

Clinical and Public Health Implications of the NASEM Long COVID Definition and Its Role in Standardizing Care – A Roadmap to Long COVID Assessment, Diagnosis, Documentation, Care Management, and Support

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Founder & President- COVID-19 Longhailer Advocacy Project

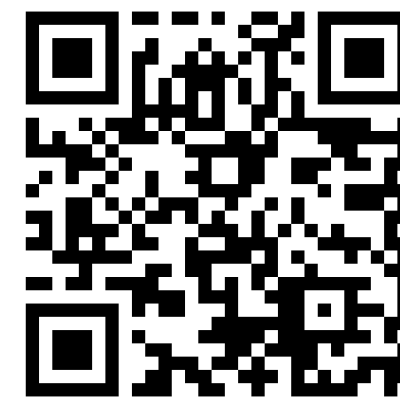
B.S., Exercise Science & Health Promotion, Former Firefighter/ Paramedic & K-12 Educator



**COVID-19 LONGHAULER
ADVOCACY
PROJECT**



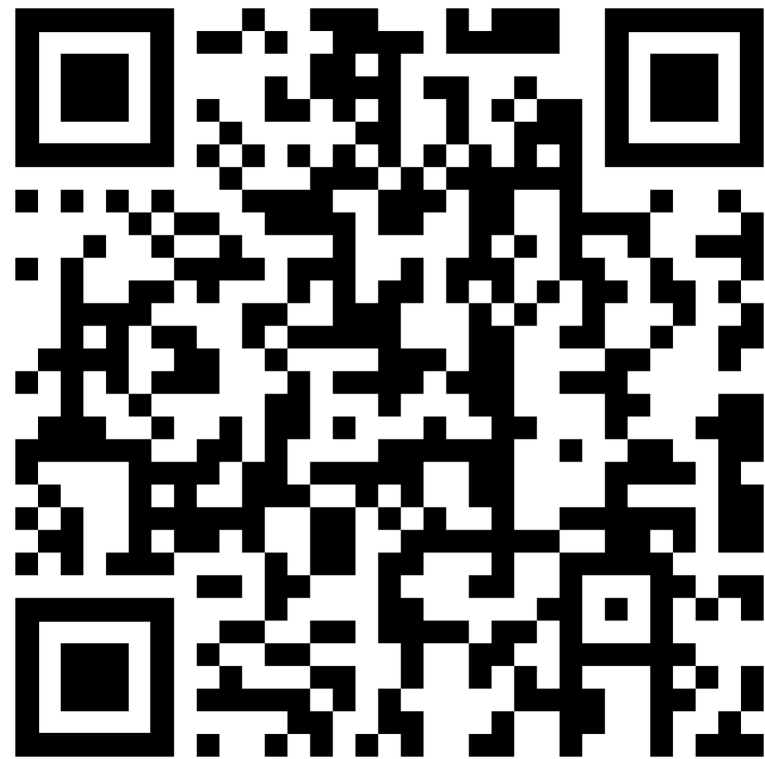
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Disclosures

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 firefighter/ 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.

N.A.S.E.M. Definition Purpose & Process

N.A.S.E.M. - National Academies of Science, Engineering, and Medicine

O.A.S.H.- Office of the Assistant Secretary of Health and Human Services

A.S.P.R. - Administration for Strategic Preparedness and Response

When the COVID-19 pandemic began, no one was prepared for the aftermath it would leave behind. When what is now known as Long COVID began being recognized, there was no standardized or consensus effort to define the disease. Over time, various health agencies, countries, individual researchers, institutes, and beyond, began making their own definitions using varying inclusion and exclusion criteria.

This led to extreme difficulty in being able to make comparisons and sense of the research to enable evidence-based actions, delaying both prevention and response. In 2023, O.A.S.H. and A.S.P.R tasked N.A.S.E.M. with developing a consensus definition for Long COVID. I had the privilege of being nominated by the Long COVID community to serve on the committee convened.

Over a year and a half, the committee completed a vigorous scientific review of over 116 studies that met review criteria, engaged over 1,300 patients and stakeholders, took a patient-centered, science-forward approach, and participated in passionate committee deliberations. We were determined to make the definition one that could overcome existing barriers, and de-stigmatize Long COVID.

The 2024 NASEM Long COVID definition aims to aid in consistent diagnosis and treatment, promote a holistic approach encouraging interdisciplinary collaboration, harmonize research, surveillance, and public health trends by supporting standardized data collection, raise awareness and educate stakeholders enhancing patient access to care, and address equity considerations for all demographic groups.

In June 2024, N.A.S.E.M. released the consensus definition alongside a report. Shortly after, HHS announced adoption of the definition across the whole of government.

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 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.

LC manifests in multiple ways. A complete enumeration of possible signs, symptoms, and diagnosable conditions of LC would have hundreds of entries. Any organ system can be involved, and LC patients can present with:

- **Single or multiple symptoms**, such as: shortness of breath, cough, persistent fatigue, post-exertional malaise, difficulty concentrating, memory changes, recurring headache, lightheadedness, fast heart rate, sleep disturbance, problems with taste or smell, bloating, constipation, and diarrhea.
- **Single or multiple diagnosable conditions**, such as: interstitial lung disease and hypoxemia, cardiovascular disease and arrhythmias, cognitive impairment, mood disorders, anxiety, migraine, stroke, blood clots, chronic kidney disease, postural orthostatic tachycardia syndrome (POTS) and forms of dysautonomia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), mast cell activation syndrome (MCAS), fibromyalgia, connective tissue diseases (CTD), hyperlipidemia, diabetes, and autoimmune disorders such as lupus, rheumatoid arthritis, and Sjogren's syndrome.

- LC can follow asymptomatic, mild, or severe SARS-CoV-2 infection. Previous infections may have been recognized or unrecognized.
- LC can exacerbate pre-existing health conditions or present as new conditions.
- LC can range from mild to severe. It can resolve over a period of months or can persist for months or years.
- 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 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 affect children and adults, regardless of health, disability, or socioeconomic status, age, sex, gender, sexual orientation, race, ethnicity, or geographic location.
- LC can be diagnosed on clinical grounds. No biomarker currently available demonstrates conclusively the presence of LC



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

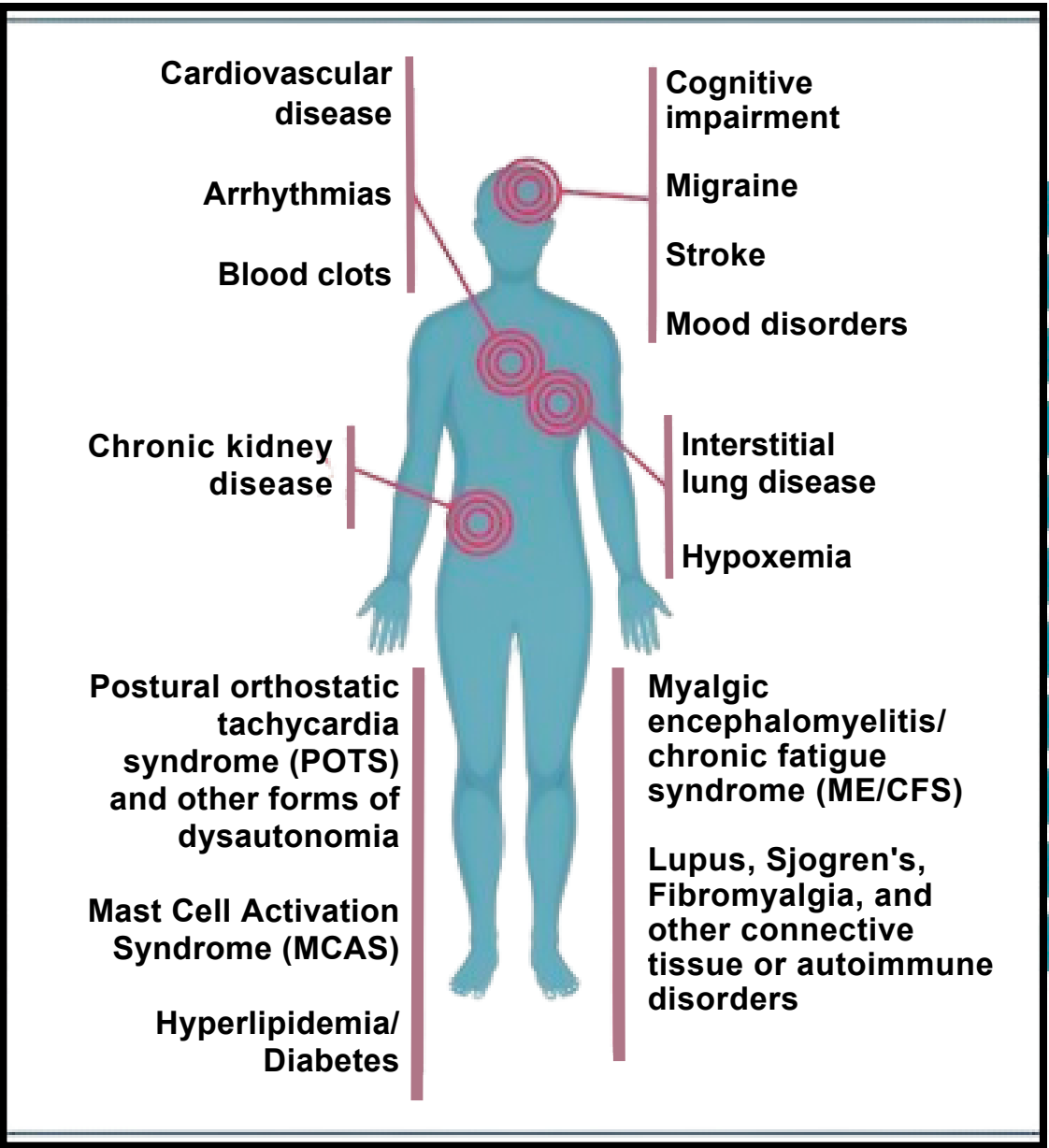


Many other symptoms have been observed.

Diagnosable Conditions

New or worsening of preexisting conditions

Pathobiology
of Long COVID



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.



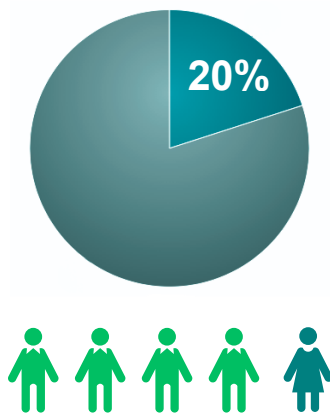
Can be continuous from acute infection or delayed in onset

N.A.S.E.M. 2024

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

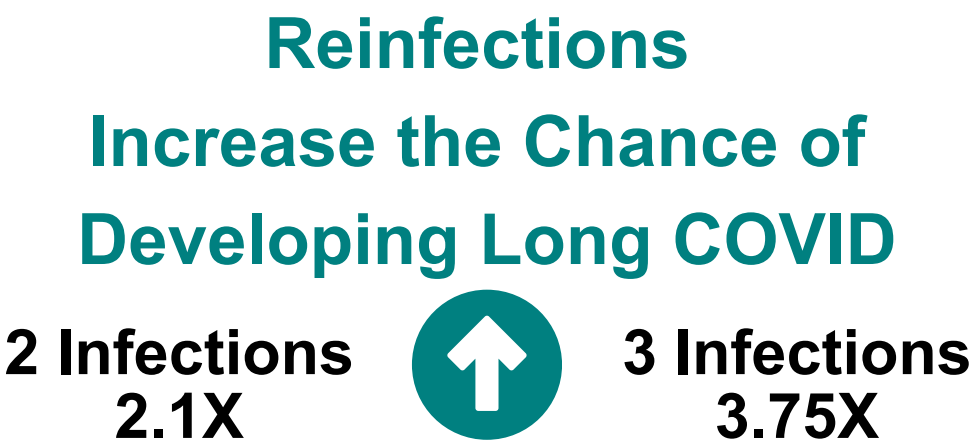
The Impacts of Long COVID

U.S. General Public



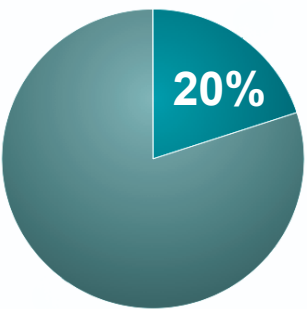
20% of people who get COVID-19 develop Long COVID. Recent global estimates rise as high as 36%. C19LAP believes this is a **significant undercount** due to a lack of testing, leading to documentation that informs public health policy.

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.**

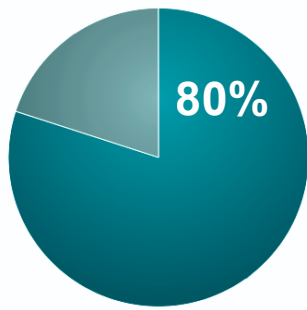


U.S. Pediatrics

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.**



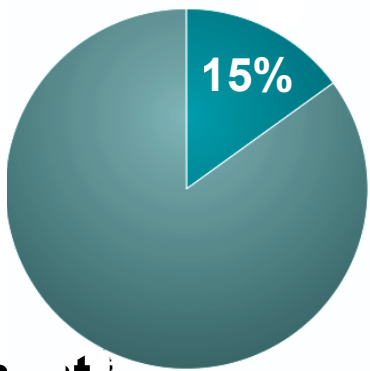
According to a publication from the CDC in JAMA Pediatrics, **80% of children with Long COVID reported activity limitation.**



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.

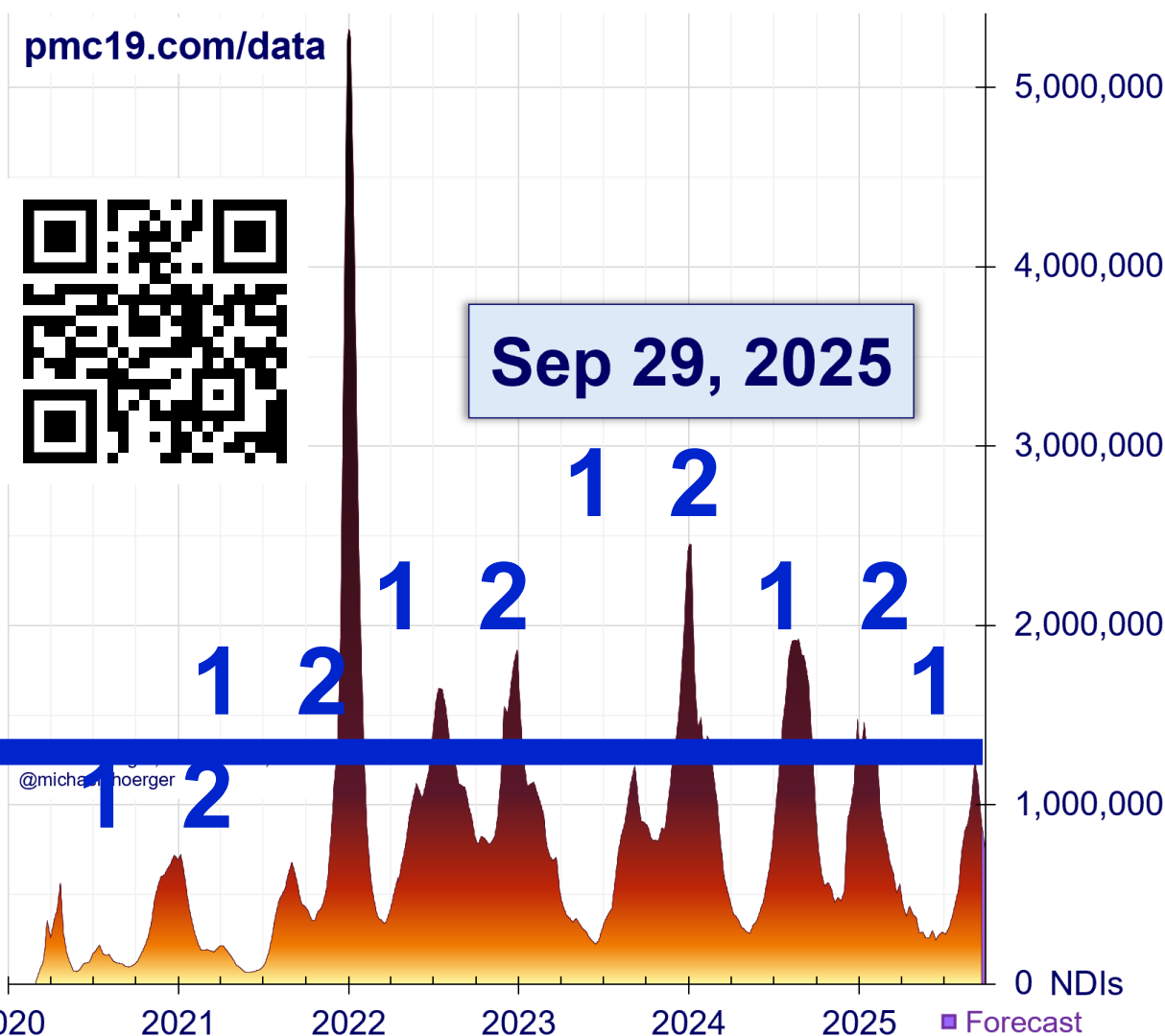
Long COVID is a public health emergency. Investment in public awareness and education, clinician training, as well as proper funding and resources are needed to address and meet this issue at scale.

The Data Says the Pandemic Never Ended

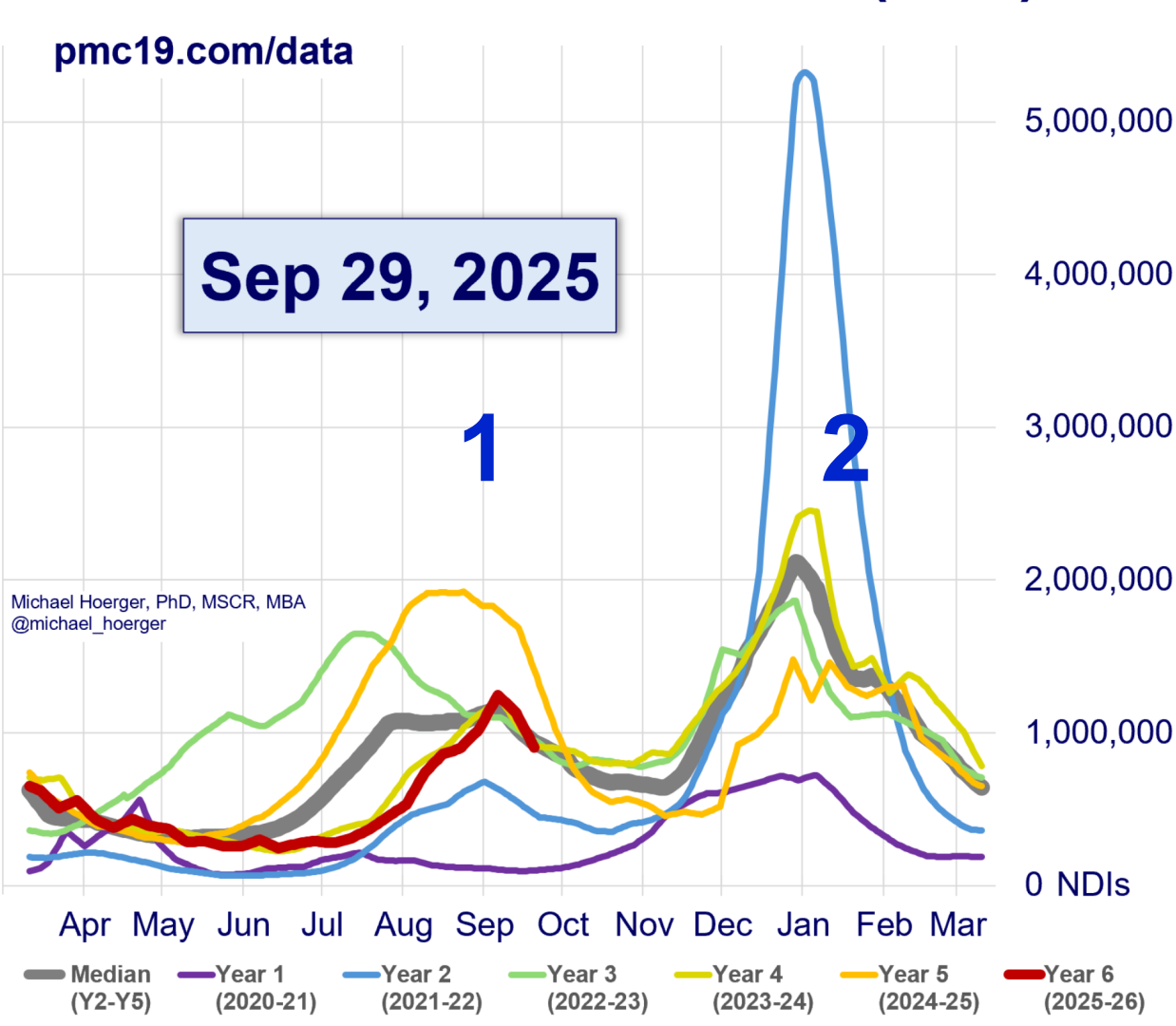
From the very start of the COVID-19 Pandemic, the U.S. failed to adequately respond. While many Long COVID efforts were underway and being stood up, public messaging began pushing the narrative that the pandemic was over and it was under control. This led to premature and costly policy rollbacks and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

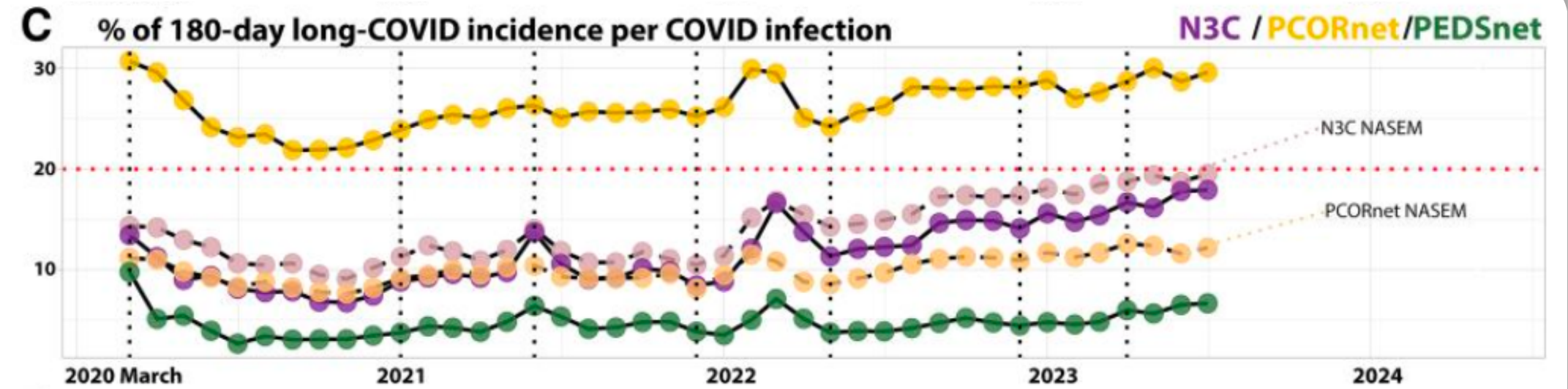
	Sep 29, 2025	pmc19.com/data
Infections		
Proportion Actively Infectious	1 in 66 (1.5%)	
New Daily Infections	743,000	
Infections the Past Week	5,540,000	
Infections in 2025	185,000,000	
Cumulative Infections per Person	4.68	
Long COVID		
Long COVID Cases Resulting from New Daily Infections	37,000 to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

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



Every Sector Has A Responsibility to the millions with Long COVID

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.

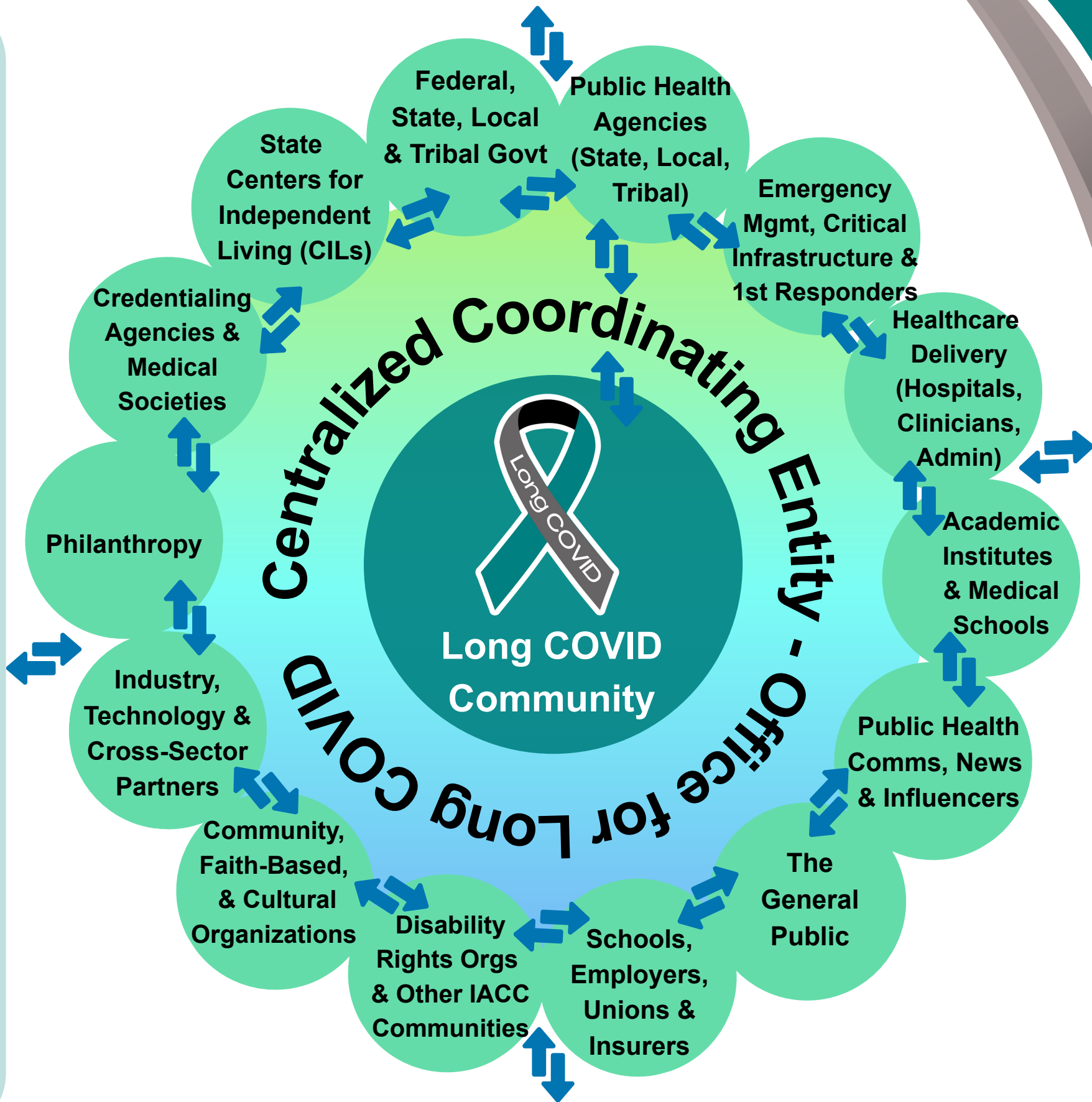
Desired Long COVID Response Model & How It Restores Trust in Public Health

Nothing About Us, Without Us

- Brainstorming
- Planning
- Recruiting
- Advertising
- Facilitation
- Analysis
- Dissemination
- Longitudinal Follow Through

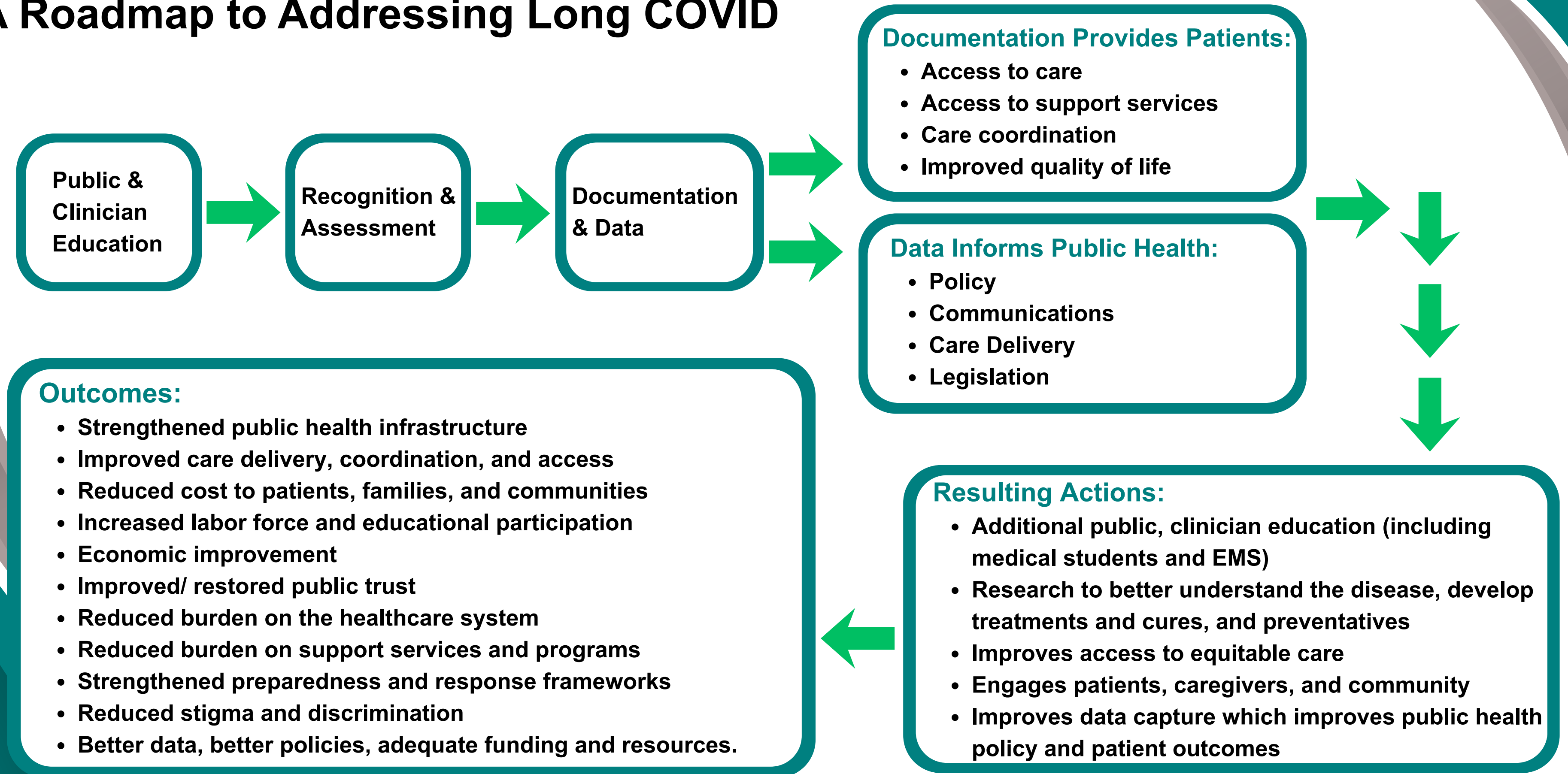
Trust in public health eroded because systems acted on communities, not with them. This model restores it by making public health responsive, participatory, and transparent, transforming it from an institution people endure into a partnership they believe in. It replaces top-down control with shared 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 that integrity is rooted in transparency, not perfection.



Impacts of Using the N.A.S.E.M. Long COVID Definition

A Roadmap to Addressing Long COVID



A Roadmap to Long COVID Assessment, Diagnosis, Documentation, Care Management, and Support

A Large-Scale National Coordinated Long COVID and COVID-19 Public and Clinician Education Initiative Developed in Partnership with the Long COVID Community and Long-Standing, Credible Long COVID Organizations.

Patients, Caregivers, Employers, Educators, and All Stakeholders (Clinicians, Researchers, Government, etc.) as Members of the General Public Are Informed and Begin to Recognize Long COVID and Seek Care, Leading to Better Documentation of Long COVID and More Willing Uptake of Mitigation Efforts.

This Documentation Allows Patients to Access Needed Care by Informed Clinicians and Provides Necessary Documentation for Work, School, Accommodations, Disability, and Other Means of Assistance and Support.

Clinicians Begin to Be Able to Assess for, Identify, and Document Long COVID in Both Existing Patients They May Have Overlooked or Dismissed and in New Patients.

This Documentation Better Informs the Prevalence of Long COVID and Produces Meaningful Data That Feeds Legislative Decisions, Including Funding for Research and Support Services, and Informs Research Priorities, Public Health Policy, and Messaging. It Strengthens Current and Future Preparedness and Response Efforts and Emphasizes the Importance of a Coordinated Response to the COVID-19 Pandemic and Its Longitudinal Health and Systemic Impacts.

- How?**
- TV
 - Radio
 - Social Media
 - Public Transit (train, bus)
 - Airports
 - Hospitals and Doctors Offices
 - Clinician CME's
 - Medical School Curriculum
 - Conferences and Grand Rounds
 - Partnership with Long COVID Organizations



C19LAP Comprehensive Guide to Long COVID (Page 497-507): Long COVID Clinical Assessment Guide for Clinicians



C19LAP Cross-Sector Guidance for a National Long COVID Public Health Response

GOAL!

Improved Patient & Public Health Outcomes and Improved Public Trust & Compliance

Each Sectors Role & Use of the N.A.S.E.M. Long COVID Consensus Definition

Clinicians and Health Systems

- Integrate the NASEM Long COVID definition into clinical protocols, EHR templates, and patient intake forms.
- Use the definition to standardize diagnosis, documentation, and coding practices across departments.
- Educate care teams on identifying and managing Long COVID consistently using the NASEM criteria.

Public Health Agencies (Federal, State, Local, Tribal, and Territorial)

- Embed the NASEM definition in surveillance systems, case reporting, and public health guidance.
- Align data collection, prevalence monitoring, and community health initiatives around the standardized definition.
- Provide training and technical assistance to local health departments and community health partners.

Researchers and Academic Institutions

- Adopt the NASEM definition as the baseline inclusion criteria for studies to ensure comparability across research.
- Update IRB protocols, grant proposals, and publications to reflect standardized case identification.
- Develop education modules and curricula that train future clinicians and researchers using the definition.

Policymakers and Government Leaders

- Reference the NASEM definition in legislation, funding mechanisms, and program design to ensure consistency across federal and state responses.
- Require its use in data reporting, program evaluation, and accountability metrics for Long COVID initiatives.

Advocacy and Patient Organizations

- Translate the NASEM definition into plain language to educate patients, caregivers, and the general public.
- Disseminate through community networks, webinars, and social media to promote awareness and self-advocacy.
- Collaborate with clinicians and agencies to ensure real-world implementation reflects lived experience.

Insurers and Disability Programs

- Apply the definition to guide eligibility for benefits, workplace accommodations, and medical necessity reviews.
- Standardize documentation requirements across payers to reduce barriers to care and coverage disputes.

Continued

Industry, Employers, and Schools

- Use the NASEM definition to develop workplace, educational, and return-to-learn accommodations.
- Train HR and student services staff on recognizing Long COVID and supporting affected individuals.

Media and Public Communication Channels

- Reference the NASEM definition when reporting on Long COVID to promote accuracy and reduce misinformation.
- Partner with patient groups and health agencies to produce educational campaigns grounded in the definition.

**Everyone and Every Sector
Has a Role in Responding
to Ongoing COVID-19
Pandemic and Long COVID.**

We Need You!



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

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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.



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