dysregulation, autoimmunity and immune priming, viral persistence, blood clotting and endothelial abnormalities, dysfunctional neurological signaling, and microbiota dysbiosis.
- In April 2024, just before the release of the National Academies' broader Long COVID definition, 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.
- There are no approved treatments for Long COVID.
- To effectively manage and mitigate Long COVID, a comprehensive cross-sector, patient-centered and driven national approach is a necessity.

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Long COVID

learn more at longhauler-advocacy.org

The only way to prevent Long COVID is to prevent COVID.

Please take & use our free N95 masks

Help protect:

- **us**
- **everyone in attendance**
- **everyone at home waiting for us**
- **strangers you encounter during travel**
- **yourself!**

Everyone is one infection away from Long COVID, chronic illness, disability, or death. Don't Risk It!

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