Long COVID Surveillance Quick Reference Guide

January 2026

OVERVIEW

Federal agencies and several state, Tribal, local, and territorial health departments (STLTs) have been conducting Long COVID surveillance activities since the chronic condition was first identified. Public health surveillance has helped monitor the burden and impact of Long COVID and how it varies across populations. It has also helped identify factors that increase risk, and strategies such as vaccination that can reduce the risk of Long COVID. Long COVID surveillance is an important step to mobilize resources for those who need them; identify and bridge gaps in care and services; provide education to providers, people impacted by Long COVID, and the public; and inform public policy.

This **Quick Reference Guide** is intended to provide epidemiologists and others working in STLTs with an at-a-glance resource to support the initiation or expansion of Long COVID surveillance.

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Acknowledgments

This resource was authored by the Council of State and Territorial Epidemiologists (CSTE) with the assistance of a consultant, Hutton Health Consulting LLC. CSTE staff members Rebekah Mathew, MPH, Jordan Peart, MPH, and Beth Daly, DrPH, MPH, contributed to this resource. This project was 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 $200,000 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.

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Overview

Federal agencies and several state, Tribal, local, and territorial health departments (STLTs) have been conducting Long COVID surveillance activities since the chronic condition was first identified. Public health surveillance has helped monitor the burden and impact of Long COVID and how it varies across populations. It has also helped identify factors that increase risk, and strategies such as vaccination that can reduce the risk of Long COVID. Long COVID surveillance is an important step to mobilize resources for those who need them; identify and bridge gaps in care and services; provide education to providers, people impacted by Long COVID, and the public; and inform public policy. This Quick Reference Guide is intended to provide epidemiologists and others with an at-a-glance resource to support the initiation or expansion of Long COVID surveillance by raising awareness about existing data sources and work that has been done to characterize Long COVID in the U.S.

Definition of Long COVID

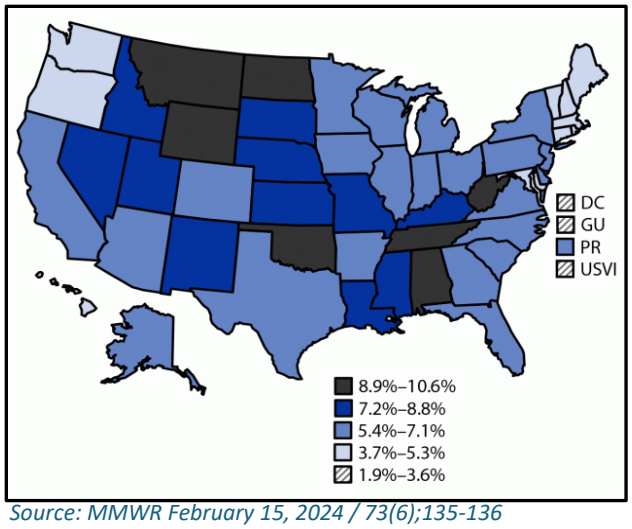
The National Academies of Sciences, Engineering, and Medicine define Long COVID as an infection-associated chronic condition occurring after a SARS-CoV-2 infection that is present for at least three months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.

The prevalence of Long COVID among adults in the U.S has varied from 6.0% to 18.9%[2] due to varying definitions of Long COVID early in the pandemic, differences in the population studied, and differences in the indicator being measured. Denominators have often included all adults or been limited to adults with prior COVID-19 infection, which increases Long COVID prevalence estimates. For analyses of symptoms or activity limitations, denominators are usually all adults with Long COVID. Some studies use "currently experiencing Long COVID" as the numerator and others use "ever experienced Long COVID" with lifetime prevalence being higher. It is important that staff working on Long COVID surveillance consider these differences in study design when comparing results between different studies and communicating about Long COVID.

Prevalence is a key surveillance indicator, measured in different ways:

- Ever experienced Long COVID
- Currently experiencing Long COVID
- Current Long COVID limits activities

Figure 1 - Prevalence of reported experience of Long COVID among adults aged ≥18 years, by jurisdiction — Behavioral Risk Factor Surveillance System, United States, 2022



Source: MMWR February 15, 2024 / 73(6);135-136

Figure 1 shows how a graphic can convey key Long COVID surveillance findings to the public. This example, from *MMWR* February 15, 2024 / 73(6);135–136 highlights how the prevalence of Long COVID varies by jurisdiction.

National Cross-Sectional Surveys

The federal government assessed Long COVID on multiple cross-sectional surveys providing prevalence estimates and public use data for secondary analysis. Below are examples of national surveys with links for documentation of methods.

Behavioral Risk Factor Surveillance System (BRFSS) The 2023 BRFSS survey included an Emerging Core with the following questions on Long COVID prevalence and limitations on daily activities:

Q. Have you ever tested positive for COVID-19 (using a rapid point of-care test, self-test, or laboratory test) or been told by a doctor or other healthcare provider that you have or had COVID-19? (A. Yes/No/Don't Know/Refused)

Q. Do you currently have symptoms lasting 3 months or longer that you did not have prior to having coronavirus or COVID-19? (A. Yes/No/Don't Know/Refused)

Q. Do these long-term symptoms reduce your ability to carry out day-to-day activities compared with the time before you had COVID-19? (A. Yes, a lot/Yes, a little/Not at all/Don't know/Refused)

National Health Interview Survey (NHIS) The 2024 NHIS included the following questions on Long COVID prevalence and limitations on daily activities:

Q. Have you ever had COVID-19? (A. Yes/No/Refused/Don't Know)

Q. Did you have any symptoms lasting 3 months or longer you did not have before having COVID-19? (A. Yes/No/Refused/Don't Know)

Q. Do you have symptoms now? (A. Yes/No/Refused/Don't Know)

Q. How much do these long-term symptoms reduce your ability to carry out day-to-day activities compared with the time before you had COVID-19? (A. Not at all/A little/A lot/Refused/Don't Know)

Household Pulse Survey (HPS) From 2022 through 2024, the HPS included the following questions on ever and current Long COVID prevalence and activity limitations:

Q. Have you ever tested positive for COVID-19 (using a rapid point of-care test, self-test, or laboratory test) or been told by a doctor or other healthcare provider that you have or had COVID-19? (A. Yes/No)

Q. How would you describe your coronavirus symptoms when they were at their worst? (A. I had no symptoms/I had mild symptoms/I had moderate symptoms/I had severe symptoms)

Q. Did you have any symptoms lasting 3 months or longer that you did not have prior to having coronavirus or COVID-19? (A. Yes/No)

Q. Do you have symptoms now? (A. Yes/No)

Q. Do these long-term symptoms reduce your ability to carry out day-to-day activities compared with the time before you had COVID-19? (Yes, a lot/Yes, a little/Not at all)

This table indicates the Long COVID indicators included by year for each of the three national surveys.

National Survey	Indicators	2022	2023	2024	2025	2026
Behavioral Risk Factor Surveillance System (BRFSS)	Ever Long COVID	X				X
	Current Long COVID		X			X
	Activity Limitations		X			X
National Health Interview Survey (NHIS)	Ever Long COVID	X	X	X	X	TBD
	Current Long COVID	X	X	X	X	TBD
	Activity Limitations		X	X	X	TBD
Household Pulse Survey (HPS)	Ever Long COVID	X	X	X		
	Current Long COVID	X	X	X		
	Activity Limitations	X	X	X		

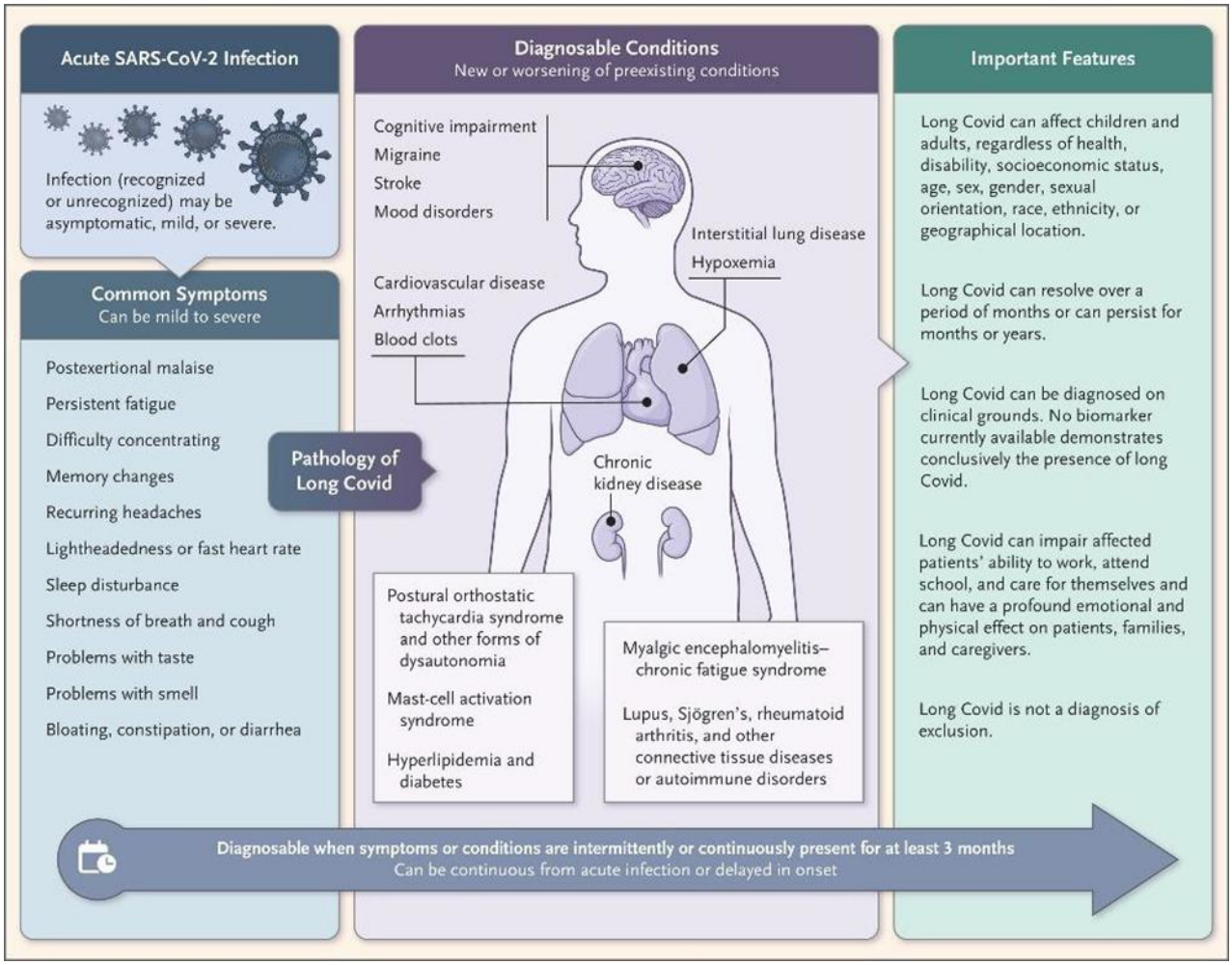
There are some key differences in the methods used in these national surveys. The BRFSS is a telephone-based survey conducted by states, while NHIS is an in-person household interview survey. The BRFSS provides information at the national and state level, and for Metropolitan Statistical Areas (MSAs) that have 500 or more respondents. Some states have conducted expanded BRFSS surveys that provide county-level data for some years. The NHIS provides information on a representative sample for the nation, but state and local level data are not reliable due to sample size. HPS was a brief online survey that measured how emerging issues impacted households across the country. National, state, and MSA level data are available through HPS for 2024 and earlier. In addition to these surveys, many STLTs have developed and administered their own surveys, or their own BRFSS state-added modules, to assess Long COVID in their jurisdiction. Several examples are referenced in Appendix A of CSTE's *State, Tribal, Local, and Territorial Public Health Agency Approaches to Long COVID-19 / Post COVID-19 Condition Surveillance: Lessons Learned, Gaps, and Needs.*

ICD-10 Code to Identify Long COVID in Electronic Health Records (EHR) and Other Healthcare Data

ICD-10 codes are readily available in a range of healthcare administrative databases. Limitations include bias towards including patients who are sicker and have health insurance. While an ICD-10 code was established for Long COVID in 2021, healthcare providers underutilize this code, limiting the utility of current ICD-10 code-based evaluations in EHRs and other data sources such as All-Payer Claims Databases.

- Key ICD-10 code for Long COVID = **U09.9, Post COVID-19 Condition, Unspecified**
  - U09.9 added in October 2021 to link diagnoses to a history of COVID-19.
  - U09.9 should not be used for patients still experiencing acute COVID-19 symptoms.
  - U09.9 largely replaced B94.8, Sequelae of Other Specified Infectious and Parasitic Diseases (*consider using B94.8 for EHRs prior to October 2021*).

Because relying upon ICD-10 codes alone for case ascertainment of Long COVID will likely be incomplete, work is ongoing to develop alternative methods using other administrative healthcare data to complement ICD-10 codes. STLTs interested in pursuing surveillance activities using healthcare data may consider developing more complex algorithms. Some helpful references are provided in the References section. Figure 2 helps illustrate the complex relationship between some common symptoms and the body systems that can be impacted as part of Long COVID. The condition can have a range of clinical presentations with some important features.



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Using Syndromic Surveillance for Long COVID

Several STLTs use syndromic surveillance to monitor emergency department and outpatient visits for Long COVID. In December 2024, broad and narrow definitions of Long COVID were published in the National Syndromic Surveillance Program's ESSENCE Knowledge Repository, providing jurisdictions with validated algorithms to use as queries in their own syndromic surveillance systems.

1. Long COVID Broad definition – requires EITHER discharge diagnosis OR free-text indication of suspected Long COVID.
2. Long COVID Narrow definition – requires BOTH discharge diagnosis AND free-text indication of suspected Long COVID.

Syndromic surveillance provides near real-time access to data that are readily accessible to STLTs. However, it likely underestimates the prevalence of Long COVID since impacted persons may only present to emergency departments or urgent care centers if they are experiencing acute symptoms.

References on Long COVID Surveillance in the United States

General Surveillance

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