



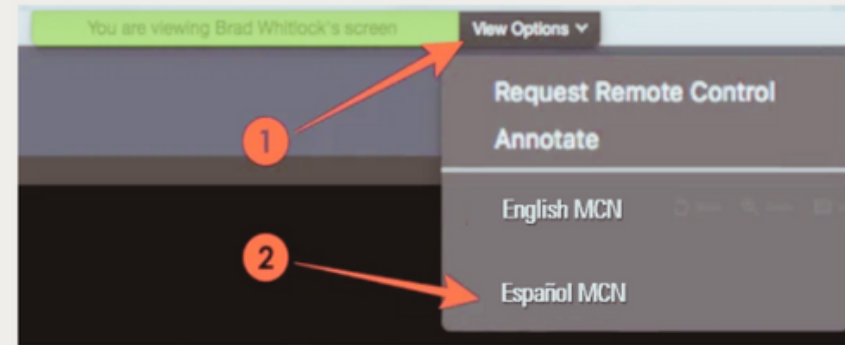
THE *witness to witness*  
ssauqim PROGRAM

Pfizer  
June 4, 2024

The Psychosocial Impact of Long COVID  
on Patients and Families

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# Continuing Education

Migrant Clinicians Network is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation.

MCN has applied for continuing medical education to the American Academy of Family Physicians. Approval is pending.



**In order to claim credit, attendees must submit the post session evaluation.**

# Disclosure of Relevant Financial Relationships

We have no relevant financial relationships that relate to this presentation, nor do we have any relevant financial relationships with ineligible companies whose products or services are related to pertinent therapeutic areas.



This webinar is supported by the National Institute of Environmental Health Sciences of the National Institutes of Health under Award Number U45ES006179.

The continuing medical and nursing education for this webinar is supported by Pfizer.

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Environmental Health Sciences or Pfizer.

# Learning Objectives

- Identify challenges patients, families, and caregivers face before, during, and after a long COVID diagnosis.
- Explain the psycho-social experience patients, families, and caregivers have when someone is suffering with Long COVID.
- Identify ways clinicians can improve the experience of patients and families when they are coping with someone who is ill with Long COVID.





# Long COVID Definitions

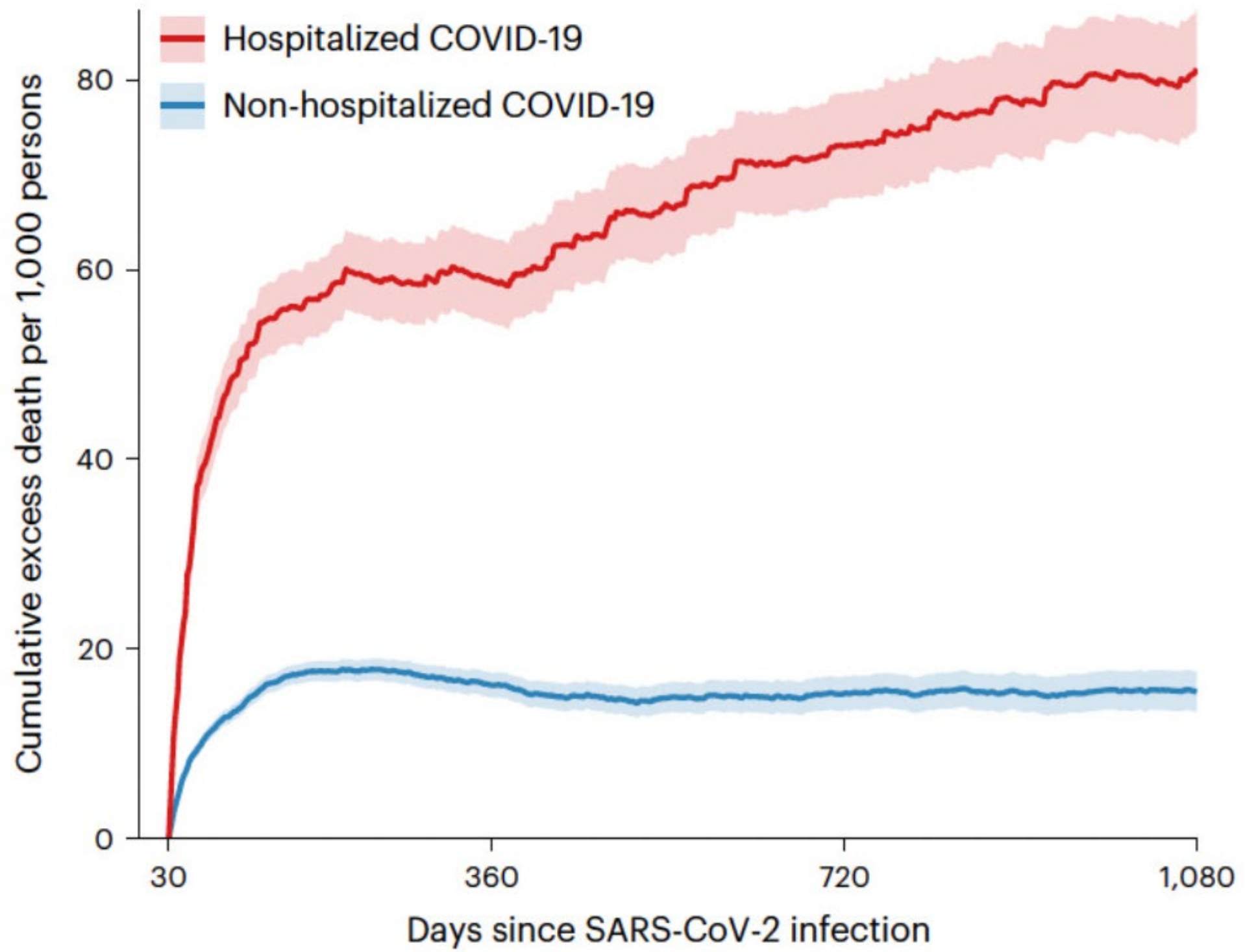
- A new study in [Annals of Internal Medicine](#) reviewed 38 publications with five definitions of Long COVID.
- They conclude that the research and clinical fields need to standardize definitions with respect to timing of onset and duration.
- Without this, confusion reigns. We may be comparing apples to oranges.

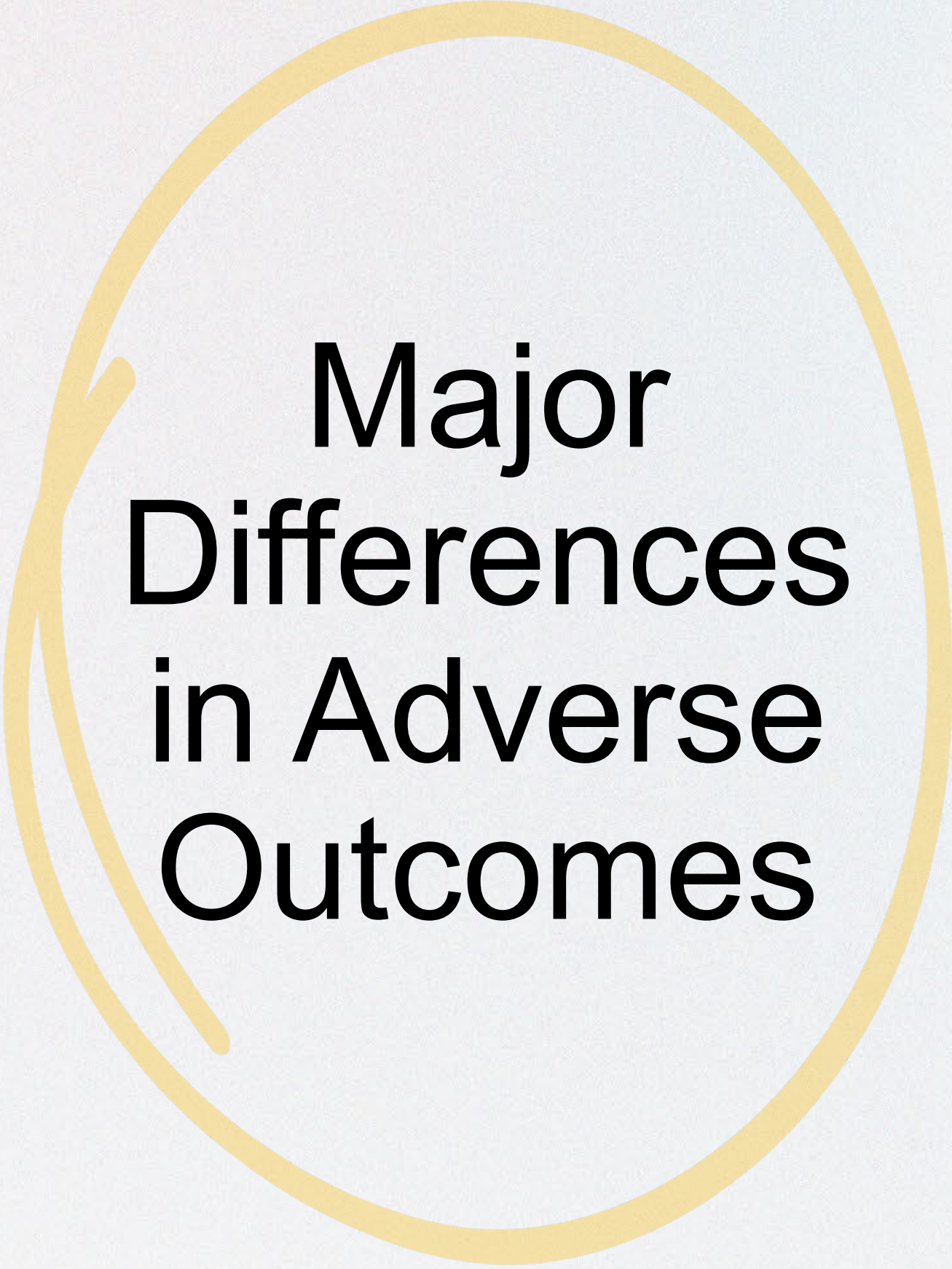


# Study in Nature Medicine

An important new study published this past week of major outcomes for 135,000 who had COVID prior to the availability of vaccines shows a highly significant difference between those who were hospitalized – that is, had severe disease – and those who had mild to moderate COVID.







# Major Differences in Adverse Outcomes

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Major adverse outcomes, including death, multi-system sequelae, and disability, were persistent at 3-year follow up in the people who initially required hospitalization.

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This suggests that the acute infection severity and host response play a critical role in subsequent outcomes.

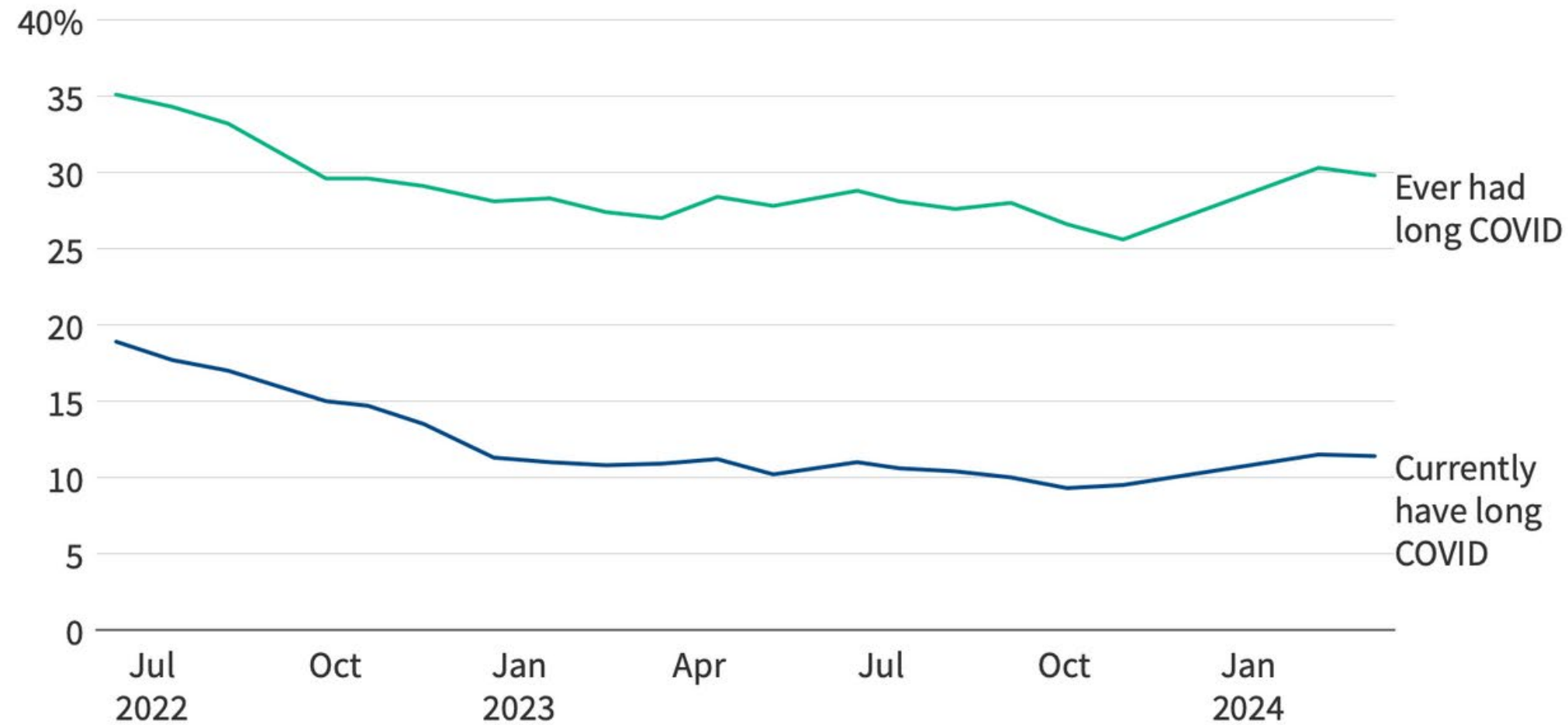
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In contrast, the people with mild to moderate COVID not hospitalized had evidence of small residual risk.

Figure 1

### Around 3 in 10 Adults Who Have Had COVID Report Getting Long COVID

Percentage of adults reporting they currently or ever had long COVID among those who have had COVID



6% of adults report symptoms one year after a COVID infection

Estimates are that 14-17 million People are living with Long COVID now

Note: The Pulse Survey, an experimental survey conducted by the Census Bureau and National Center for Health Statistics, asked respondents whether they had any symptoms of COVID that had lasted longer than 3 months. This figure reports the findings between 6/13/2022 and March 4, 2024.

Source: [National Center for Health Statistics. Post-COVID Conditions](#). Data accessed March 28, 2024. • [Get the data](#) • [Download PNG](#)

**KFF**

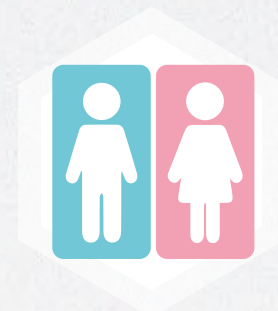
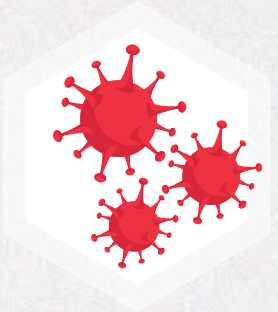
# Conclusion from Comprehensive [Article](#) on Long COVID

Long COVID is widespread.

Its incidence varies markedly across sub-groups in the population.

However, there is little to no research specifically looking at essential workers or farmworkers as categories of Long COVID. ( We do know rates of COVID for essential workers and farmworkers.)

Long COVID is much higher among women than it is among men.



# Conclusion from Comprehensive [Article](#) on Long COVID



Long COVID varies by ethnicity, being highest among whites.

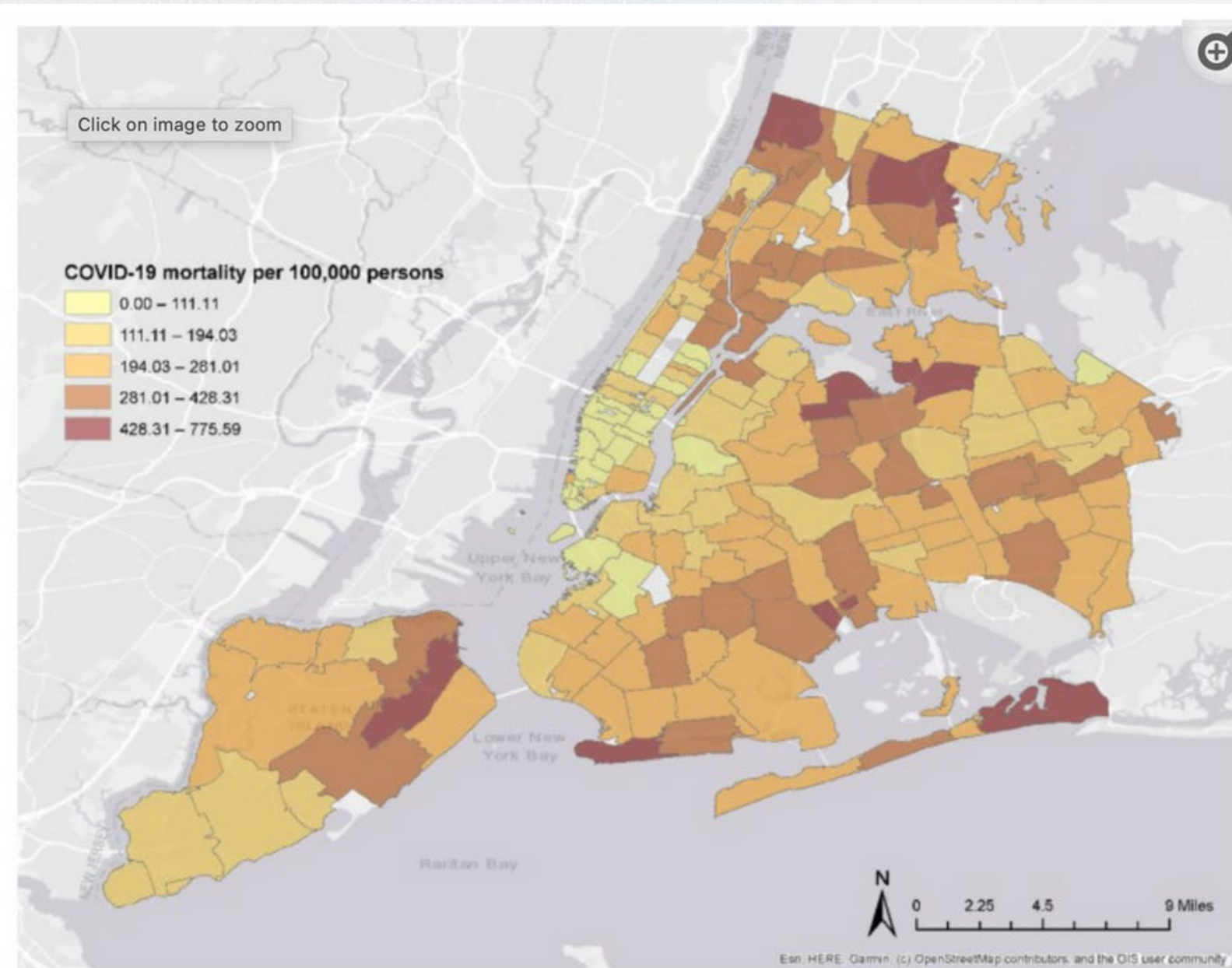


It is hump-shaped in age. Middle-age largest group with Long COVID.

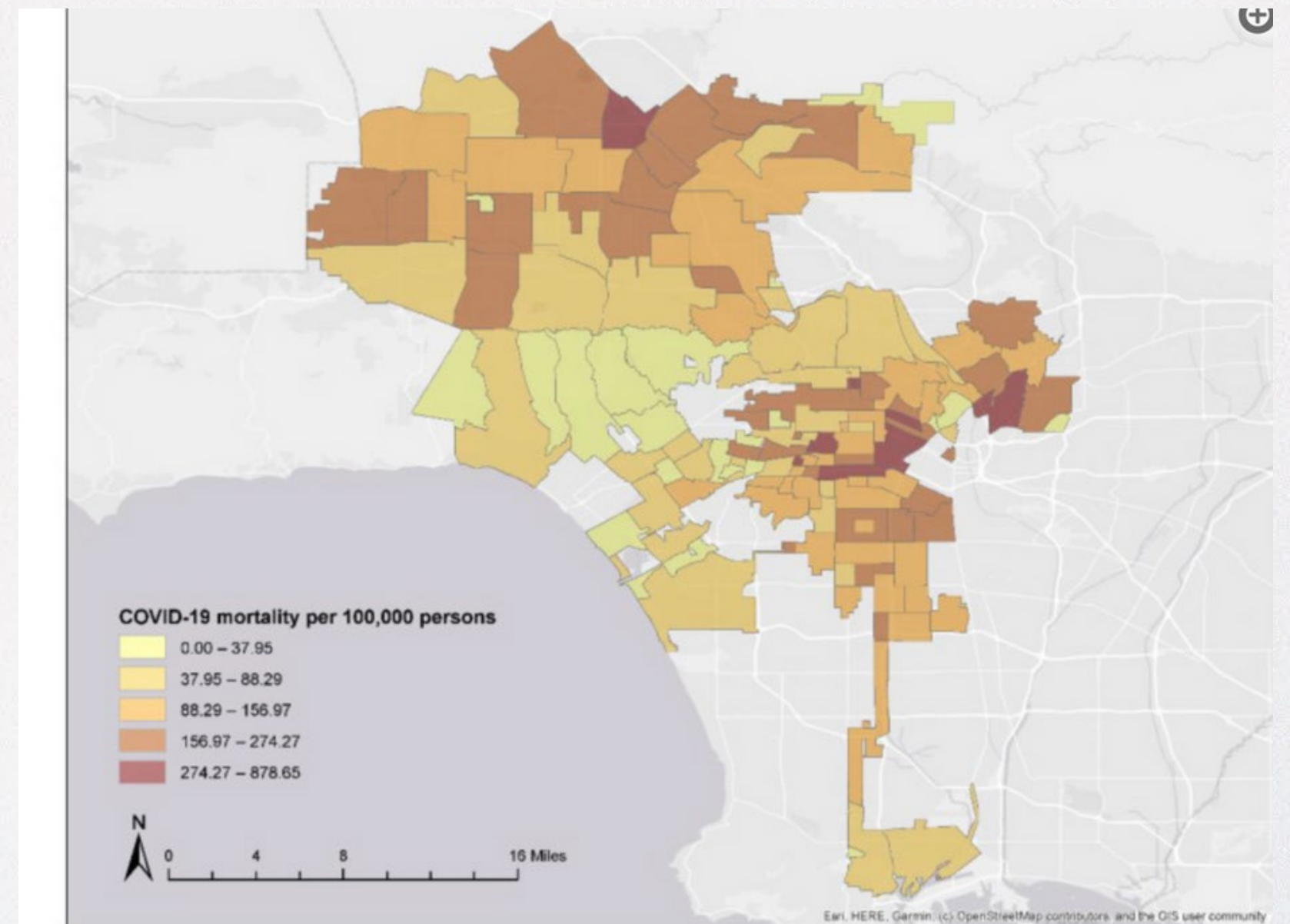


Long COVID varies greatly by location. It is highest in states in the south such as West Virginia and Mississippi—lowest in Hawaii.

# Communities with larger proportions of non-citizen had higher COVID-19 mortality rates



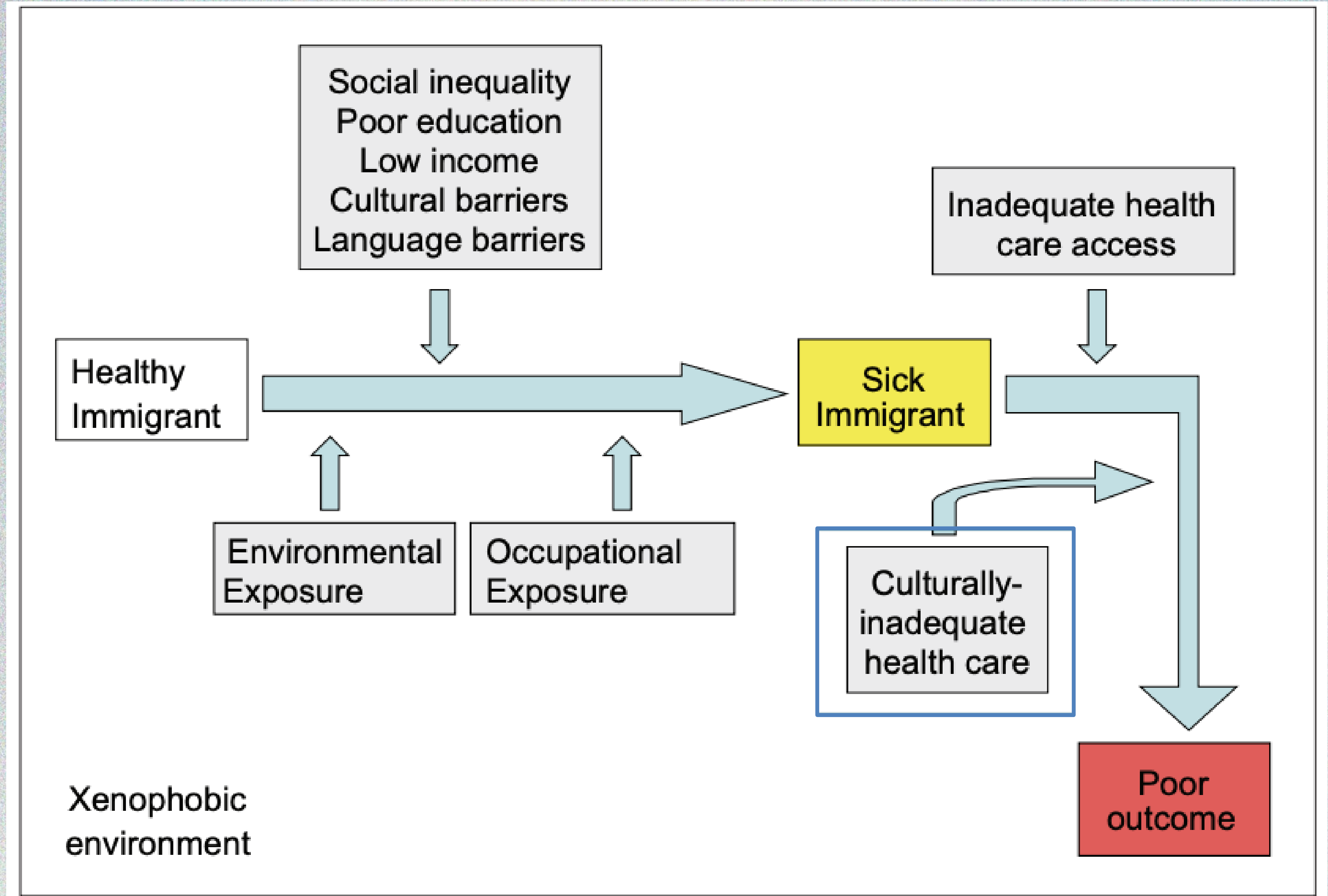
New York City ZIP Code Tabulation Area COVID-19 Mortality Rates.



Los Angeles City/Community COVID-19 Mortality Rates.

Douglas JA, Bostean G, Miles Nash A, John EB, Brown LM, Subica AM. Citizenship Matters: Non-Citizen COVID-19 Mortality Disparities in New York and Los Angeles. *Int J Environ Res Public Health*. 2022 Apr 21;19(9):5066.

Structural racism leads to health inequities by creating disparities in risk, access to care, and quality of care.



We are going to look at the sequence of how Long COVID unfolds medically and then psychologically and interpersonally.



# The COVID Scenario Unfolds for Patients and Families

- Is the person truly sick and if so with what?
- Getting a COVID test: Where? PCR, Rapid. Finding them. Waiting for results
- What to do during the waiting time? Range: 15 mins to 48 hours
- If positive, can the person isolate? If an adult, decisions: go to work, tell employer, isolate, childcare/parental care?
- If child is positive: how do you isolate a child? Who takes care of the child?



# The COVID Scenario Unfolds for Patients and Families

- How to quickly learn what to do: monitor for serious illness, treat for comfort.
- When to call PCP, when to go to urgent care, when to go to the ED.
- What if the person has underlying medical issues? Which ones matter?
- Does the person qualify for a treatment?  
(<https://www.yalemedicine.org/news/covid-19-treatment-drugs>)
- Steps to get a treatment started within the first 5 days if over 65 or have underlying medical conditions.

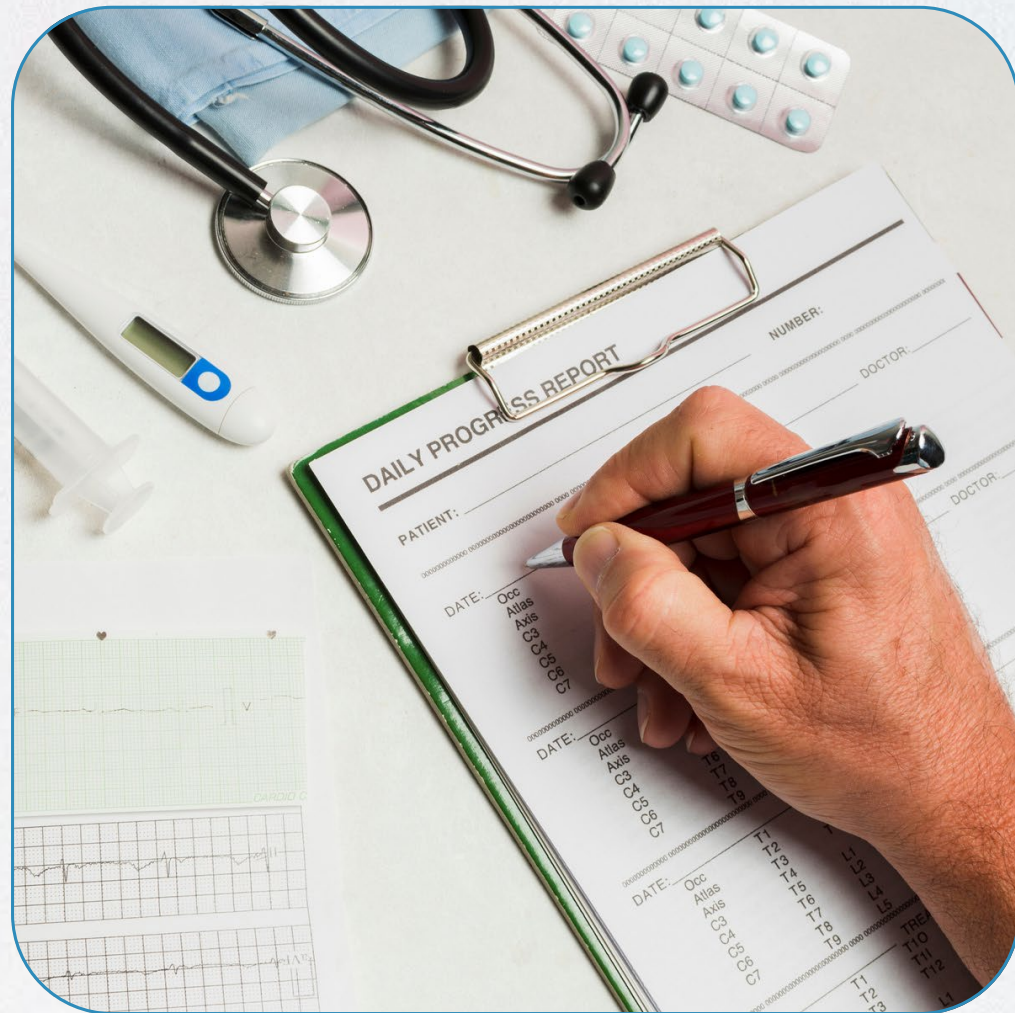


# Transition from Acute to Long COVID

- Patients and families are uncertain about what's going on.
  - I'm tired. How tired is tired? How long is it normal to be tired?
  - I'm not thinking clearly. I can't remember things.
  - Should I see a healthcare provider or is this going to resolve in time?
- Problem of definition for clinicians.
  - At least five definitions.



# Lack of Clarity Contributes to Difficult Adjustment



No universal definition

Both health care workers and family members may greet a person's symptoms with skepticism or frustration due to no clear definitions and protocols established

Not many specialized services yet

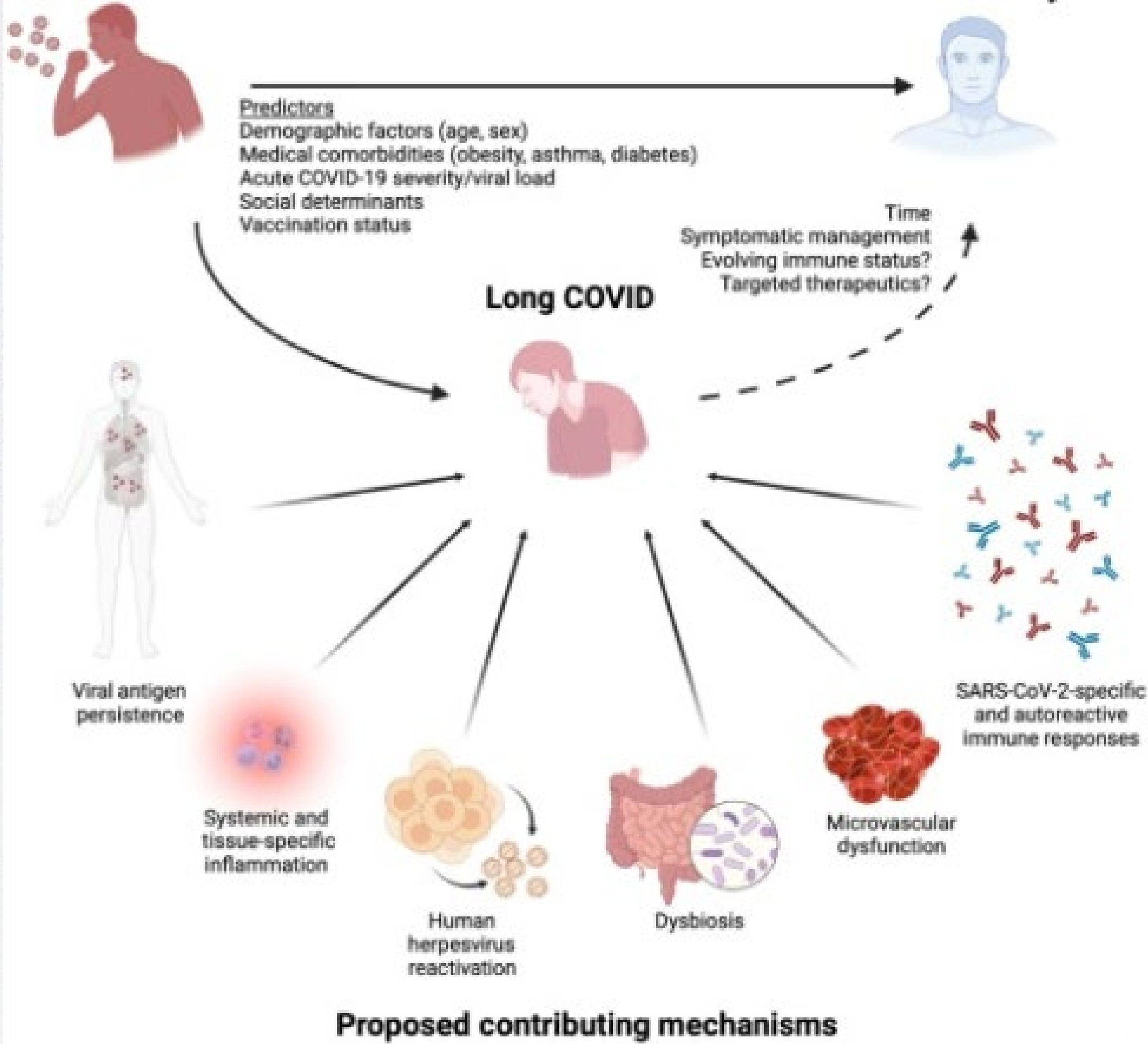
Long wait times for service even if you live near a center

# The science of Long COVID

- The COVID-19 virus can persist in the blood and tissue of patients for more than a year after the acute phase of the illness has ended, and for more than two years in tissue samples from people who had COVID according to [new research](#) from UC San Francisco that offers potential clues to why some people develop long COVID.

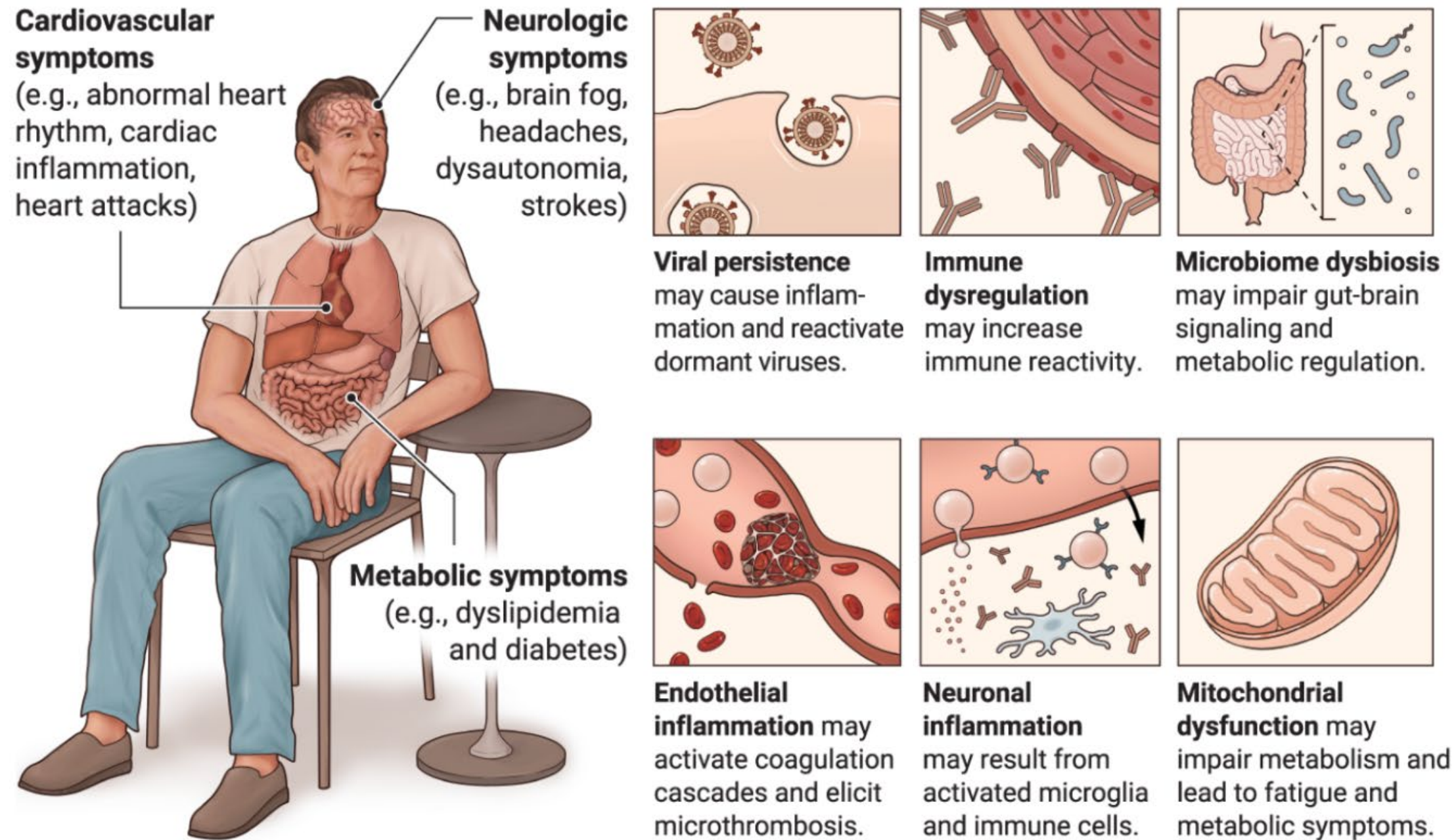
# Acute COVID-19

# Full recovery



## Many forms of Long Covid

Long Covid is a multisystemic disease with sequelae that affect almost all organ systems. Various putative mechanisms that underlie these sequelae are not mutually exclusive and may explain the myriad health effects seen in Long Covid. Therapeutics that target these pathways, such as antivirals, anti-inflammatory agents, microbiome restoration, and anticoagulant drugs, may ameliorate symptoms.



GRAPHIC: A. MASTIN/SCIENCE

# Which family members can get COVID?

- Children
- Teens
- Adults
- Elders

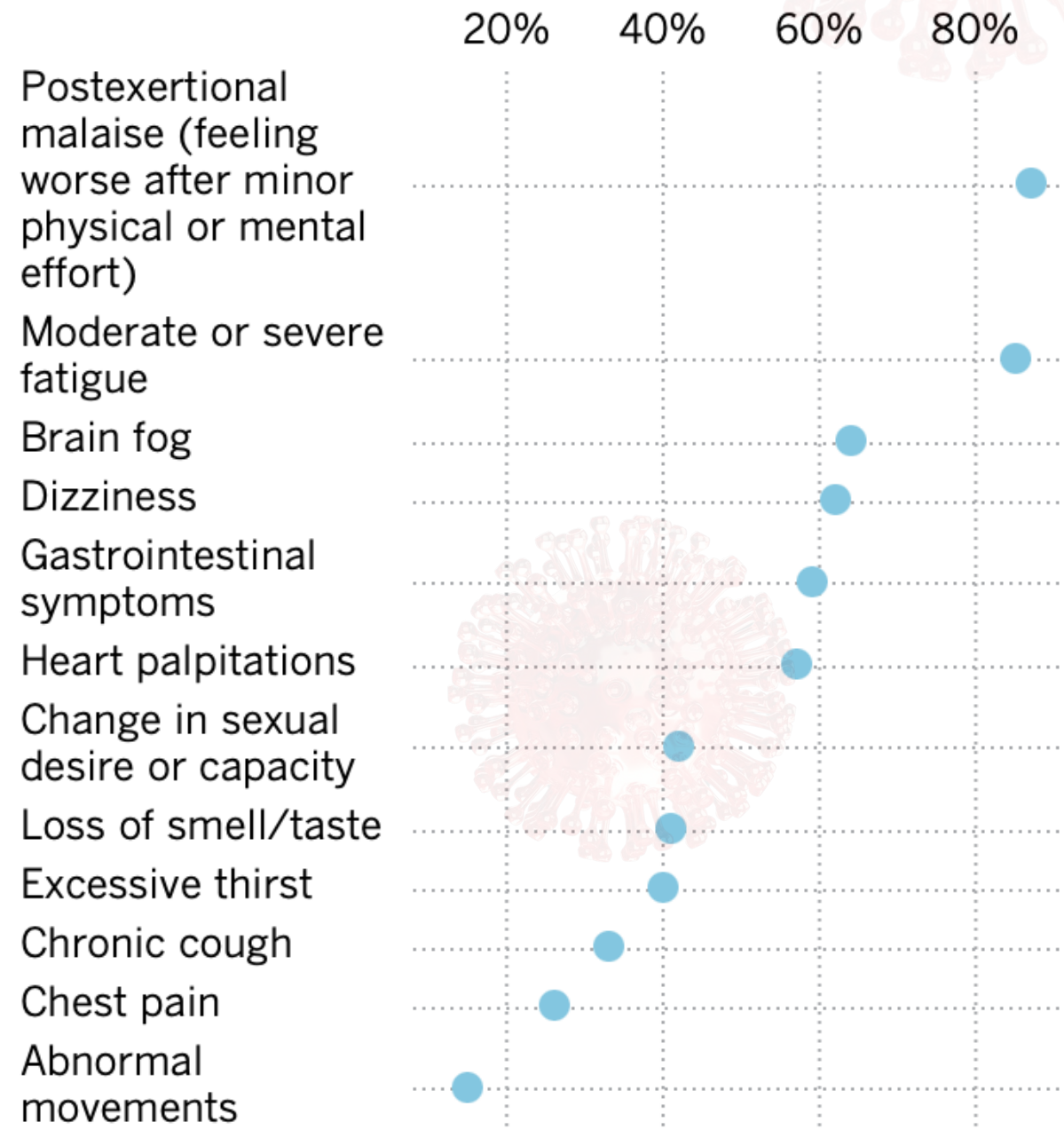




# Most common symptoms of long COVID

Postexertional malaise and fatigue were among the most common symptoms reported by long COVID patients six months after their acute coronavirus infection.

## Percentage of long COVID patients reporting symptom



Journal of the American Medical Assn.

LOS ANGELES TIMES

# Long COVID Symptoms as They Impact Family Life and Work Life



## Symptoms:

- Brain Fog
- Fatigue
- Lack of Concentration
- Executive Functioning Decline
- Memory
- Difficulty Breathing
- Depression
- Anxiety

# Self-Loss

People who live with a painful gap between who they have been and who they are now are living with self-loss.



# Ambiguous Loss

The person is there but they are not the person they used to be.



**SELF-  
LOSS**



**AMBIGUOUS  
LOSS**

**TWO SIDES OF A COIN**

# Long-Term Questions

Will I be able to earn a living?

Will I be able to care for those who depend on me?



# Mental Health Burden



- sleep–wake disorders
- anxiety and fear-related disorders
- trauma- and stress-related disorders
- use of non-opioid and opioid analgesic drugs, antidepressant agents, sedatives and anti-anxiety medications.

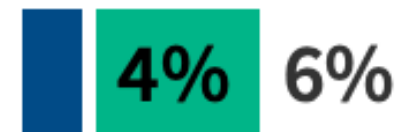
Figure 2

## Most Adults with Long COVID Report that it Limits Their Activities at Least a Little

Percentage of adults reporting that they have activity limitations from long COVID as of March 4, 2024

■ Long COVID Limits Activities "a Lot" ■ Long COVID Limits Activities "a Little"

Of all adults



Of adults who currently have long COVID



Note: The Pulse Survey, an experimental survey conducted by the Census Bureau and National Center for Health Statistics, asked respondents whether they had any symptoms of COVID that had lasted longer than 3 months and among adults who respond "yes," whether the symptoms limit their day-to-day activities "a lot," "a little," or "not at all." The survey characterizes "a lot" responses as "significant" activity limitations.

Source: [National Center for Health Statistics. Post-COVID Conditions](#). Data accessed March 28, 2024. • [Get the data](#) • [Download PNG](#)



FIGURE 1

**Self-Reported Impact of Long COVID Symptoms on Employment among Adults Ages 18 to 64, December 2022**

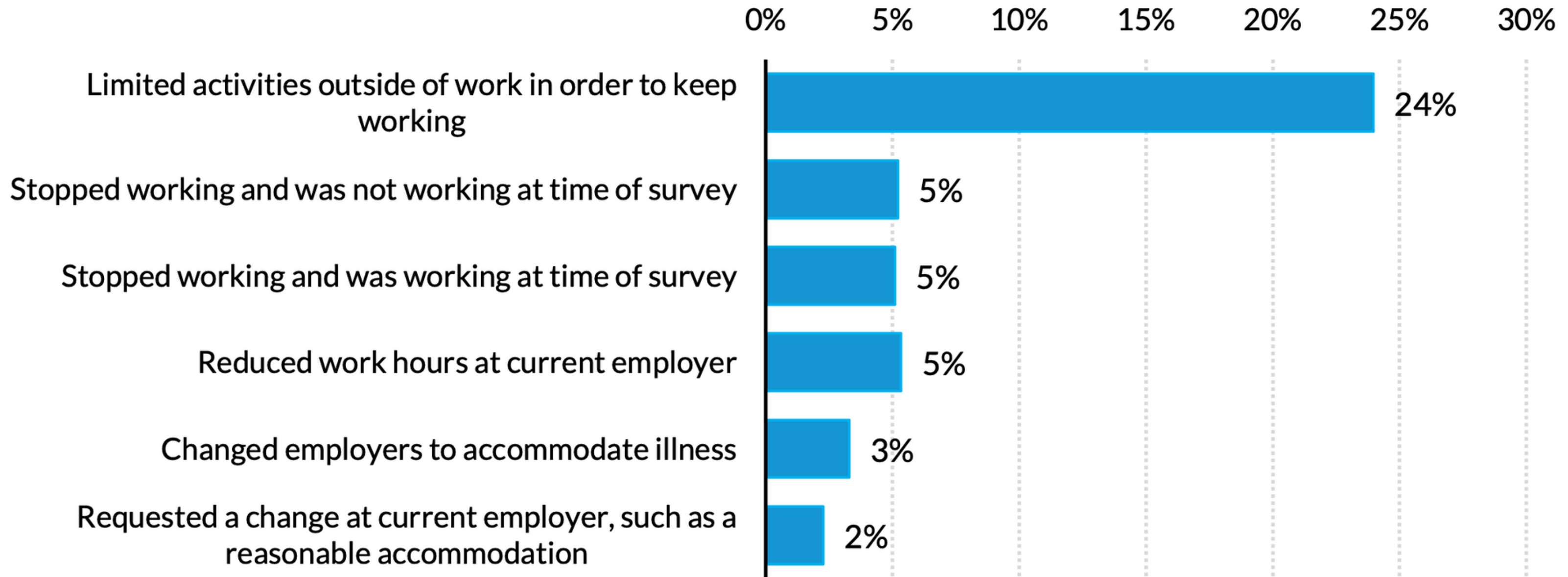


FIGURE 3

Household Food Insecurity in the past 12 Months among Adults Ages 18 to 64, by Self-Reported COVID-19 and Long COVID Status, December 2022

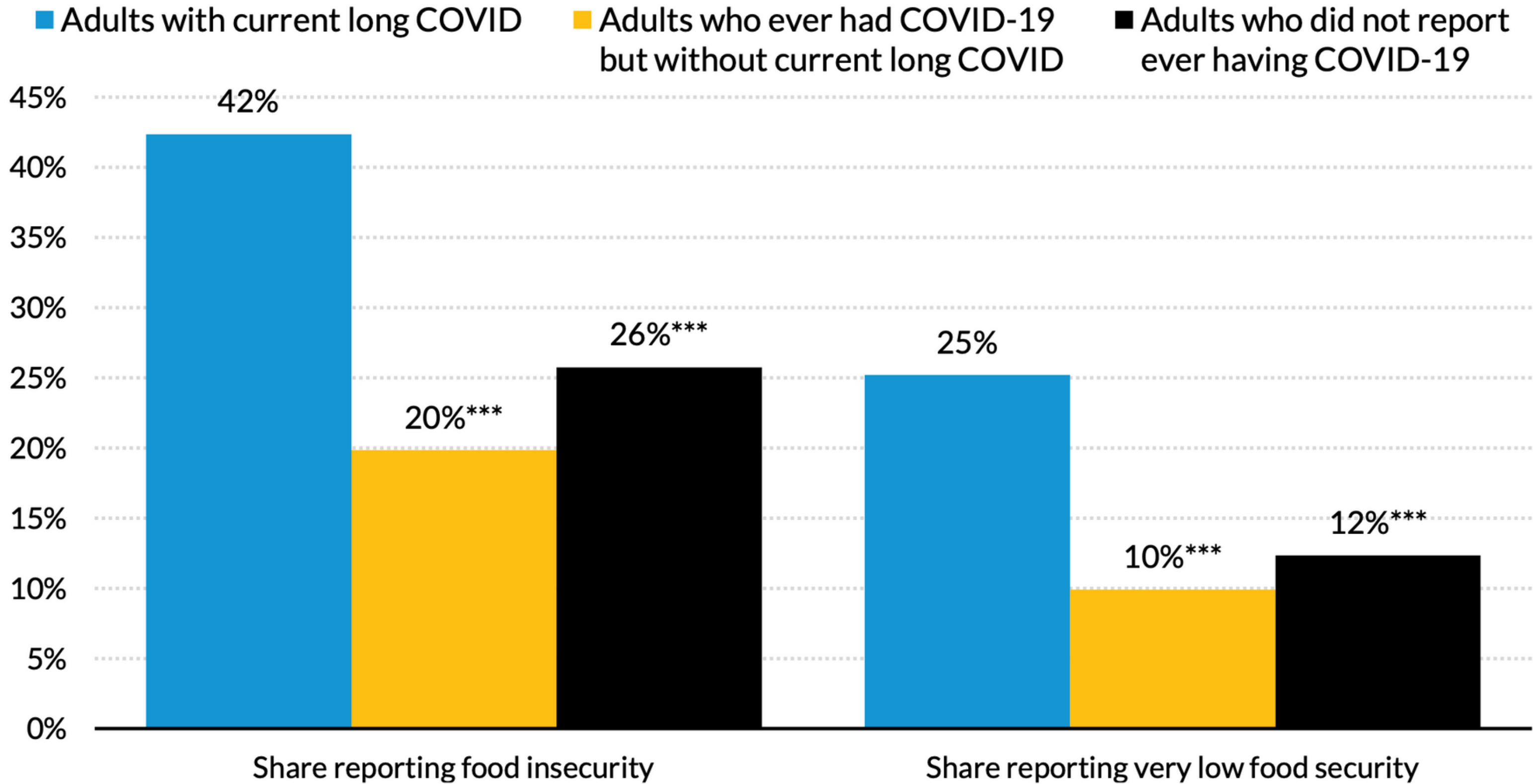
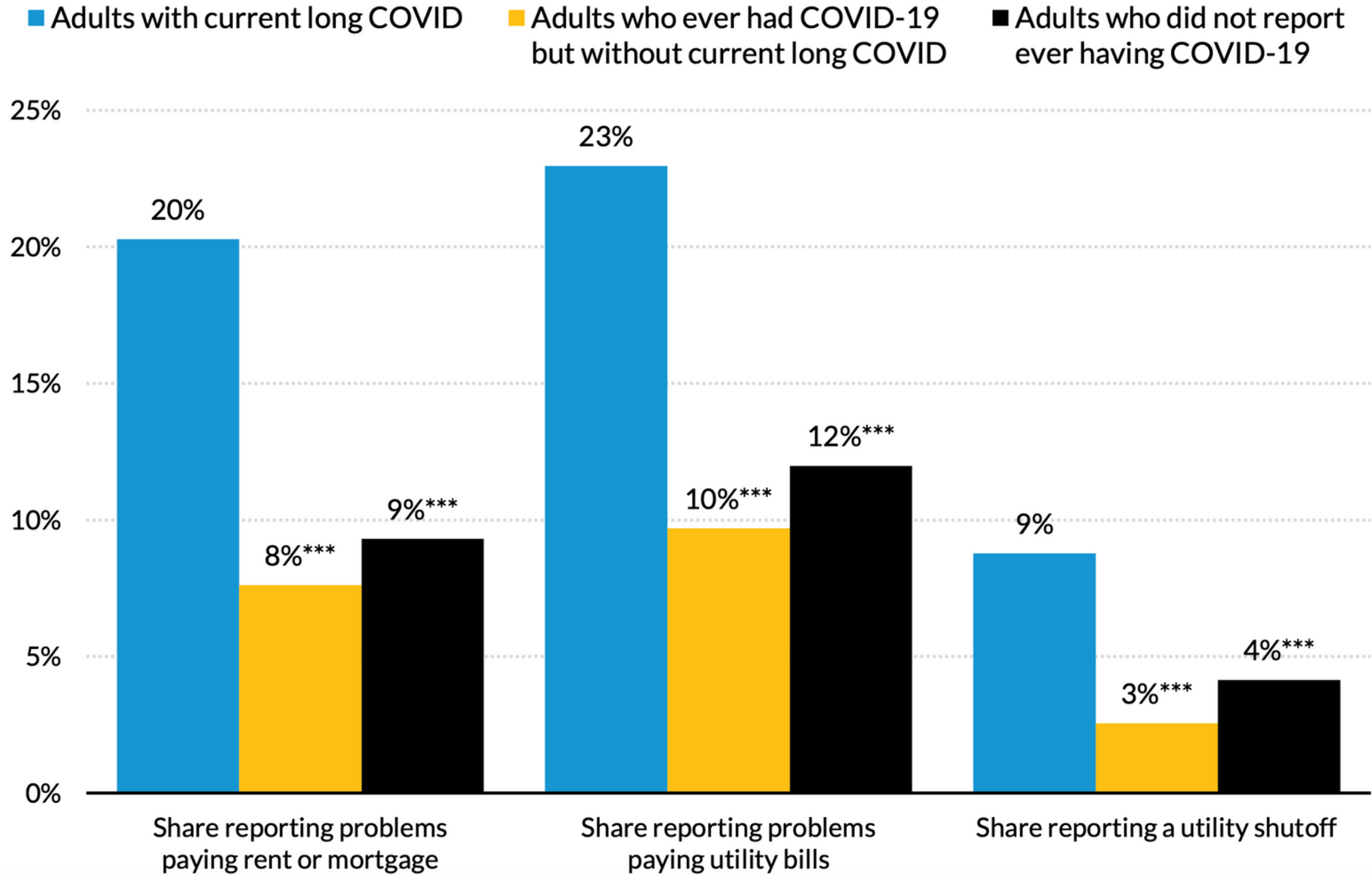


FIGURE 4

**Problems Paying for Housing Costs in the past 12 Months among Adults Ages 18 to 64, by Self-Reported COVID-19 and Long COVID Status, December 2022**

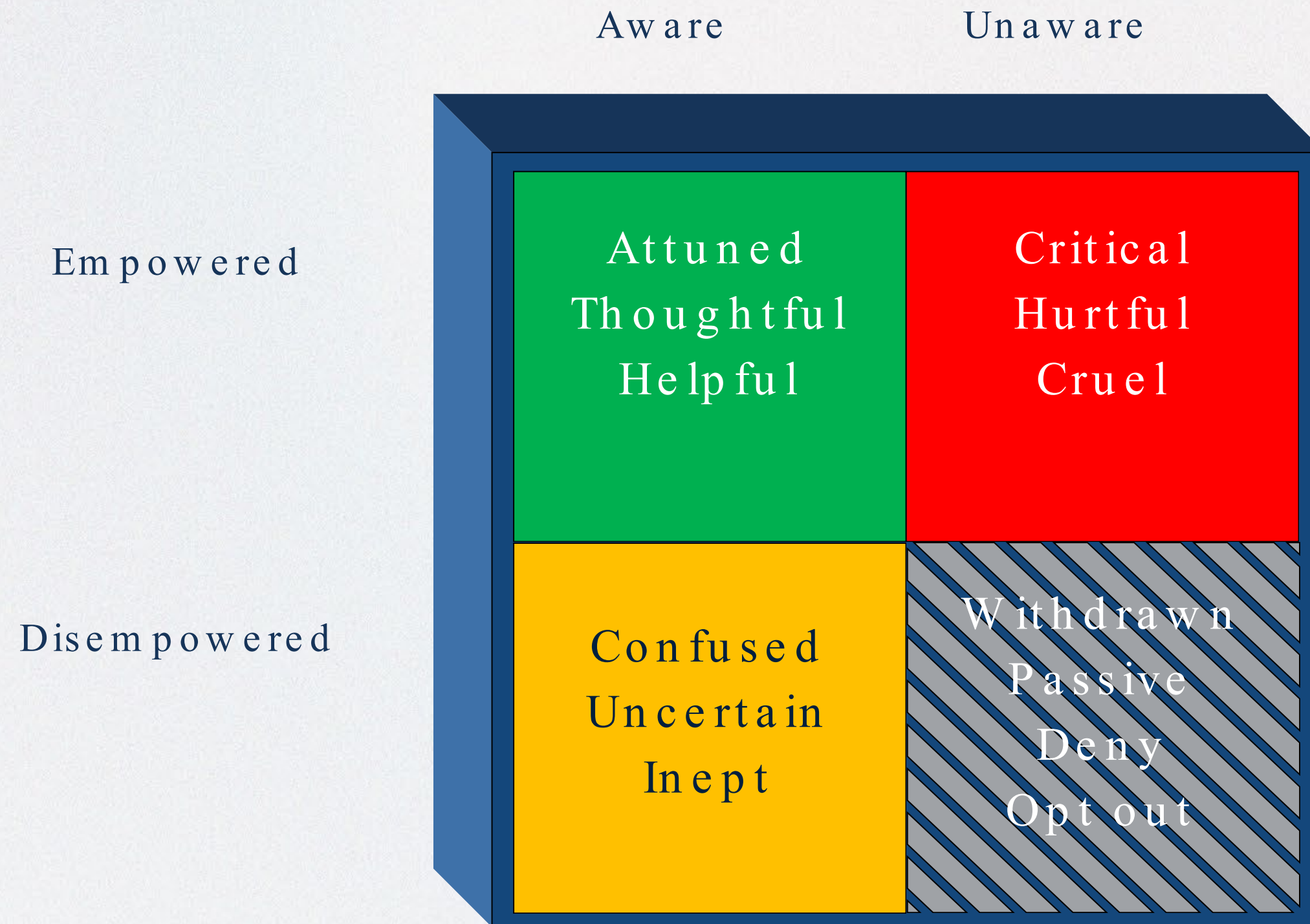


# What does it mean to witness someone with Long COVID?

Whether you are a health care worker or a friend or a family member, witnessing is the experience we are all having when we know someone with Long COVID.



# Witness Positions



# Caring for Someone with Long COVID



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Medical course varies considerably

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The patient and caregiver may have worries about impact on work, other family members, childcare or income, all of those factors

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The patient may feel mildly or very ill

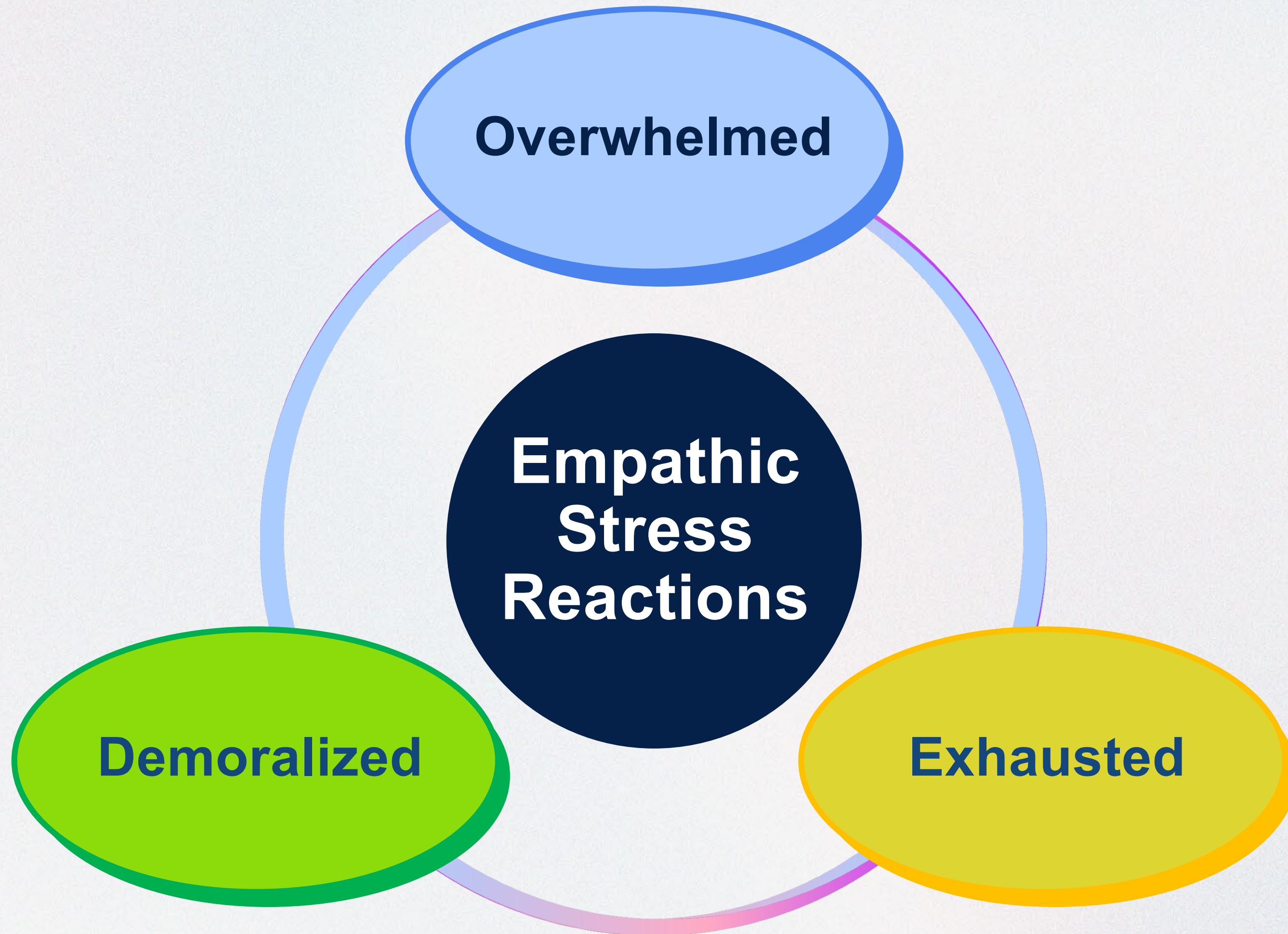
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How to provide symptomatic relief?

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Where to get specialized services?

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# Difficulty of Getting Medical Care for Long Covid Conditions

This requires a lot of work on the part of the patient or patient's family

Long Covid patients describe “Being a patient is a full-time job; being an advocate is overtime.”

Anger, frustration, despair are added to the burdens





# Summary:

Looking ahead, 5% to 10% of adults in the U.S. may continue to experience long COVID at any point in time, but research to improve diagnosis and treatment moves slowly.

Although rates of long COVID have stabilized, the 14-17 million adults with long COVID may experience many employment and material hardships with 4 in 10 reporting food insecurity, 2 in 10 reporting difficulty paying rent or mortgage, and 1 in 10 reporting that they had to stop working for a period of time because of their symptoms.

# What can family members do?

Be a good listener

Make it a “we” not a “you” experience. “You are not alone. We are in this together.”

Be an advocate with the health care system

Remember that most people will get better

# What can clinicians do?



- Understand and empathize with patients and family members coping with Long COVID and its aftermath.
- Use available guidelines to establish if workman's compensation is available to your patients. Know your state policies.
- Help patients and families minimize shame if the person is unvaccinated. Many people did not have work that made it easy to get to vaccination sites.

# Models of Care for Treating patients with Long COVID

## 5 core principles:

1. a core “lead” team,
2. broad multidisciplinary expertise,
3. comprehensive access to diagnostic and therapeutic services,
4. a patient-centered approach, and
5. providing capacity to meet demand.



# What about Paxlovid?

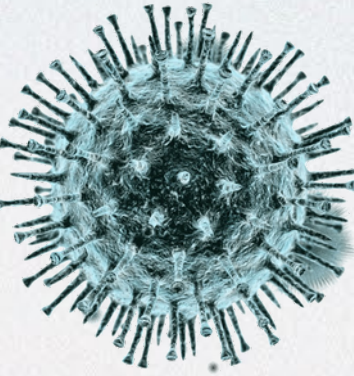
- There was a recent publication of a large study on Paxlovid, a treatment for COVID, in the New England Journal of Medicine:

From the accompany editorial:

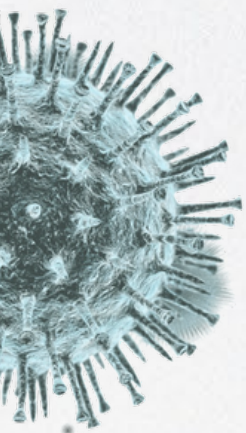
“Thus, it appears reasonable to recommend nirmatrelvir–ritonavir primarily for the treatment of Covid-19 in older patients (particularly those  $\geq 65$  years of age), those who are immunocompromised, and those who have conditions that substantially increase the risk of severe Covid-19, regardless of previous vaccination or infection status.”

- However, Paxlovid may not reduce risk of Long COVID, as had once been thought.

# Does Vaccination Protect Against Long COVID?



- A [new study](#) based on 4,605 participants in the Michigan COVID-19 Recovery Surveillance Study shows that the prevalence of long COVID symptoms at 30 and 90 days post-infection was 43% to 58% lower among adults who were fully vaccinated before infection.
- Clinicians should still recommend vaccination as it does seem to decrease risk of Long COVID.
- The study appeared in the *Annals of Epidemiology*.



# Burnout in the Context of Long COVID for Doctors: Take care of yourself!

- Burnout and depression among doctors — while encouragingly better than 2022— remain higher than before COVID.
- For doctors caring for long COVID patients, the sense of helplessness when recovery is slow weighs heavily.
- At the Mount Sinai Center for Post-COVID Care in New York City, the director, Zijian Chen, MD, who helped launch the clinic in May 2020:
  - "Sometimes you're faced with patients who you're trying to do everything for, but they're not just not getting better. It's really frustrating because we want everybody to get better. So, there's that lack of fulfillment there that can cause a sense of burnout."
- Doctors caring for Long COVID patients need to support each other.



# Policy Recommendations: Healthcare workers can be policy advocates also

- More research needed
- Address social determination of health
- Expand safety net assistance and increase benefits of the programs serving people with disabilities
- Provide universal paid leave
- Make workplaces more accommodating



# Resources for Long COVID Researchers



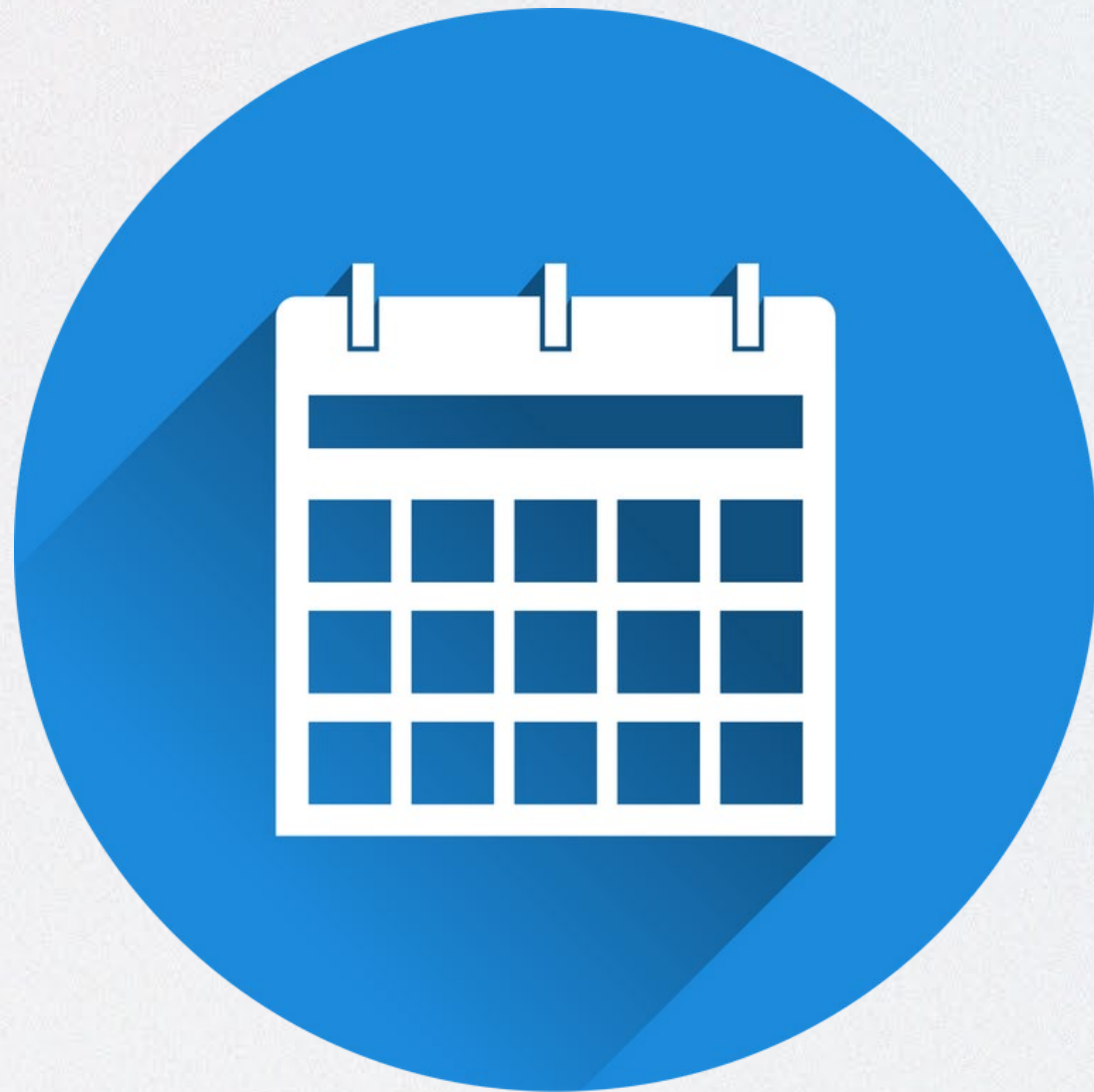
**PATIENT-LED  
RESEARCH  
COLLABORATIVE**

<https://patientresearchcovid19.com/resourcesfor-long-covid-researchers/>

## DATE

June 5, 2024

11:00AM - 12:00PM ET



An ad hoc committee of the National Academies of Sciences, Engineering, and Medicine drafted a detailed report on the current status of diagnosis, treatment, and prognosis of long-term health effects related to Long COVID. In a public release webinar, members of the committee will provide an overview of key conclusions and answer audience questions.

- [REGISTER](#)

# Additional Resources



- Emerging and Re-Emerging Viruses: What Clinicians Need to Know, From COVID-19 to Avian Flu
- MCN – COVID-19 Resource Hub
- Long COVID – ACOEM Guidance Statement
- Farmworker Justice, Long COVID: Farmworker Rights and Protections

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and a lot more at

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

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Please take a few minutes to submit the evaluation for this webinar. If you would like to receive a Certificate of Attendance, Continuing Nursing Education, or Continuing Medical Education, submission of the evaluation is required.

## Long COVID: Supporting Patients and Families



# ¿Y qué de Paxlovid?

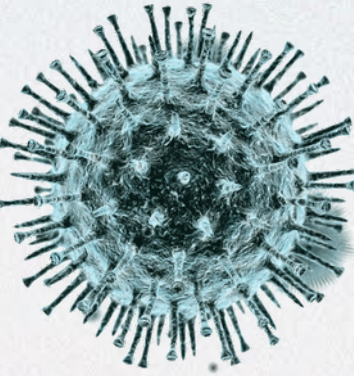
- Recientemente se publicó un estudio extensivo sobre Paxlovid, un tratamiento para COVID-19, en el New England Journal of Medicine:

Nota editorial que acompaña la publicación:

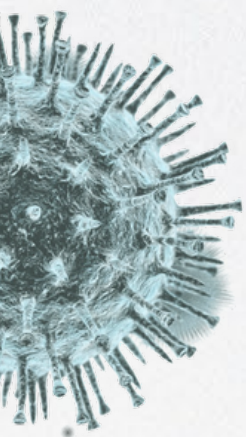
"Por lo tanto, parece razonable recomendar nirmatrelvir-ritonavir principalmente para el tratamiento de COVID-19 en pacientes de edad avanzada (en particular a los mayores de 65 años), los que están inmunocomprometidos y los que tienen condiciones que aumentan sustancialmente el riesgo de desarrollar COVID-19 grave, independientemente de la vacunación previa o el estado de la infección."

- Sin embargo, es posible que Paxlovid no reduzca el riesgo de COVID-19 prolongado, como se pensaba.

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