



# State and Territorial Perspectives on Surveillance and Epidemiology of Long COVID

*NASEM Committee Examining the Working  
Definition for Long COVID*

May 12, 2023

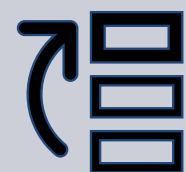
# Background



ASTHO launched a rapid query to state and territorial health officials in April 2023 to understand current priorities, gaps, and challenges associated with Long COVID.



43/59 jurisdictions completed the survey.



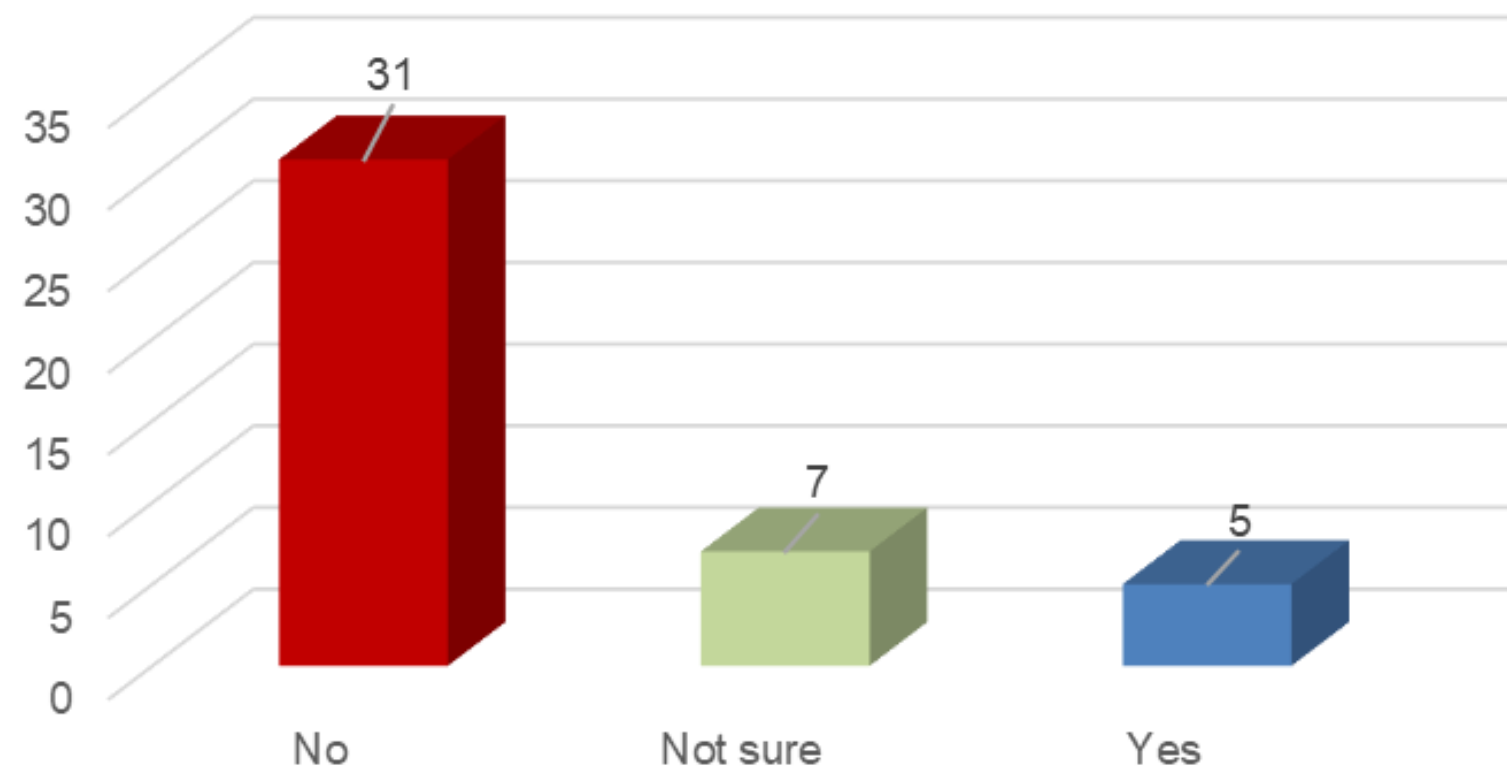
Jurisdictions ranked the following as the top three **most immediate needs** related to Long COVID:

1. The need for a standard definition.
2. Surveillance efforts and best practices.
3. Prevention and mitigation strategies.

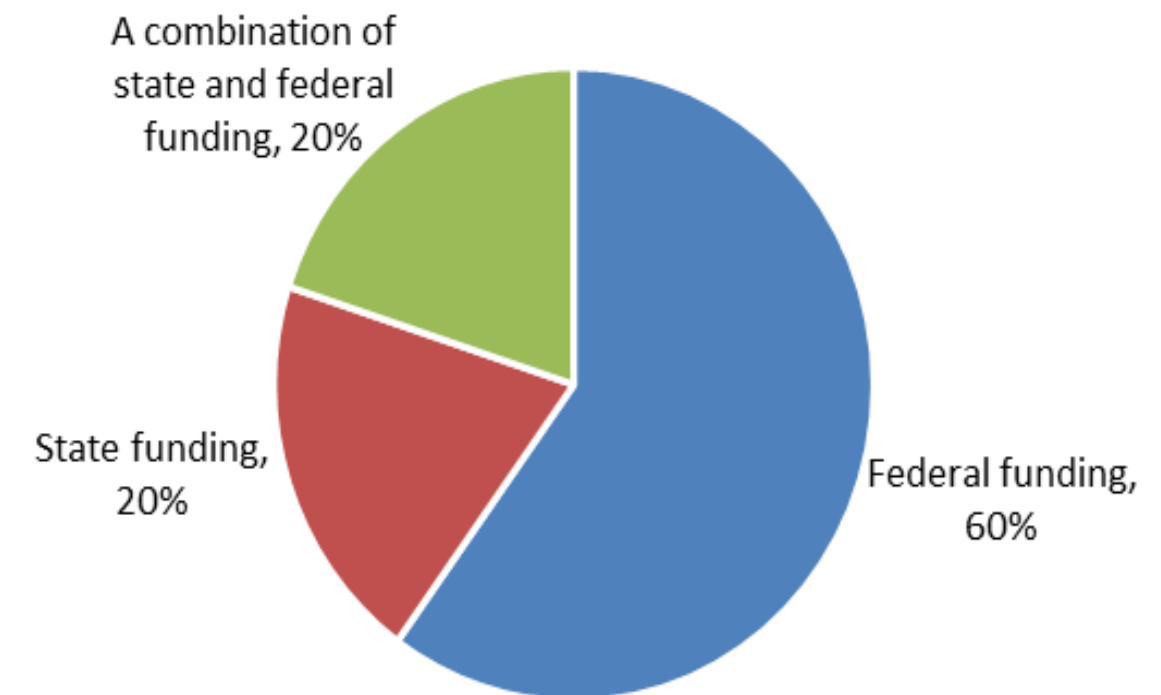
# Dedicated Funding

**Has your jurisdiction been allocated dedicated funding to support Long COVID efforts? [N=43]**

**Jurisdiction allocated dedicated funding support to long COVID efforts [N=43]**



**Type of dedicated funding [N=5]**



# Most Immediate Funding Needs



Provider engagement, training, and education.



Public communication/media campaigns to raise awareness.



Health department staffing to coordinate Long COVID work.



Comprehensive support for chronic disease prevention and intervention.

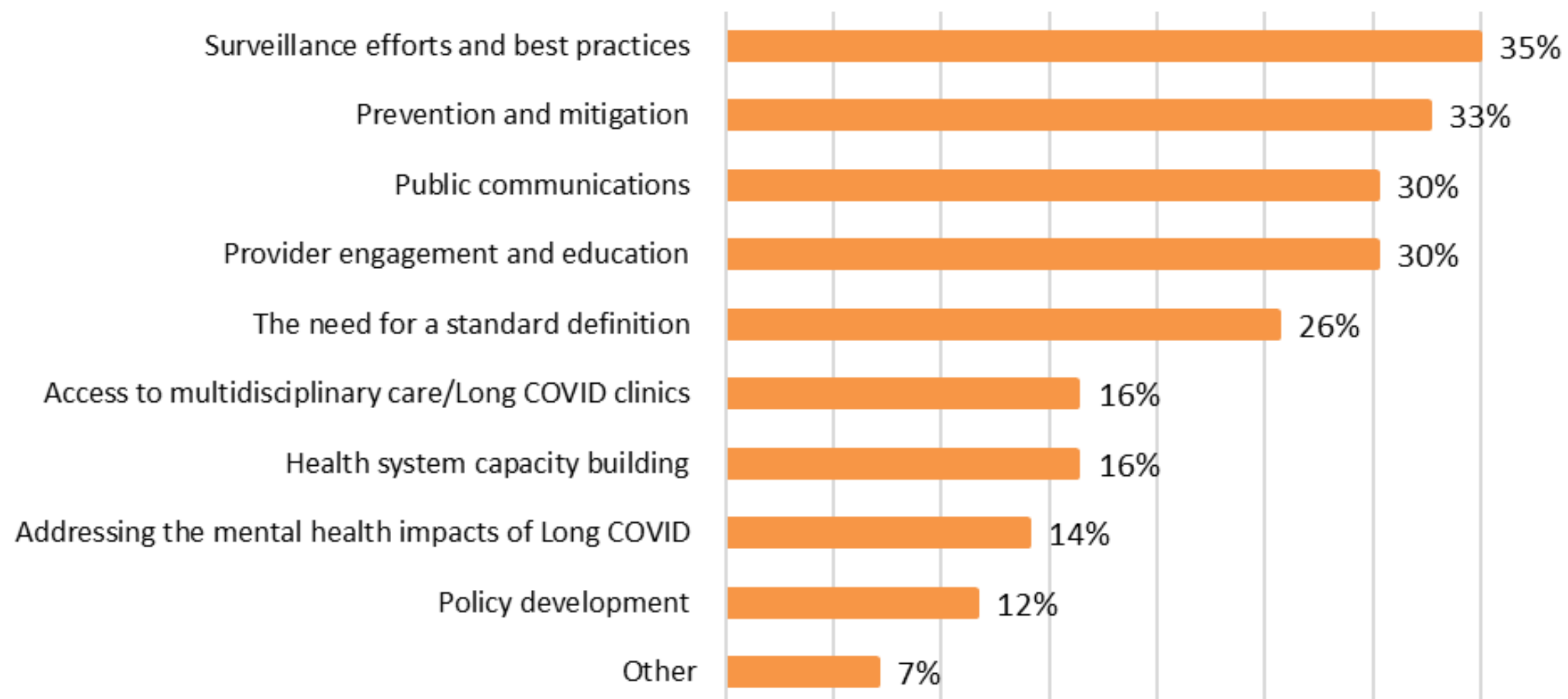


Data collection and surveillance systems for Long COVID.

# Current Activities

## Activities state and territorial health departments are CURRENTLY conducting to address or respond to long COVID

N=43





# Partner Engagement

**Have you engaged with any of the following organizations to address health care coverage or access issues for Long COVID?**

|                                | Yes       | Not yet, but we're working on it | No        | Not sure |
|--------------------------------|-----------|----------------------------------|-----------|----------|
| Insurers (non-Medicaid) [N=40] |           | 9, 22.5%                         | 29, 72.5% | 2, 5%    |
| Medicaid [N=42]                | 4, 9.5%   | 11, 26.2%                        | 25, 59.5% | 2, 4.8%  |
| Healthcare systems [N=42]      | 12, 28.6% | 8, 19%                           | 20, 47.6% | 2, 4.8%  |
| Providers [N=42]               | 15, 35.7% | 4, 9.5%                          | 22, 52.4% | 1, 2.4%  |
| Other, please specify [N=11]   | 5, 45.5%  |                                  | 6, 54.5%  |          |

Other:

- “Community organizations, local public health, employers, schools, media”
- “State and Federal social security”
- “Academia”
- “Federal agencies”

# Data Collection and Surveillance

If your jurisdiction is currently conducting (or has conducted) data collection, analyses, or surveillance for Long COVID, please note which approaches you are using. Select all that apply. [N=43]

- **60.5%** of respondents responded that to date, they have **not** conducted data collection, analyses, or surveillance for Long COVID.
- **20.9%** are conducting a survey(s) of persons with COVID-19 to assess prevalence and clinical/epidemiologic features of Long COVID at a point in time.
- **11.6%** are conducting syndromic surveillance (e.g., using emergency department data to assess where Long COVID is mentioned in either chief complaint or ICD-10 codes).
- **4.7%** of respondents are establishing a population-based registry to follow persons with Long COVID over time.



# Research and Scientific Data Needs



01

Better definition of classic signs and symptoms.

02

More data on the course, natural history, and prognosis of Long COVID.

03

Epidemiology and risk factors of Long COVID.



# Questions?

**Marcus Plescia, MD, MPH**  
Chief Medical Officer  
[mplescia@astho.org](mailto:mplescia@astho.org)

**Jessica Baggett, MPH**  
Senior Advisor, Public Health  
Response  
[jbaggett@astho.org](mailto:jbaggett@astho.org)

[www.astho.org](http://www.astho.org)

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## From the Chief Medical Officer: Leadership Considerations for Long COVID

**FEBRUARY 28, 2023 | MARCUS PLESCIA**

One of the most challenging issues I faced in clinical practice was helping patients navigate chronic illness and disability. Some conditions were well understood with resources and support readily available. However, in many cases, symptoms were difficult to characterize, the underlying causes were unclear, and the role of depression and other mental health conditions as a primary or contributing factor were difficult to quantify. Many chronic conditions are associated with significant stigma and isolation. At the community level, behavioral health and other resources to support these conditions continue to be limited.



**Author**



**Marcus Plescia,  
MD, MPH  
ASTHO**  
Chief Medical Officer



## Long COVID Policy Statement

**POSITION**

ASTHO recommends implementing evidence-based strategies to prevent Long COVID and the development of policies to support those currently living with post-COVID conditions.

**BACKGROUND**

While many people diagnosed with COVID-19 recover completely, some individuals report symptoms that persist or emerge weeks to months after their initial infection.<sup>1</sup> One in five COVID-19 patients aged 18–64 years and one in four patients aged ≥65 years have experienced at least one condition that might be attributable to previous COVID-19 infection.<sup>2</sup> Among patients with symptomatic SARS-CoV-2 infections who survived the acute phase in 2020 and 2021, 6.2% experienced at least one of the three “Long COVID” symptom clusters (i.e., persistent fatigue with bodily pain, cognitive or neurological problems, or ongoing respiratory problems).<sup>3</sup> The disease burden associated with Long COVID can have many adverse consequences on individuals, families, and communities.

**Recommendations:**

- **Continue to promote effective SARS-CoV-2 mitigation strategies** to prevent Long COVID.
- **Develop and implement surveillance strategies** to better understand and monitor the incidence and prevalence of Long COVID.
- **Develop policies** that increase access to care and support for people with Long COVID.
- **Support research** on the pathophysiology and clinical course of Long COVID.

## [ASTHO Policy Statement on Long COVID](#)

