

A healthcare worker wearing a white lab coat, a face shield, and a surgical mask is engaged in a conversation with a patient. The patient is seen from the side, with long dark hair tied back. The background is a bright, clinical setting with large windows. A semi-transparent blue rectangle is overlaid on the left side of the image, containing the title text.

Long COVID Health Briefing

MAY 8, 2023

What is Long Covid, really?

- Long COVID and long-haulers are *largely patient driven terminologies*
- Per HHS: “Long COVID is broadly defined as **signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection**. The signs, symptoms, and conditions are present **four weeks or more after the initial phase of infection**; may be multisystemic; and may present with a relapsing– remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. **Long COVID is not one condition**. It represents **many potentially overlapping entities**, likely with different biological causes and different sets of risk factors and outcomes.” [\(1\)](#)
- Formal terms for long COVID include:
 - Post-Acute Sequelae of SARS-CoV-2 infection (PASC)
 - Post COVID Condition (PCC). [\(1\)](#)

(1): Department of HHS. “What Is Long COVID?” *COVID.gov*, Department of HHS, <https://www.covid.gov/longcovid/definitions>.

Census Survey of Long COVID

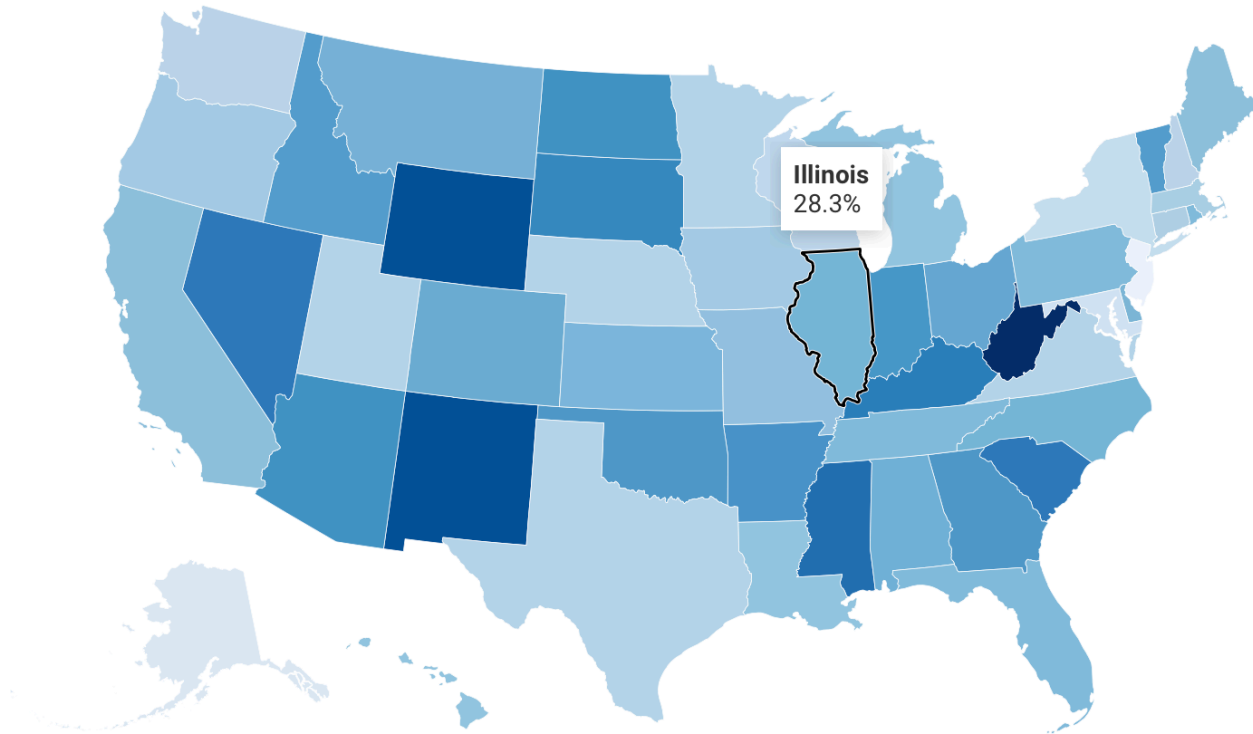
According to US Census Bureau Household Pulse Survey, **28.3% of Illinois residents who have had COVID report experiencing long COVID** ⁽¹⁾

This is around the national average of **27%**

(2) Prevalence of Long COVID by State

Percentage of adults infected with COVID-19 who had symptoms lasting three months or longer. Estimates based on data collected from March 1–13.

17 41



Source: U.S. Census Bureau Household Pulse Survey • Chris Gilligan



- (1): "Long Covid - Household Pulse Survey - Covid-19." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 19 Apr. 2023, <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>.
- (2): Gilligan, Chris. "Long COVID by Age, Race and Gender." *US News and World Report*, 29 Mar. 2023, <https://www.usnews.com/news/healthiest-communities/articles/2023-03-29/the-demographics-of-long-covid>.

What are the risk factors for patients reporting long COVID?

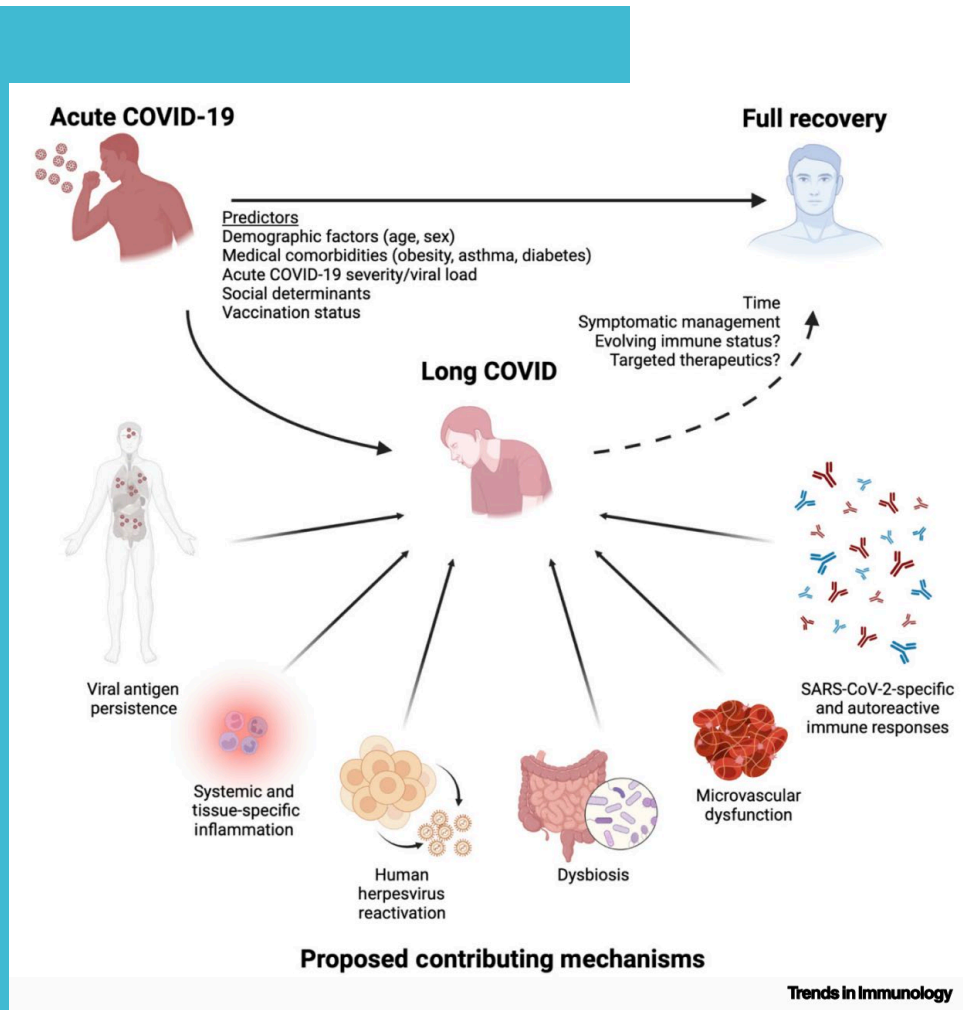
Notable risk factors are:

- COVID-19 severity, most notably **hospitalized patients and those who were in the ICU**
 - Of note, those with mild to moderate disease can still experience long COVID (1)
- Those with **pre-existing conditions**
 - This includes high blood pressure, chronic lung disease (1.55x more likely), obesity (1.10x more likely), and depression (1.31x more likely) (2)
 - Another study demonstrates that asthma (1.24 more likely), diabetes (1.06 more likely), Ischemic heart disease (1.28 more likely), and immunosuppression (1.50 more likely) may predispose individuals to develop long COVID (3)
- Those who are **not vaccinated** (more on this later)
- **Smokers** are also 1.12x more likely to develop long COVID (2)

(1): "Long Covid or Post-Covid Conditions." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 16 Dec. 2022, <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>

(2): Subramanian, A., Nirantharakumar, K., Hughes, S. *et al.* Symptoms and risk factors for long COVID in non-hospitalized adults. *Nat Med* 28, 1706–1714 (2022). <https://doi.org/10.1038/s41591-022-01909-w>

(3): Tsampasian V, Elghazaly H, Chattopadhyay R, et al. Risk Factors Associated With Post-COVID-19 Condition: A Systematic Review and Meta-analysis. *JAMA Intern Med.* Published online March 23, 2023. doi:10.1001/jamainternmed.2023.0750



How does long COVID happen?

- There are several theories of how long Covid develops including: (1)
 - **Viral reservoir or persistence**: viral proteins and/or RNA has been found in long COVID patients. This means that parts of the SARS-CoV-2 virus can survive in the patient for long periods of time, even after the acute phase.
 - **Autoimmunity**: There can be tissue damage that is mediated by auto-antibodies (antibodies targeting the host's own tissues)
 - **Tissue damage and dysfunction**: Tissue damage can also occur due to the host immune response/inflammation in the acute phase that ends up having long term consequences. Damage is not usually caused directly by viral replication, rather by host response.

(1): Iwasaki, Akiko, and David Putrino. "Why We Need a Deeper Understanding of the Pathophysiology of Long Covid." The Lancet Infectious Diseases, vol. 23, no. 4, 2023, pp. 393–395., [https://doi.org/10.1016/s1473-3099\(23\)00053-1](https://doi.org/10.1016/s1473-3099(23)00053-1).

(2): Peluso MJ, Deeks SG. Early clues regarding the pathogenesis of long-COVID. Trends Immunol. 2022 Apr;43(4):268-270. doi: 10.1016/j.it.2022.02.008. Epub 2022 Mar 8. PMID: 35272932; PMCID: PMC8901423.

Symptoms of Long COVID

There are **over 200 reported symptoms** of long COVID (not every patient is the same)

The most common symptoms include (1):

- Fatigue
- Fever
- Respiratory issues, such as shortness of breath, cough, or difficulty breathing
- Loss/alteration of taste and smell
- Cognitive alterations
- "Brain fog" ie problems with memory and concentration
- Mental health issues, such as anxiety, depression, and PTSD
- And many, many more...

Clinicians should be made aware that presentation of long COVID is highly variable



FIGURE. System-Based Conditions^a Reported Following COVID-19 Infection¹⁰

(1): Mayo Clinic Staff. "Covid-19: Long-Term Effects." Mayo Clinic, Mayo Foundation for Medical Education and Research, 28 June 2022, <https://www.mayoclinic.org/diseases-conditions/coronavirus/in-depth/coronavirus-long-term-effects/art-20490351>.

(2): <https://www.clinicaladvisor.com/home/topics/infectious-diseases-information-center/long-covid-diagnosis-treatment/>

Disease course (are patients in for the long haul?)

The duration of long COVID varies greatly, with some cases lasting for weeks and some lasting years.

It was demonstrated that around 15% of patients with long COVID had complete symptom recovery at the one year mark [\(1\)](#)

The prevalence for the majority of symptoms decreased over time, with a couple exceptions.

Symptoms prevalence typically plateaued around 6-8 months



<https://schneiderjobs.com/blog/how-long-is-semi-truck>

(1): Tran, Viet-Thi, et al. "Course of Post Covid-19 Disease Symptoms over Time in the Compare Long Covid Prospective e-Cohort." Nature Communications, vol. 13, no. 1, 2022, <https://doi.org/10.1038/s41467-022-29513-z>.

Treatment

- Patients **first point of contact should be their primary care provider**. They should meet with their healthcare providers **every 2-3 months**, depending on disease severity.
 - The CDC has compiled a checklist for patients to use at their first appointment to assist with the first meeting with their provider (<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/post-covid-appointment/appointment-checklist.pdf>)
- **Rehabilitation interventions have been shown to lessen severity of long COVID**, with improvements in QOL (quality of life), muscle strength, and other symptoms [\(1\)](#)
- Comprehensive rehabilitation plans are **multi-disciplinary**, including:
 - physical and occupational therapy
 - speech and language therapy
 - vocational therapy
 - neurologic rehabilitation
- Other interventions include **patient support groups** and **returning to exercise as tolerated**

(1): Fugazzaro, Stefania, et al. "Rehabilitation Interventions for Post-Acute COVID-19 Syndrome: A Systematic Review." International Journal of Environmental Research and Public Health, vol. 19, no. 9, 2022, p. 5185., <https://doi.org/10.3390/ijerph19095185>.

Disability and Long COVID

- Long COVID is now considered a disability that is covered by ADA (Americans with Disabilities Act) [\(1\)](#)
- The individual is covered if they have a physical or mental impairment that **substantially limits one or more major life activities**.
 - Of note, individuals with the diagnosis of long COVID may not necessarily have disability due to their condition.
- Although it is too early to tell how many people will have disability due long COVID, the number is predicted to be significant as **10-35 million working age adults may have long COVID** [\(2\)](#)
 - Of people with long COVID, **27% report severe activity limitations**
 - Estimates of workforce impact of long COVID are up to **4.5 million individuals missing from the workforce**, contributing to current labor shortages [\(2\)](#)

(1): (OCR), Office for Civil Rights. "Guidance on 'Long Covid' as a Disability Under the ADA." HHS.gov, 11 Aug. 2021, <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>.

(2): Burns, Alice. "What Are the Implications of Long Covid for Employment and Health Coverage?" Kaiser Family Foundation, 10 Aug. 2022, <https://www.kff.org/policy-watch/what-are-the-implications-of-long-covid-for-employment-and-health-coverage/>.

The importance of health equity and Long COVID

- Race and ethnicity may be an independent risk factor for developing long COVID (1). With adjusted odds ratio's, those of **black, mixed, or "other" ethnicities had higher likelihood to develop long COVID** (2)
- In another study, Long COVID seems to disproportionately affect **women, Hispanic individuals, those of "other or multiple races", transgender individuals, and the elderly.** (3)
- Additionally, **lower socioeconomic status** is associated with an 11% increase in long COVID (2)
- This raises significant concerns that long COVID will exacerbate pre-existing disparities in health

(1): Tanne, Janice Hopkins. "New Study: US Studies Show Racial and Ethnic Disparities in Long Covid." BMJ, 2022, <https://doi.org/10.1136/bmj.n535>.

(2): Subramanian, Anuradha. "Symptoms and Risk Factors for Long Covid in Non-Hospitalized Adults." *Nature Medicine*, vol. 28, no. 6, 2022, pp. 1706–1714., <https://doi.org/10.1038/s41591-022-01909-w>.

(3): Gilligan, Chris. "Long Covid: Age, Race and Gender." *US News and World Report*, 29 Mar. 2023, <https://www.usnews.com/news/health/best-common-sense/articles/2023-03-29/the-demographics-of-long-covid>.

So, what can be done to prevent long COVID?



<https://www.nytimes.com/2023/01/26/health/covid-vaccines-boosters.html>

- **Vaccination is the most important component in long COVID mitigation.**
 - Several studies have shown vaccination to be protective in a dose dependent fashion.
 - One such study showed that with
 - one vaccine dose, you are 14% less likely to develop long COVID
 - two doses, you are 75% less likely
 - three doses, you are a staggering **84% less likely (1)**.
 - This highlights the importance of reaching out to communities that have been **historically marginalized by the healthcare system, as COVID-19 vaccination rates can be lower in these communities.**
 - For example, **Black and Hispanic** Medicare recipients were less likely to receive COVID-19 vaccination. Additionally, **those who earned less than \$25,000** were also less likely to receive vaccination (2)
- Therapeutics: While vaccination remains the cornerstone strategy, a recent cohort study found that **nirmatrelvir (Paxlovid), lessened the chance of developing long COVID by 26% (3)**

(1); Azzolini, Elena, et al. "Association between BNT162B2 Vaccination and Long Covid after Infections Not Requiring Hospitalization in Health Care Workers." *JAMA*, vol. 328, no. 7, 2022, p. 676., <https://doi.org/10.1001/jama.2022.11691>.

(2): Cheng Z, Li Y. Racial and ethnic and income disparities in COVID-19 vaccination among Medicare beneficiaries. *J Am Geriatr Soc*. 2022 Sep;70(9):2638-2645. doi: 10.1111/jgs.17920. Epub 2022 Jun 7. PMID: 35639044; PMCID: PMC9348368.

(3): Xie, Yan, et al. "Association of Treatment with Nirmatrelvir and the Risk of Post-COVID-19 Condition." *JAMA Internal Medicine*, 2023, <https://doi.org/10.1001/jamainternmed.2023.0743>.

Patient Resources

- There are at least 15 clinics specializing in care of long COVID, 8 of which are located in Chicago
 - A list of available clinics in Illinois is compiled here: <https://www.survivorcorps.com/pccc-il>
- There are long COVID research trials that patients enroll in. One way patients can do this is through the "Recover Initiative" run by the NIH.
 - <https://studies.recovercovid.org/#main>
 - The study is looking to recruit community leaders as well: <https://recovercovid.org/leadership#community>
- CDC checklist for patients to use when visiting their PCP: <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/post-covid-appointment/appointment-checklist.pdf>

Some salient points about long COVID

- Long COVID has a varied presentation and encompasses a large range of symptoms, which clinicians should be aware of.
- Long COVID has affected a large portion of the population, including a substantial number of individuals in Illinois.
- Vaccination is the most important part of long COVID prevention strategy. Therapeutics may also play an important role in prevention.
- Long COVID presents a risk for exacerbating health disparities.
- It is important that all persons experiencing long COVID have regular follow-up with their primary care physician to discuss their symptoms

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