

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**

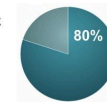
2 Infections 2.1X  **3 Infections 3.75X**

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.**



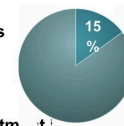
According to a publication from the CDC in JAMA Pediatrics, **80% of children with Long COVID reported activity limitation.**



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.

Each Sector's 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

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.

- 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

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.

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.



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

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.

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.

GOAL!

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