

Strategies and Innovations to Address Long COVID

Background

Long COVID, or post-COVID condition, is a chronic condition that occurs after SARS-CoV-2 infection and afflicts approximately 20 million people in the United States. It is a <u>multifaceted disease</u> with symptoms or health problems lasting for at least three months as a continuous, relapsing, remitting, or progressive disease state affecting one or more organ systems. In 2024, the National Academies of Sciences, Engineering, and Medicine released a report <u>defining Long COVID</u> to harmonize terminology and measurement approaches.

Long COVID has far-reaching implications beyond individual health, affecting health care systems and broader societal structures. Global <u>economic impact</u> of Long COVID is estimated to be approximately \$1 trillion per year, including medical costs, productivity losses, and other compounding effects. Ongoing prevention efforts for Long COVID rely upon vaccination and primary prevention strategies for COVID-19 infection. The lasting impact of Long COVID requires unique health policy approaches, sustained research funding, and coordinated health and public health action to support affected individuals and mitigate long-term societal costs.

Key Challenges

- 1. **Diagnostics:** There is no laboratory test for diagnosis nor standardized clinical diagnostic test. As a result, clinical clarity in diagnosis remains challenging. Reduced testing for acute COVID-19 infection has also hindered diagnosis and public health disease surveillance of Long COVID.
- Engagement: COVID-19 pandemic fatigue and reduction in trust can make it challenging to establish a trusted public health response to support impacted communities. Information is constantly evolving as more is learned about the condition, which can lead to confusion and misinformation. There is also little real-time data on community needs related to Long COVID to help tailor messaging or provide effective education.
- 3. **Funding:** Many jurisdictions do not have dedicated Long COVID funding and are grappling with cuts to federal and state funding for Long COVID. Without sustained funding, it is challenging to retain dedicated staff increasing reliance on part-time personnel and continue initiatives.





Jurisdiction Highlights: Advancing Long COVID Efforts

Colorado

In 2022, the Colorado General Assembly passed <u>HB22-1401</u>, directing the Office of Saving People Money on Health Care (OSPMHC) to examine and make policy recommendations that address the impacts of post-viral illness resulting from COVID-19, and directing the office to support efforts improving public health outcomes in the state. OSPMHC releases <u>annual reports</u> summarizing Long COVID impacts in Colorado, as well as key activities and accomplishments. Key statewide activities include developing <u>surveys</u> to assess socioeconomic impacts of Long COVID in Colorado, conducting a <u>modeling study</u> to examine factors and utilization patterns pre- and post-Long COVID diagnosis, and launching an initiative to better understand the association between clinical events prior to death and the designation of Long COVID on death certificates. Additionally, a Colorado Long COVID Community of Practice was established to discuss recent developments, share lessons learned, and inform strategies for surveillance and care, plus web/social media content to raise awareness.

Minnesota

The Minnesota Department of Health (MDH) launched the Long COVID program in 2021 to increase awareness and monitor potential long-term health issues following COVID-19 infection. In 2023, MDH secured <u>state funding</u> to expand the program and offer grants to organizations that support communities disproportionately impacted by COVID-19. Key initiatives include raising awareness about Long COVID and other infectious-associated chronic conditions (IACCs) through presentations, social media, and <u>online resources</u>; engaging individuals affected by Long COVID and conditions like myalgic encephalomyelitis/chronic fatigue syndrome; conducting epidemiological surveys and studies; forming a Long COVID Provider Guiding Council to foster collaboration, education, and system improvements among health care providers; and establishing the Long COVID Community Voices partner group, which led to a statewide network of organizations addressing Long COVID needs. Additionally, MDH has started a steering team of professionals and people with lived experience to guide the development of an actionable statewide framework for addressing IACCs and identify opportunities for cross-sector collaboration.

New York City

The New York City Department of Health and Mental Hygiene has focused its efforts on raising awareness and community engagement around Long COVID. Key activities include multilingual trainings for community and faith-based organizations and other partners to incorporate Long COVID information into their messaging with their respective communities, a study to assess long-term impacts of COVID-19 on New Yorkers, a three-part messaging campaign to share lived experience and stories of those living with Long COVID, and web/social media content to raise general awareness.



Key Considerations

- Utilize public health resources such as the <u>10 Essential Public Health Services framework</u>, <u>"The Role of U.S.</u> <u>Public Health Agencies in Addressing Long COVID</u>" and the <u>health+ "Long COVID Human-Centered Design</u> <u>Report</u>" to guide implementation of robust programs for Long COVID and related conditions.
- Share information on health agency websites, newsletters, or other forums to help raise awareness. Access to relevant information and resources is critical.
- Foster relationships and trust with various partners (e.g., health care, community-based organizations, and patient and caregiver communities) to learn about challenges/needs related to Long COVID and opportunities for collaboration.
- Collaborate with trusted messengers, such as community health workers and champions, to share community specific and linguistically appropriate information. Focus outreach efforts on under-resourced populations through culturally responsive frameworks.
- Partner with clinicians and health care systems to support clinical education and share relevant patientfocused resources for Long COVID and associated conditions.
- Promote sustained investment and support for Long COVID policies and research. Engage with key partners including health agency leadership, governor's offices, state legislators, and advocacy groups to raise support for initiatives. Utilize local data and stories to show impact and advocate for dedicated resources.

We would like to thank the members of the ASTHO Long COVID Community of Practice for their expertise and insights in the development of this brief. This project is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$350,000 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.