

VIRTUAL BRIEFING

# Long COVID and Health Equity in the Commonwealth

**Tuesday**  
**January 30, 2024**  
**10:00 a.m. – 11:30 a.m.**

*Hear from those living with Long COVID,  
researchers, clinicians, community  
organizers, and advocates.*

*Learn about what we know and don't know  
about Long COVID and health equity  
in the Commonwealth.*

***Sponsored by***

**The MA Black and Latino Legislative Caucus**

**Rep. Marjorie Decker, House Chair,**

**Joint Committee on Public Health**

**Rep. Mindy Domb**

## **SPEAKERS**

### **Cheryl Clark, MD, ScD,**

Executive Director and SVP, Institute for Health Equity Research, Evaluation and Policy, Inc. Massachusetts League of Community Health Centers, and Associate Chief, Division of General Internal Medicine & Primary Care, Brigham and Women's Hospital, Associate Professor, Harvard Medical School

### **Estevan Garcia, MD, DrPH,**

Chief Medical Officer, Massachusetts Department of Public Health

### **Netia McCray,**

Executive Director, Mbadika

### **Elizabeth Gay, MD,**

Director of the COVID Recovery Center, Assistant Professor of Medicine

### **Linda Sprague Martinez, Ph.D.,**

Professor in the Department of Medicine, and Director of the Health Disparities Institute at UConn Health

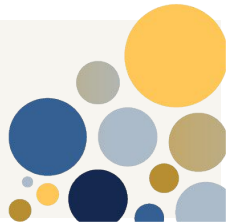
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Rep. Mindy Domb

# Long COVID Briefing Part I:

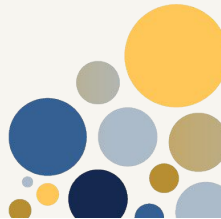
## Long COVID and Health Equity in the Commonwealth: What we know and what we don't know

January 30, 2023



# Conflicts and Affiliations

- No conflicts to declare
- Affiliations
  - Executive Director and Senior Vice President, Institute for Health Equity Research, Evaluation and Policy, Massachusetts League of Community Health Centers
  - Division of General Internal Medicine & Primary Care, Brigham and Women's Hospital, Harvard Medical School
  - Boston RECOVER



# Boston RECOVER Community Partnership Table's Top Goals

**Mission:** Centering community and social justice to attain equity in recovery from Long COVID

## 1 Research

Learn about and get involved in research and clinical trials regarding Long COVID that reflect the diversity of the Greater Boston community.

## 2 Community Education

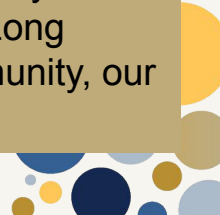
Learn about Long COVID, health equity, and how to better address them.

## 3 Clinical Care and Social Support

Learn about and access clinical care and social supports to address Long COVID and get effective and equitable care.

## 4 Institutional and Policy Change

Learn about and get involved in advocating for policy and institutional changes to more effectively address Long COVID and advance health equity — in our community, our site, and our country.



# What Is Long COVID?

**Cheryl R. Clark MD, ScD**

Boston RECOVER Investigator

Brigham and Women's Hospital



**RECOVER**

Researching COVID to Enhance Recovery

*An Initiative Funded by the National Institutes of Health*

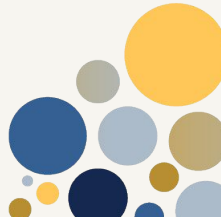
# Long COVID Is Common

## In the US

- Up to **23 Million** affected
- Up to 1 Million out of work

## In Massachusetts

- **Up to 20%** of COVID+ have long COVID symptoms
- Sources: National Health Interview Survey 2022; National Government US Government Accountability Office GAO-22-105666; MA Behavioral Risk Factor Surveillance Survey 2022



# How Is Long COVID Defined?

Long-Term Health Effects Stemming from COVID-19 and  
Implications for the Social Security Administration

NATIONAL  
ACADEMIES

Sciences  
Engineering  
Medicine

*Working definition:*

*Signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection*

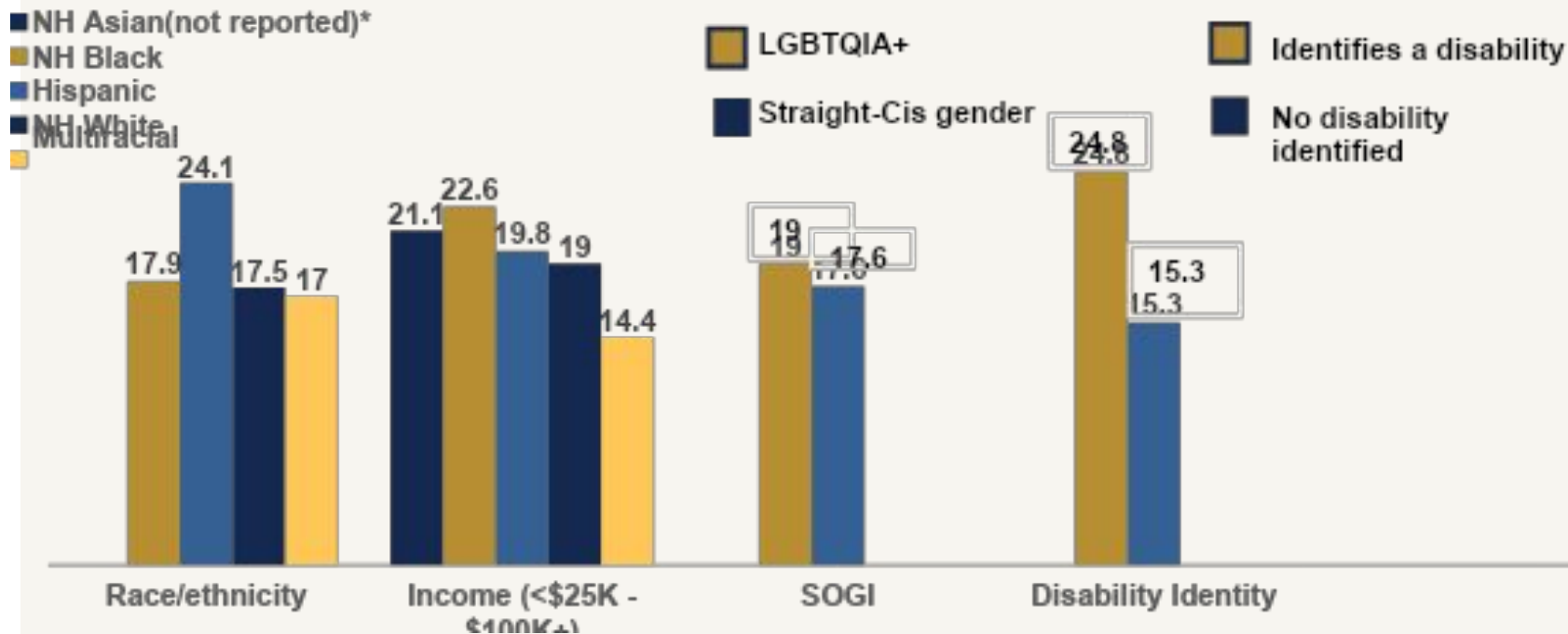
- **Timing:** 4 weeks or more after initial infection
- **Involvement:** Multisystem
- **Progression:** Can relapse, remit or progress (get better or worsen)
- **Severity:** Possible severe and life-threatening events even months or years after infection.
- **Complexity:** Long COVID is not one condition



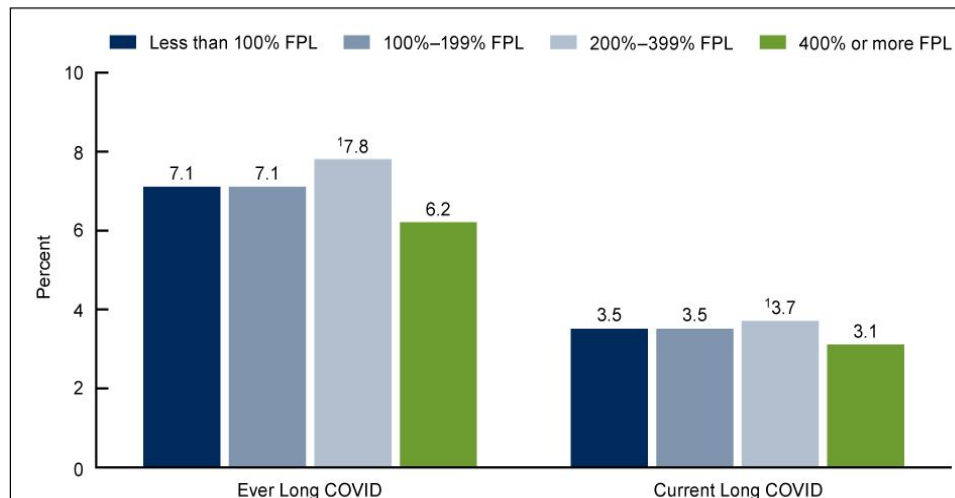
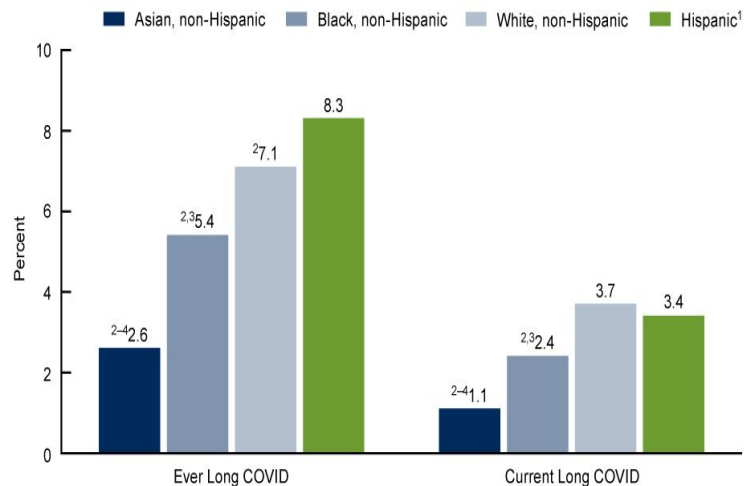


# Demographics of Long COVID Vary

## Massachusetts BRFSS 2022



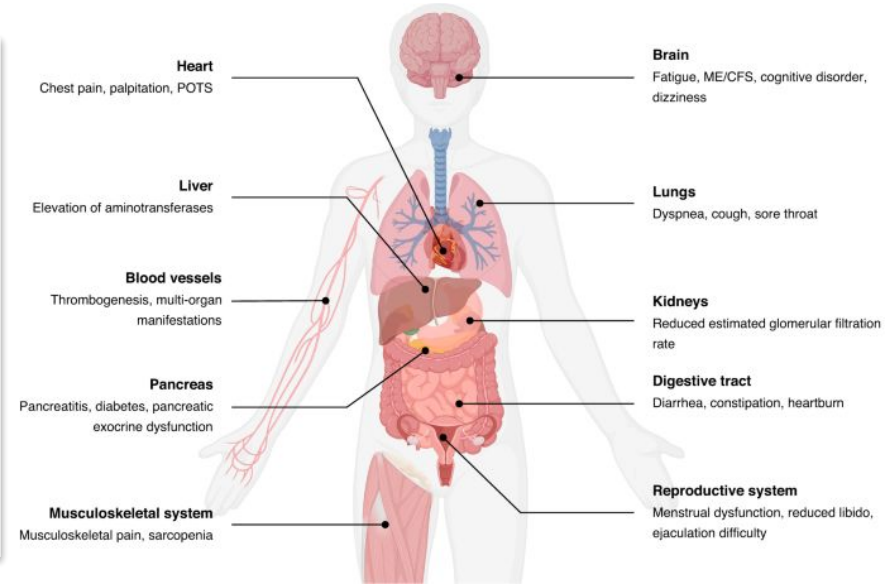
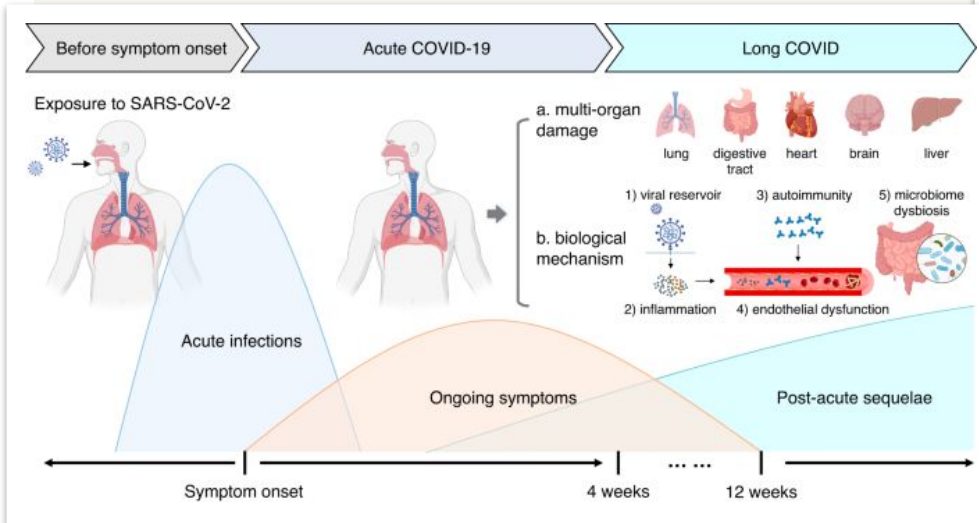
# US Statistics On Long COVID



Source: National Center for Health Statistics

[recoverCOVID.org](https://recoverCOVID.org)

# How Does Long COVID Affect Health?

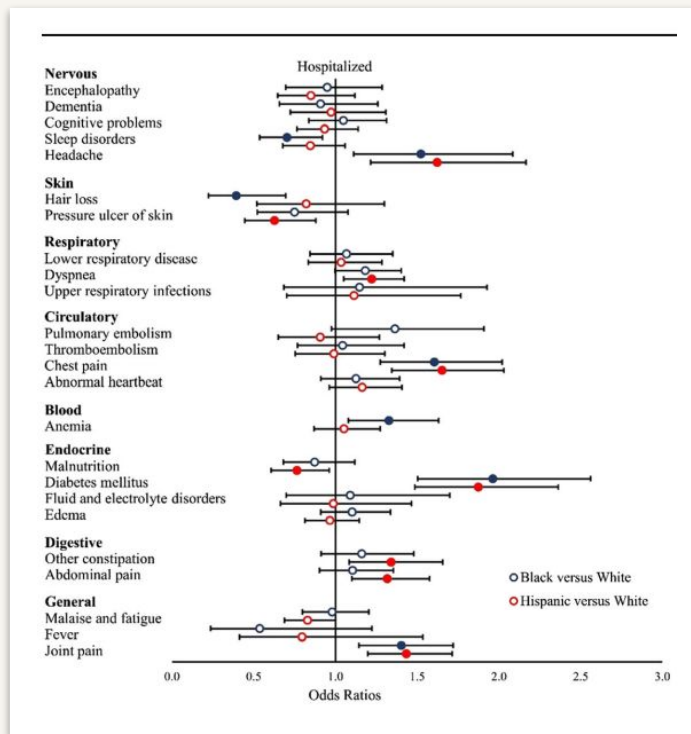


- Source: Li et al. STTT 2023

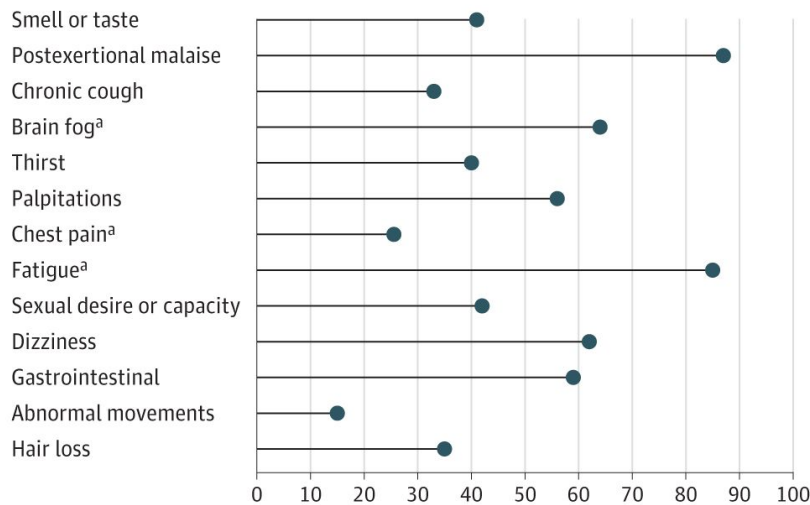


# Health Effects of Long COVID Vary

## New York US RECOVER Cohort



### B Symptom frequencies



Sources: Khullar et al JGIM 2023; Thaweethai et al. JAMA 2023

# Primary Care Is Needed for Multisystem Chronic Disease Care

## *Decline in primary care capacity during COVID*



### **CAPACITY**

**METRICS FOCUSED  
ON THE PRIMARY  
CARE WORKFORCE  
AND PIPELINE**

[EXPLORE](#) ►

In 2020, Massachusetts had a higher proportion (3.6%) of physicians leaving primary care than the United States overall (3.3%), and these proportions increased from 2018.

In 2020, 33.7% of primary care physicians in Massachusetts were aged 60 or older, an increase from 31.8% in 2018.



### **EQUITY**

**METRICS FOCUSED  
ON ASSESSING  
INEQUITIES IN THE  
SYSTEM**

[EXPLORE](#) ►

There were substantial racial and ethnic disparities in access to and utilization of primary care.

In 2021, only 64% of Hispanic residents reported that they had a preventive care visit in the last year, versus 81% of White residents.

# This Too Is Long COVID

- Grief and loss



- Socioeconomic insecurity



- Diminishing access to Care

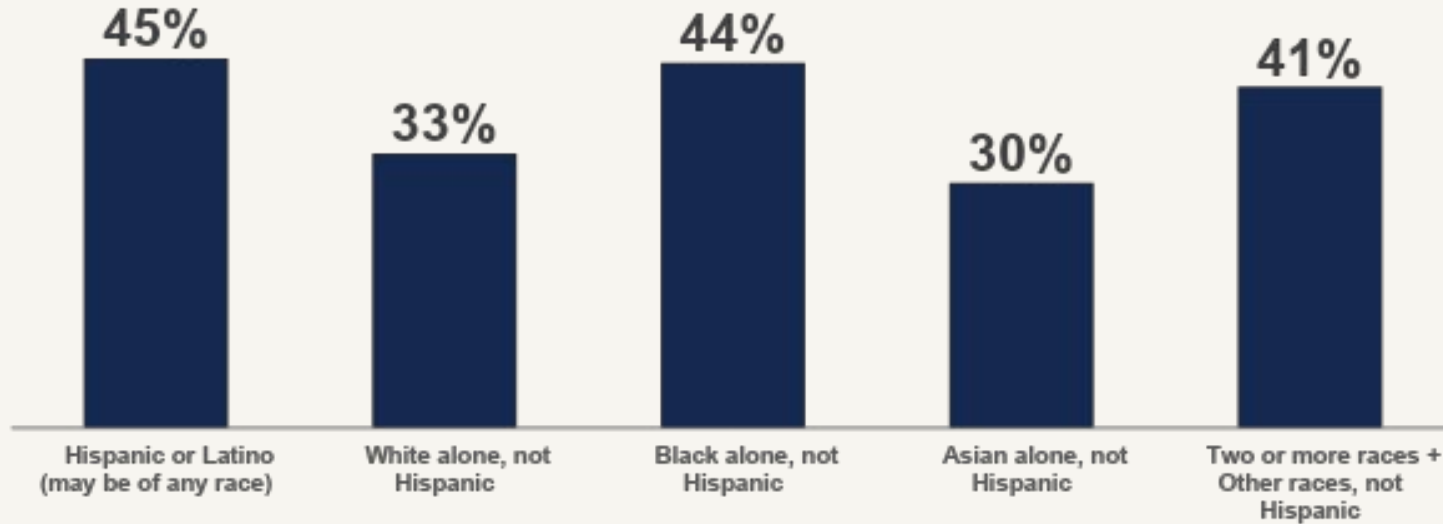


- Sources: American Heart Association; BCRC Community Table

# Multisector Policy Is Needed to Address the Context of Long COVID

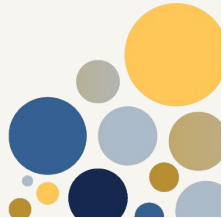
US Census Pulse Survey October 18 – October 30, 2023

Difficulty Paying for Usual Household Expenses in Past 7 Days



## Four Take Home Points

- Impact of Long COVID is biological and social
- Data is needed to track its impact in Massachusetts
- Primary care capacity needed for chronic disease
- Address structural inequities







# RECOVER

Researching COVID to Enhance Recovery

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*An Initiative Funded by the National Institutes of Health*

recoverCOVID.org



# Massachusetts Department of Public Health

## Long COVID: What we know

January 30, 2024

Estevan Garcia MD, DrPH, MPA, FAAP

Chief Medical Officer

# Discussion Topics

- Other names
- Definitions
- What we know
- Who can get Long COVID?
- Possible mechanisms of Long COVID
- Impact of Treatment and Vaccines

# Also Known as

- Post-Covid Conditions
- Long-haul COVID
- Post-acute COVID-19
- Long-term effects of COVID
- Chronic COVID
- Post-acute sequela of SARS CoV-2 infection

# Long COVID Defined (CDC)

- Patient created term
- Signs, symptoms, and conditions that continue or develop after initial SARS-CoV-2 infection
- Present 4 weeks or more after the initial phase of infection
- May be multisystemic
- May present with a relapsing–remitting pattern and progression or worsen over time, with the possibility of severe and life-threatening events even months or years after infection
- Not one condition
- Definition will be revised in iterative manner as data becomes available

# Long COVID – What we know

- May occur in approximately 10% of severe acute respiratory syndrome SARS-CoV-2 infections (actual number is unknown and depends on the definition used)
- 65 million individuals worldwide
  - Disease burden from mild to debilitating
- More than 200 symptoms identified impacting multiple organ systems
- According to the CDC, people most commonly report
  - Tiredness or fatigue, post-exertional malaise, fever
  - Difficulty breathing, cough, chest pain
  - Difficulty thinking, headache dizziness, sleep difficulties
  - Diarrhea and stomach pain
- Radiologic findings observed
  - Olfactory bulb, brain, heart, lungs
- Other findings
  - Microclots indicating hypercoagulation

# Long COVID – Possible Mechanisms

- Research is building on prior experience of other post-viral sequelae as well as other possibly related conditions
  - Myalgic encephalomyelitis (ME)
  - Chronic fatigue syndrome (CFS)
- Specific viral infections that offer informative pathways for COVID-19
  - Epstein Barr Virus (EBV)
  - Measles Virus
  - Chikungunya Virus
- Evidence that symptoms may be associated with persistent viral components in some, but not all, patients

# Who can get Long COVID?

- Anyone infected with the virus that causes COVID-19 can develop Long COVID
  - Occurs more often in people with severe illness
- Each time an individual is infected by virus causing COVID-19 they are at risk of developing Long COVID
- People at greatest risk
  - Severe COVID-19 disease (hospitalization/ICU)
  - Underlying health conditions
  - Unvaccinated individuals
- Health inequities may increase risk of Long COVID for certain communities



# Impact of Vaccine and Treatment on Long COVID

- Vaccination
  - Recent study found that vaccines in children were 35% effective in preventing Long COVID for up to a year, primarily by preventing infection
  - Multiple studies support protective effects of vaccines in adults against Long COVID
- Paxlovid
  - Recent study evaluating Paxlovid treatment in vaccinated, nonhospitalized individuals who received treatment within 1 month of first infection did not find reduction in Long COVID
    - Did not look at most severe cases
- More research needed

# How to Protect Yourself from Long COVID

- Avoid COVID-19 infection
  - Avoid reinfections
- Stay up to date with COVID-19 vaccines
- Basic infection prevention strategies
  - Stay home when sick
  - Wash hands and surfaces frequently
  - Avoid close contact with someone with COVID-19
  - Masking when COVID-19 activity is high
  - Test and treat when appropriate

# More Information

- Find and join a RECOVER study: [About the Initiative | RECOVER COVID Initiative](#)
- The U.S. Department of Health and Human Services (HHS) has published a guide of federal programs and recommendations: [HHS: Services and Supports for Longer-Term Impacts of COVID-19 \(PDF\)](#).
- The Centers for Disease Control and Prevention (CDC) offer resources to help you prepare for your appointment:
  - [Patient Tips: Healthcare Provider Appointments for Post-COVID Conditions](#)
  - [Healthcare Appointment Checklist for Post-COVID Conditions \(PDF\)](#)
    - [Español: Lista de verificación para las citas de atención médica por afecciones pos-COVID \(PDF\)](#)
  - [Preparing to Discuss Post-COVID Conditions with a Healthcare Provider \(PDF\)](#)
    - [Español: Cómo prepararse para hablar sobre afecciones pos-COVID con un proveedor de atención médica \(PDF\)](#)

# Connect with DPH



@MassDPH



Massachusetts Department of Public Health



[mass.gov/dph](https://mass.gov/dph)

MBADIKA

# IMPACTS OF LONG COVID

## A PATIENT PERSPECTIVE

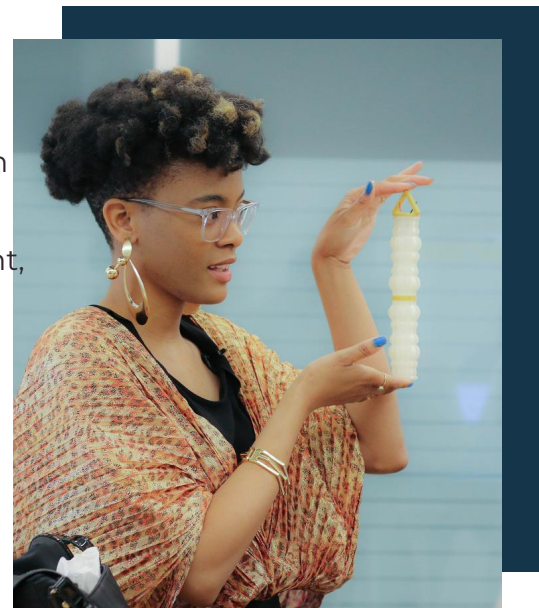
**NETIA MCCRAY**

**EXECUTIVE DIRECTOR, MBADIKA**

Focus on making STEM (Science Technology Engineering Mathematics) education accessible to learners of all ages, including socioeconomically disadvantaged communities, which have been disproportionately affected by various employment, disability, educational, and developmental outcomes.

### Experience

- Executive Director, Mbadika [2010 - Present]
- B.S. Political Science, Massachusetts Institute of Technology (MIT), Class of 2014



MARCH 2020 - PRESENT

MARCH 2020 - PRESENT

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PRIME

abc NEWS  
INDIANA

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NEWSLIVE

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abc  
NEWSLIVE

# **JUNE 2022**

**\*\*U.S. Census Bureau and National Center for Health Statistics, June 2022**

## Long COVID Household Pulse Survey

National Center for Health Statistics

U.S. Census Bureau

20-minute Online Survey to evaluate the impact of the COVID-19 pandemic in the United States.



**Phase 3.5 - June 2022**

Survey evaluated the presence of long-term symptoms among those reporting symptoms lasting 3 months or longer post COVID-19 infection.

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# 2 in 5



**U.S. Adults reporting a previous COVID-19 infection.\*\***

**\*\*U.S. Census Bureau and National Center for Health Statistics, June 2022**

# 1 in 5



**Americans with a past COVID-19 infection still reporting  
"long COVID" symptoms at least three or more months post  
infection.\*\***

**\*\*U.S. Census Bureau and National Center for Health Statistics, June 2022**

# 1 in 13



**U.S. Adults with "long COVID" symptoms at least three or more months post COVID-19 Infection.\*\***

**\*\*U.S. Census Bureau and National Center for Health Statistics, June 2022**

## Long COVID Household Pulse Survey

National Center for Health Statistics

U.S. Census Bureau

### Phase 3.5 -

**June 2022**

Survey evaluated the presence of long-term symptoms among those reporting symptoms lasting 3 months or longer post COVID-19 infection.

### Phase 3.6 -

**September 2022**

Survey expanded to evaluate if those reporting symptoms had a reduced ability to carry out their daily activities compared to pre-COVID-19 infection.

### Phase 3.8 -

**Spring 2023**

Present survey evaluates if those reporting symptoms not only have a activity limitations, but also measure if they experience significant daily activity limitations, compared to pre-COVID-19 infection.

# MAY 2023

**\*\*U.S. Census Bureau and National Center for Health Statistics, June 2022**

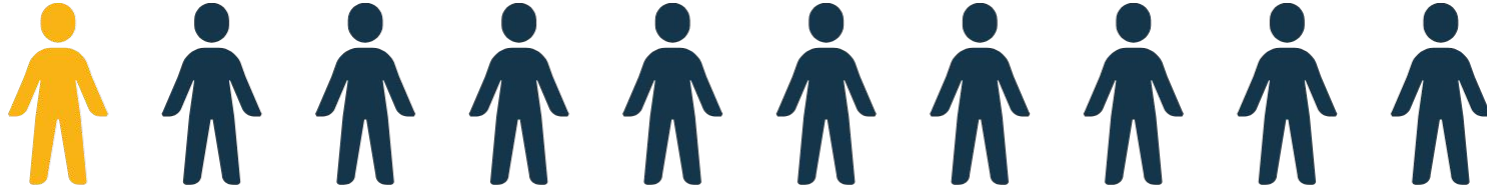
# 1 in 2



**U.S. Adults reporting a previous COVID-19 infection.\*\***

**\*\*U.S. Census Bureau and National Center for Health Statistics, June 2022**

# 1 in 10



**U.S. Adults with "long COVID" symptoms at least three or more months post COVID-19 Infection.\*\***

**\*\*U.S. Census Bureau and National Center for Health Statistics, June 2022**

# 4 in 5



**Americans reporting "long COVID" symptoms at least three or more months post infection reporting activity limitations.\*\***

**\*\*U.S. Census Bureau and National Center for Health Statistics, Spring 2023**



# 1 in 4



**Americans reporting "long COVID" symptoms at least three or more months post infection reporting SIGNIFICANT activity limitations.\*\***

**\*\*U.S. Census Bureau and National Center for Health Statistics, Spring 2023**

**OCCUPATION**

**EDUCATION**



**SOCIOECONOMIC**

**STATUS**

**INCOME**



## LONG COVID AND HEALTH EQUITY IN THE COMMONWEALTH

Elizabeth Gay, MD

Director, Covid Recovery Center, Brigham and Women's Hospital

Program director, pulmonary and critical care medicine fellowship



## CASE

Mr. A is a 62-year-old who developed Covid causing respiratory failure, requiring intubation and then tracheostomy/PEG tube placement. Complications included:

MRSA and E.coli pneumonias

CVA with seizures

Acute renal failure

Drug induced liver injury

Stress cardiomyopathy

Small bowel obstruction

**His recovery has included the following services:**

Acute rehabilitation (LTACH) and physical therapy

Specialty care through pulmonary, neurology, ENT and GI

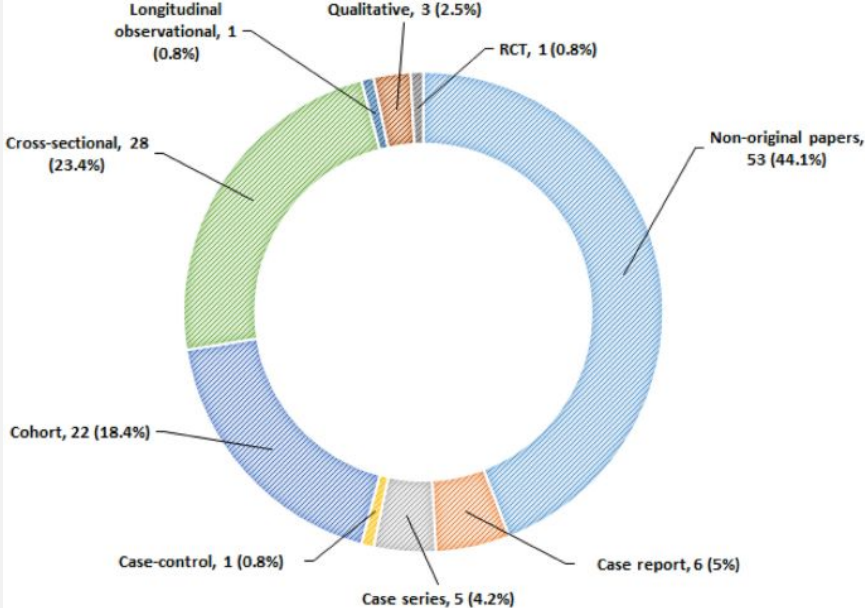
Speech therapy for swallowing and cough

Cognitive therapy for brain fog

He has slowly regained stamina but has not returned to work for the department of corrections.

## A MODERN ILLNESS

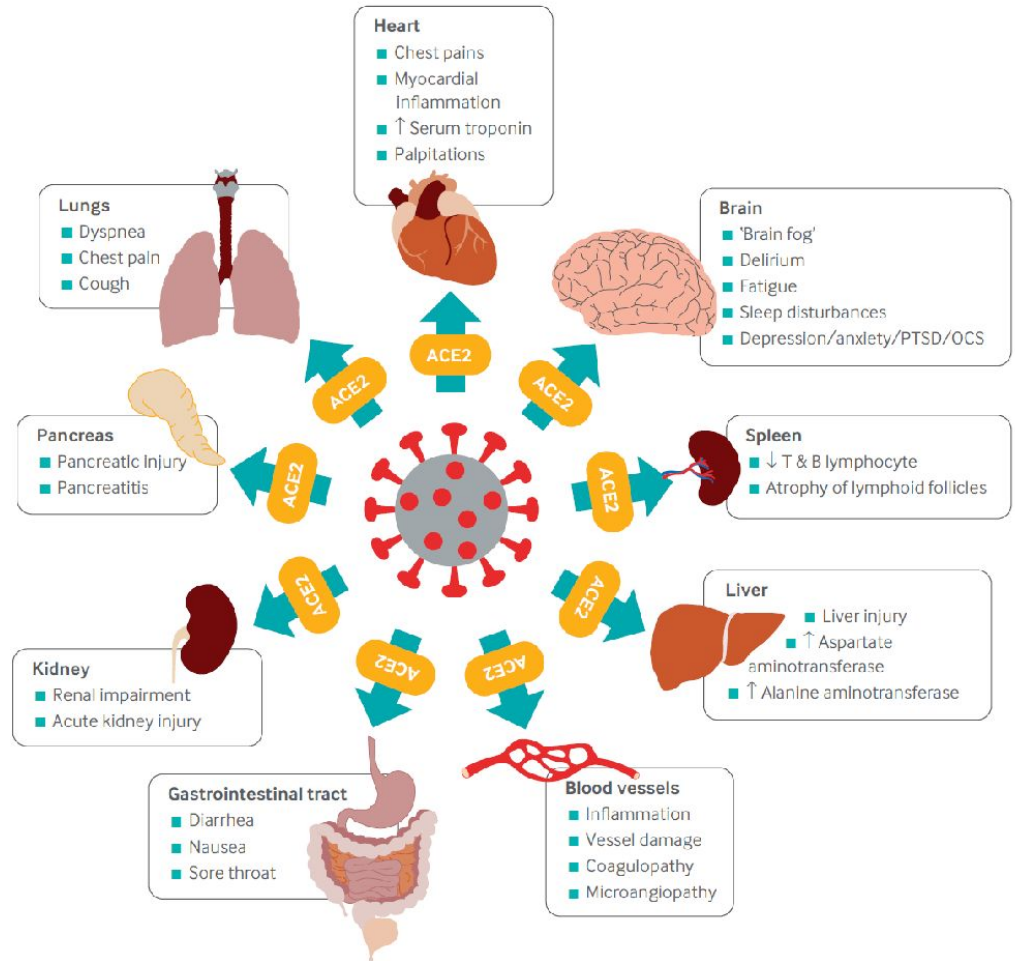
## Challenges: debates on nomenclature and diagnosis



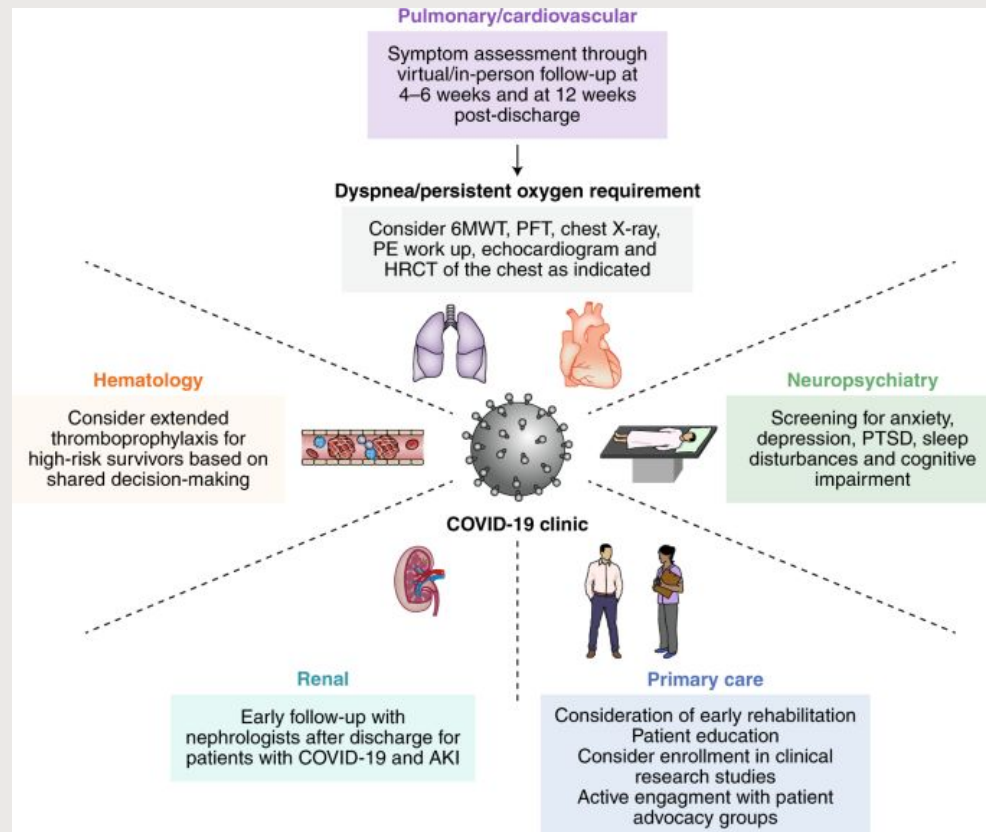
Phillips, Steven, and Michelle A. Williams. *New England Journal of Medicine* 385.7 (2021): 577-579.

Akbarialiabad, Hossein, et al. *Infection* 49.6 (2021): 1163-1186.

# PATHOPHYSIOLOGY



PROPOSED CARE IS  
COSTLY AND NOT  
EASILY ACCESSIBLE

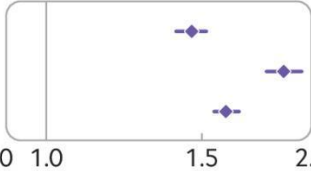
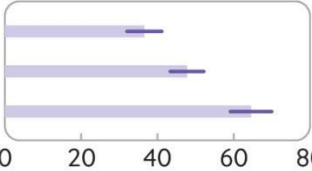
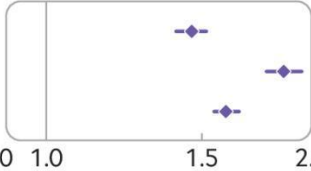
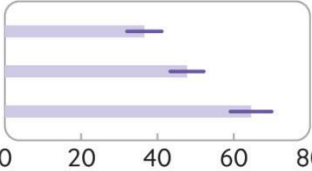
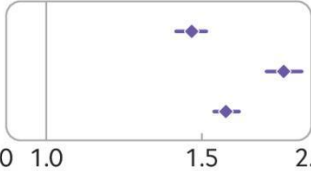
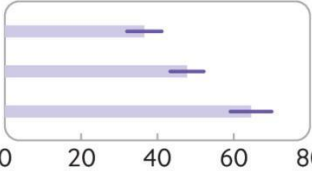


## OUR NEXT PUBLIC HEALTH DISASTER?

- Estimates suggest that up to 1 million people may be out of labor force at any given time due to long Covid, leading to direct earning losses.
- Patients with long Covid are often young and working in service industries.
- Long Covid may contribute to economic vulnerability on an individual level.
- Health care costs may rise if a substantial portion of long Covid patients seek testing.

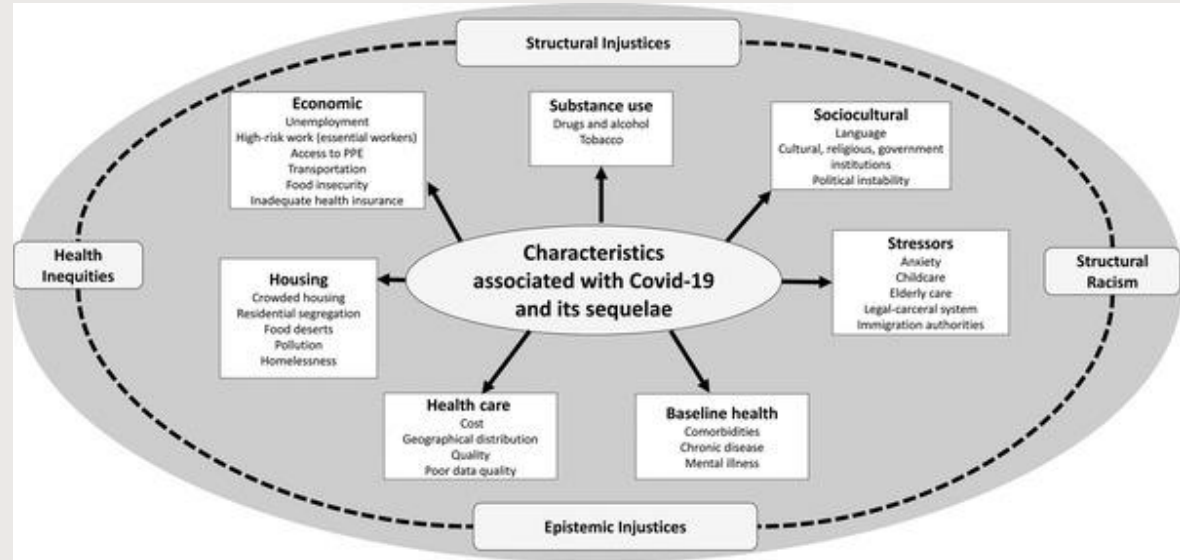


# MENTAL HEALTH

Outcome	Hazard ratio (95% CI)	Hazard ratio (95% CI)	Risk difference per 1000 people at one year (95% CI)	Risk difference per 1000 people at one year (95% CI)
Any mental health diagnosis	1.46 (1.40 to 1.52)		36.48 (31.93 to 41.19)	
Any mental health related drug prescription	1.86 (1.78 to 1.95)		47.60 (43.26 to 52.12)	
Any mental health diagnosis or prescription	1.60 (1.55 to 1.66)		64.38 (58.90 to 70.01)	

# EQUITY CONCERNS

- COVID-19 has disproportionately impacted historically disadvantaged communities of color and patients from socioeconomically disadvantaged backgrounds.
- African American and LatinX individuals suffer more infections and higher mortality. These inequities reflect legacies of structural racism, unequal resource investment and the impact of systems that perpetuate health disparities.



# BWH CRC Analysis

Hierarchical clustering by sex, race, language, and insurance status.

- **Cluster 1 patients:**

More likely to be LatinX, to utilize interpreter services, have government insurance, and to have had an ICU admission.

- **Cluster 2 patients:**

Predominantly White with commercial insurance and with the lowest percentage of ICU admissions.

- **Cluster 3 patients:**

More likely to be Black or Latin X, identify as non-Hispanic, not utilize interpreter services, and have commercial insurance

	Cluster			
	1	2	3	P-value
n, total 1285	437	686	162	
Age in years (mean (SD))	47.69 (14.85)	47.54 (16.11)	45.80 (13.40)	0.498
Sex n, (%)				0.247
Male	120 (27.5)	194 (28.3)	51 (31.5)	
Female	312 (71.4)	490 (71.4)	111 (68.5)	
Nonbinary	5 (1.1)	2 (0.3)	0 (0.0)	
Race, n, (%)				<0.001
African American	26 (5.9)	0 (0.0)	71 (43.8)	
American Indian or Alaskan				
Native	1 (0.2)	0 (0.0)	1 (0.6)	
Asian	9 (2.1)	0 (0.0)	26 (16.0)	
LatinX	88 (20.1)	0 (0.0)	45 (27.8)	
Other	3 (0.7)	0 (0.0)	18 (11.1)	
White	310 (70.9)	686 (100.0)	1 (0.6)	
Non-Hispanic Ethnicity n, (%)	347 (84.4)	456 (98.3)	75 (68.8)	<0.001
Interpreter Utilization (%)	34 (82.9)	1 (0.8)	2 (7.4)	<0.001
Smoking status, n, %				0.333
Current	16 (4.0)	22 (5.0)	4 (3.6)	
Former	71 (17.6)	101 (22.9)	23 (20.9)	
Never	316 (78.4)	319 (72.2)	83 (75.5)	
Insurance status, n, (%)				0.005
Commercial	294 (67.3)	529 (77.1)	117 (72.2)	
Government	142 (32.5)	153 (22.3)	44 (27.2)	
None	1 (0.2)	4 (0.6)	1 (0.6)	
ICU admission, n, (%)	19 (27.9)	42 (9.9)	14 (12.4)	<0.001

## Compared to Cluster 2:

- Cluster 1- more ICU stays and symptoms, but less likely to access support groups, care coordination and psychoeducation
- Cluster 3- more ICU stays but fewer reports of symptoms like brain fog, fatigue. Increased use of community resources.

Outcome	Age adjusted odds ratio, 95% CI; Cluster 1 Compared To Cluster 2	P-value	Age adjusted odds ratio, 95% CI; Cluster 3 Compared To Cluster 2	P-Value
<i>ICU Admission</i>	3.87 (1.84 - 8.14)	<.0001	1.5 (0.674 - 3.33)	0.32
<i>Symptom Report</i>				
Cough	3.92 (2.52 - 6.1)	<.0001	0.818 (0.455 - 1.47)	0.5
Dyspnea on exertion	3.37 (2.16 - 5.25)	<.0001	1.04 (0.633 - 1.7)	0.88
Anxiety	3.13 (1.88 - 5.23)	<.0001	0.437 (0.215 - 0.888)	0.022
Fatigue	4.01 (2.21 - 7.31)	<.0001	0.585 (0.338 - 1.01)	0.055
Brain fog	2.6 (1.57 - 4.31)	0.0002	0.46 (0.267 - 0.794)	0.0053
<i>Type of Social Services Support</i>				
Psychoeducation for chronic illness	0.132 (0.056 - 0.313)	<.0001	0.991 (0.496 - 1.98)	0.98
Navigating government benefits	1.18 (0.0736 - 19)	0.91	13.1 (1.34 - 127)	0.027
Financial/housing concerns	1.18 (0.0733 - 18.9)	0.91	8.6 (0.772 - 95.9)	0.08
Support groups	0.222 (0.0844 - 0.587)	0.0024	0.689 (0.235 - 2.02)	0.5
Care coordination	0.212 (0.0614 - 0.734)	0.014	1.34 (0.481 - 3.75)	0.57
Provision of community resources	4.08e-08 (0 - Inf)	0.99	3.52 (0.928 - 13.3)	0.064
Other	2.87e-08 (0 - Inf)	1	3.07e-08 (0 - Inf)	1

## RESEARCH GOALS

- Understand pathophysiology- mechanisms, role of immune response, genetic and host risk factors
- Investigate role of therapies, role of vaccinations
- Understand implications for long term health of individuals and populations

## POLICY IMPLICATIONS

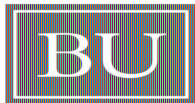
- **Exacerbation of underlying systemic issues**
  - Shortages of primary care and mental health services
  - Lack of providers in poor and rural communities
  - Racial and ethnic disparities in care
  - Incentives for expensive testing over more comprehensive but less lucrative care

# Long Covid impacts on diverse Black and Latinx MA residents

Linda Sprague Martinez, PhD, Professor & Director  
Health Disparities Institute, UConn Health

Nihaarika Sharma, MSW, MPH, Project Manager

Orion Shayne Ojala, Graduate Research Assistant  
Boston University School of Social Work



Boston University School of Social Work



# Project Team

*Janice John, Cambridge Health Alliance*

*Angelo Lima, Archipelago Strategies Group*

*Josiane Martinez, Archipelago Strategies Group*

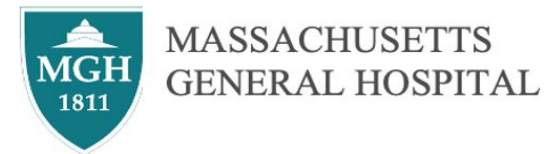
*Cheryl R. Clark, Brigham and Women's Hospital*

*Ingrid V. Bassett, Massachusetts General Hospital*

*Linda B. Hudson, Tufts University School of Medicine,  
Department of Public Health and Community Medicine*

*Rebecca Lobb, Boston University School of Medicine, Clinical  
and Translational Science Institute*

*Tracy A. Battaglia, Boston University School of Medicine,  
Boston Medical Center, Boston, Clinical and Translational  
Science Institute*



Acknowledgement: This research was supported by the Massachusetts Consortium on Pathogen Readiness at the Harvard Medical School. The content is solely the responsibility of the authors and does not necessarily represent the official views of the funding entity.

Thank you to **Jacqui Lindsay** of the BCRC RECOVER Table and **Benjamin P. Linas** of the MA CEAL team for their contributions, advising and support. Thanks to the MA residents and Long COVID Clinic directors who took the time to speak with our team.



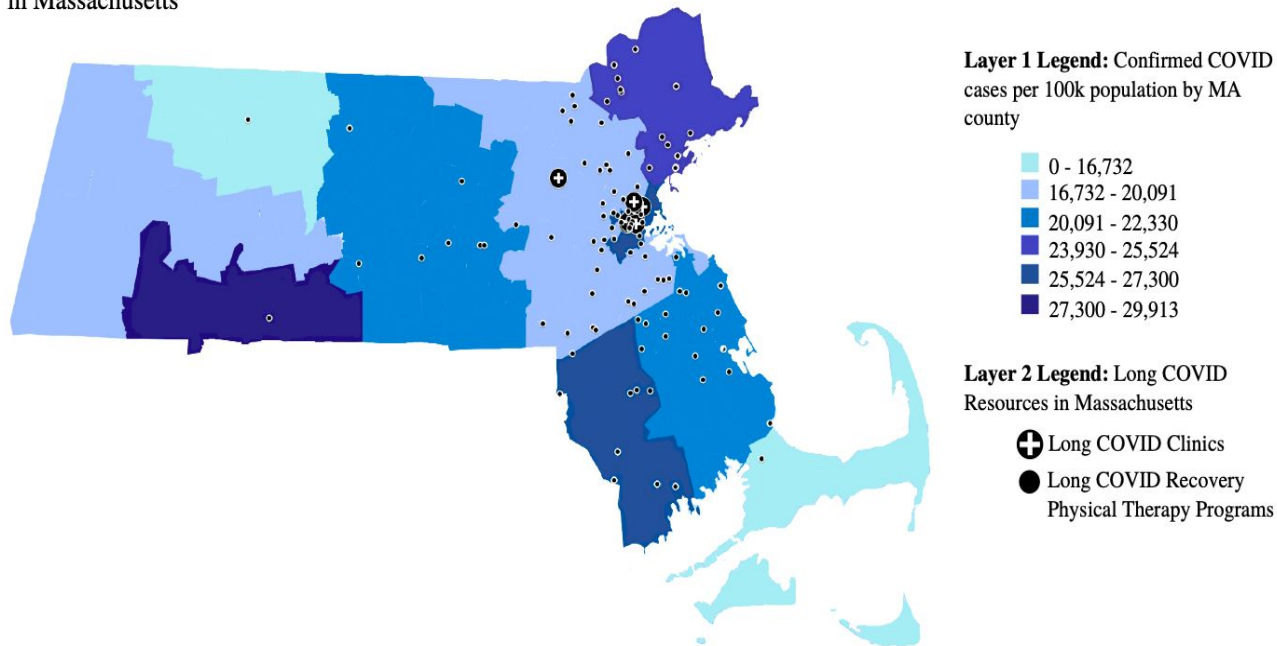
# MassCPR Health Equity Core: Aims & Scope

Identify Impact	Increase Awareness	Influence Policy
Identify the impact of Long COVID on diverse communities in Massachusetts and barriers to Long COVID treatment	Increase awareness of and access to Long COVID treatment and resources among communities in Massachusetts and the primary care providers serving them	Influence relevant policies at the organizational, municipal, state, and national levels

**Initial Scope:** Focus on Diverse Black and Latinx communities in Massachusetts

# Long Covid Care Assessments

**Figure.** Per Capita COVID Cases by County through March 25, 2022 and Distribution of Long Covid Clinical Resources in Massachusetts



*Note.* Data source: Coronavirus COVID-19 Global Cases by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University; the Census American Community Survey; the Department of Health and Human Services; and the Bureau of Labor and Statistics. Retrieved from <https://coronavirus.jhu.edu/us-map> on March 25, 2022

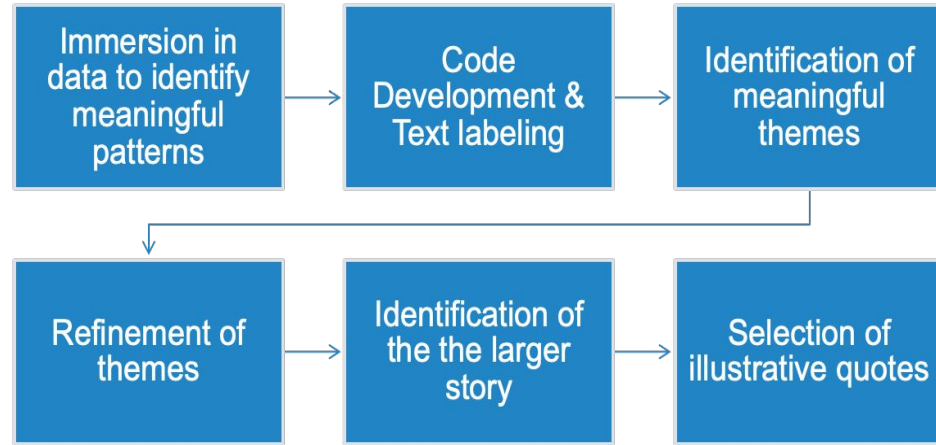
# Long Covid Focus Groups

Goal: to explore the impact of Long Covid on diverse Black and Latinx communities across MA

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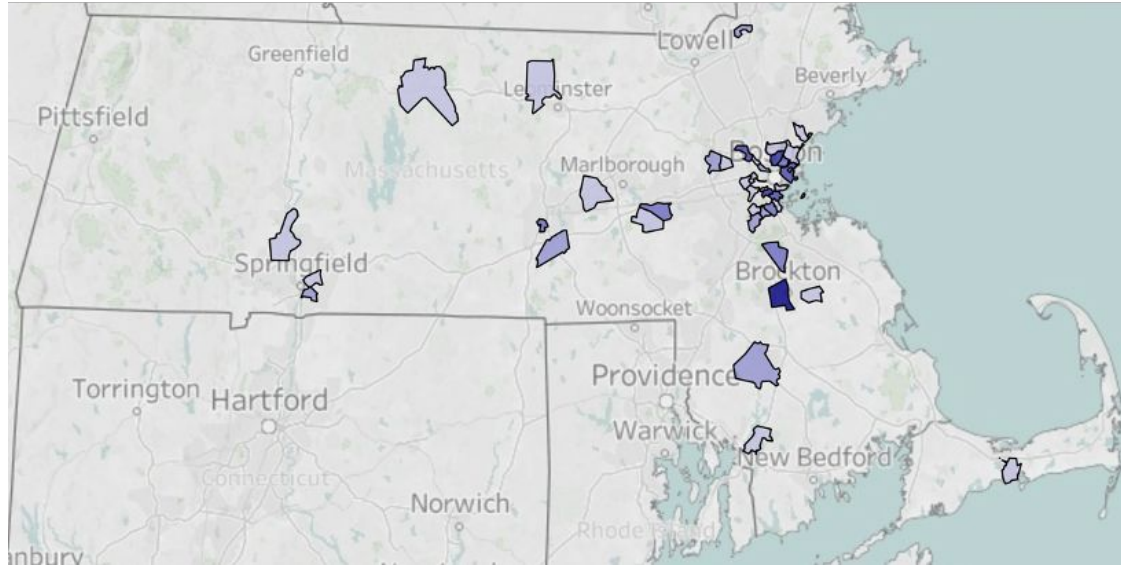
# Methods

- ▷ Conduct focus groups conducted in English, Spanish, Haitian Kreyol, Portuguese, Cape Verdean Creole
- ▷ Availability Sampling: Individuals experiencing Long Covid themselves or caring for someone with Long Covid who identify as Black or Latinx
- ▷ Recruitment: Media outreach, community partner outreach
- ▷ Procedures: Zoom based groups recorded, transcribed and translated.
- ▷ Data Management and Analysis: Nvivo, thematic analysis analysis.



Braun & Clark, 2006

# Participant Demographics



11 groups in five languages:

- 2 in English
- 2 in Haitian Creole
- 1 in Portuguese
- 6 in Spanish

99 participants

- 30 identify as Black
- 69 identify as Latinx and more than one race

# Described Symptoms

Fatigue

Exhaustion

No stamina

Inability to feel rested

Headaches

Hair loss

Cloudy, foggy mind

Shortness of breath

Cough

Excess phlegm

Chest pain

Vomiting

Muscle and joint pain

Spasms

Body aches

Memory Loss

Forgetfulness

Depression

Anxiety

Inability to regain balanced  
sugar levels

Dizziness

Vertigo

Spinning sensation

Floating sensation

Inner ear pain

Difficulty concentrating

Loss of sense of smell

Loss of appetite

Weight loss

# Awareness of Long Covid as a Diagnosis

- ▷ In 9 of the 11 groups the majority of participants had not heard of Long COVID, but appreciated having language to describe what they were experiencing.

*...at a UCB Table Talk...that was my first time ever hearing the term “long Covid”. I’ve always felt like these symptoms happened directly after Covid, but I never had like language to kind of express that. It wasn’t Covid, you know, [it was] like an active kind of Covid, but I felt these things, and I’d take a test, and it’d be negative. I was relieved that there was a concept of Covid kind of lingering*

# Awareness of Long Covid as a Diagnosis

- ▷ In the two English language groups participants had heard of long COVID, but felt that it was not part of the main stream discourse.

*In terms of Long Covid. I don't know, people are not, at least in my circles, are not talking about the long term symptoms. I think Covid is some one of these kind of taboo things that you really don't talk about, because you don't want to be alienated or stigmatized. So maybe that's the reason why people are not talking too much about it.*



# Impacts



# “I’m struggling”



*I experienced [shortness of breath] after Covid, ... headaches, ...it's like I'm struggling to get out [of the house]...It's been taxing, and it's been a lot, honestly. ...I just don't have the stamina and the energy early in the morning. I try to get up early and do a little workout and find some energy in a way that usually works. And I do a lot of herbal stuff that helps, but I can definitely see a shift in my mind, I'm cloudy minded like my brain is foggy, and it goes and comes. Some days are better than others. I should have been documenting this stuff, and I didn't because it's just so much going on. But it's like, why am I so foggy minded? Why can't I focus, and things like that?*

# “I feel bad every day”



*The first time I felt bad about Covid was in September and December 2020. Between May and September 2021, my body, I had pain in my muscles and legs, I got dizzy many times, I vomited, I had headaches sometimes. My sinus symptoms never went too. Every symptom, I have it. I feel bad every day, I'm tired. Sometimes I think I'm being crazy because many days I feel bad. For almost the entire year 2021...*

# “... it's harder...”



*...the fatigue is a huge factor as well as the brain fog...I have noticed a huge shift in my ability to sleep and gain rest, feel rested. It could be a nap, or it could be a good eight to ten hours of sleep on a, you know, on a weekend, or even sometimes during the week, because exhaustion is also a factor, and no matter what I do, no matter how I'm sleeping, I cannot wake up and feel rested. ... I also believe my stamina is affected as far as like how I'm able to get through tasks, and how they exhaust me faster than they previously did. Whether It's something as simple as like brushing my teeth, .... Just it's harder. Folding laundry takes longer because it's like I fold three things, and I'm like, Oh, my God! My arms hurt so much! My shoulders are like what's going on here so definitely, I notice an increase in fogginess, fatigue, and, like physical exhaustion, the exertion.*

*“I don’t think that MDs really care. ...I had the same thing with my primary care office, I told them everything I was going through and got nothing.”*

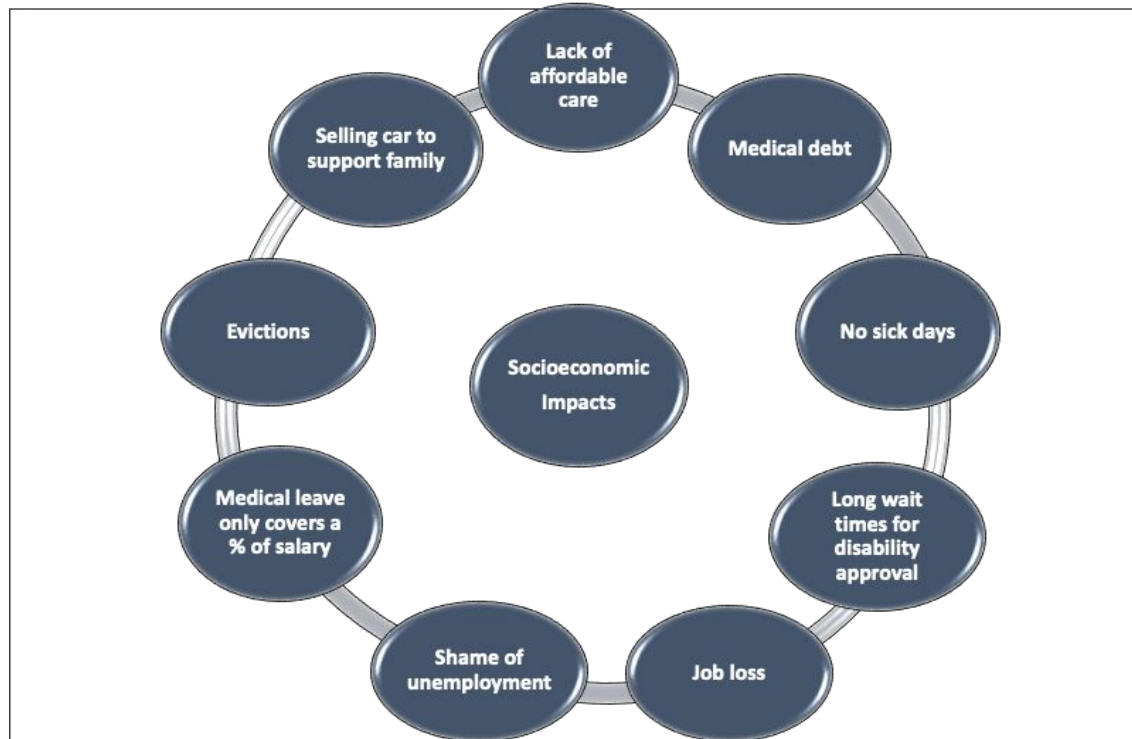
**Health Care**

# “I don’t go anymore”



*I’ve given up. Honestly, I don’t go anymore. I’ve been once or twice like once in urgent care and one time to my primary care doctor, but they couldn’t really do anything for me. They talked about the [long COVID] clinic at [hospital name]. And that was it. They can’t give you resources. They don’t know themselves right so like this is all new to everybody, and this is where organizations need to take that into consideration...how do we better...*

# Impacts on work, family, and socioeconomic conditions



**“I couldn’t get myself completely situated yet.”**



*We had two cars, but we had to sell one. The resource we were getting to help with rent, which stopped ... I didn’t recover to the point where I was able to buy a second car again. I had to sell it [the car] and I was left with one car, I didn’t get back on my feet to the point of being able to get my car back, I couldn’t get myself completely situated yet.*



**“I don't want her to lose her home.”**



*My sister has definitely been impacted in terms of her job. She had to take a short-term leave two times, because she wasn't well...she didn't have the energy and was ...foggy minded, things like that. ... Her mental health is down the drain. I can see it. We all see it, me and my other sister are seeing it .... She doesn't even have the energy to take care of the children. I go to her house...it's upside down ...she has a home. I don't want her to lose her home.*

**“...having a long COVID tends to affect all economic, social, family, and psychological aspects”**



*I am sorry for my relatives with long COVID; they just had to reduce their workload. ...to seek health services, which have a cost associated ... the fees and the payments that must be paid, the time that must be taken away from their work, from their leisure time to be able to go to the therapies. ... having a long COVID tends to affect all economic, social, family, and psychological aspects*

## “...it was hard to fight for disability”



*...I was trying to go through the process of getting approved for disability. I went three months without getting paid and it was hard to fight for disability ... I was a slow and I didn't know what I was doing, ...all this paperwork, calling this doctor and doing this and doing that, and I'm trying to get better at the same time. ...I took a hit on that. ...three months of lost income.*

# LONG COVID IMPACT STUDY

## What is Long Covid?

After Covid-19 infection, some people keep feeling unwell or experiencing symptoms. Long Covid can include Covid symptoms that last for 1-3 months after getting sick with Covid-19, but may also include new symptoms.

### Common symptoms include:

- Extreme tiredness (fatigue)
- Brain fog
- Difficulty breathing
- Chronic Pain
- Mental Health Challenges

## Our Research Process

Our team met with 11 groups of diverse Black and Latinx residents to better understand how Long Covid has impacted their families and communities. Residents also shared recommendations for better Long Covid support in Massachusetts.

## What did residents share with us about Long Covid?

- Many people are experiencing symptoms of Long Covid and feeling unwell but did not know what Long Covid was or how common it is. Lack of information in multiple languages about Long Covid makes accessing resources more difficult.
- Long Covid has made it harder for people to go to work and do other daily activities that they used to be able to do. This has impacted their physical and emotional wellbeing.
- Since many Long Covid symptoms make it harder to work, it has also caused stress because of financial difficulties with paying rent/mortgages, etc.
- Doctors often dismiss symptoms of Long Covid because they also don't have information about Long Covid. There are also limited known treatments for Long Covid currently.
- Difficulties getting referrals and the costs of healthcare are obstacles for addressing Long Covid symptoms.
- Applying for state economic support programs such as long-term disability is currently too challenging because of complex paperwork and diagnostic test requirements.
- Better outreach about symptoms of Long Covid can help Black & Latinx residents advocate for themselves and access support and care.

## Next Steps

It is important that we talk to our friends, families, communities, and leaders about Long Covid to increase awareness so people can seek support.

Our state government has not taken much action to support communities impacted by Long Covid.

If you want to take further action, call your state representative/senator and ask them to pass legislation to support people with Long Covid.

While we urge the State to create resources, you can learn more about Long Covid and some ways to manage it at home through the UK NHS website: <https://www.yourcovidrecovery.nhs.uk/i-think-i-have-long-covid/>

This research was conducted by



# Have you heard about Long Covid?

**HAVE YOU HEARD ABOUT LONG COVID?**

LONG COVID IS REAL.  
You are not alone.




**HAVE YOU HEARD ABOUT LONG COVID?**

LONG COVID IS REAL.  
You are not alone.



**HAVE YOU HEARD ABOUT LONG COVID?**

LONG COVID IS REAL.  
You are not alone.



**HAVE YOU HEARD ABOUT LONG COVID?**

LONG COVID IS REAL.  
You are not alone.



## Why am I still sick?

**I RECOVERED FROM COVID-19. WHY AM I STILL SICK?**

LONG COVID IS REAL.  
You are not alone.



**I RECOVERED FROM COVID-19. WHY AM I STILL SICK?**

LONG COVID IS REAL.  
You are not alone.



**I RECOVERED FROM COVID-19. WHY AM I STILL SICK?**

LONG COVID IS REAL.  
You are not alone.



# Still feeling unwell.


**STILL FEELING UNWELL LONG AFTER HAVING COVID-19?**

LONG COVID IS REAL.  
You are not alone.



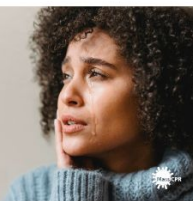
**STILL FEELING UNWELL LONG AFTER HAVING COVID-19?**

LONG COVID IS REAL.  
You are not alone.



**STILL FEELING UNWELL LONG AFTER HAVING COVID-19?**

LONG COVID IS REAL.  
You are not alone.



## You may have Long Covid.

**FATIGUE, HAIR LOSS, HEADACHES, COUGH, FOGGY MIND, DEPRESSION? YOU MAY HAVE LONG COVID.**

LONG COVID IS REAL.  
You are not alone.




**FATIGUE, HAIR LOSS, HEADACHES, COUGH, FOGGY MIND, DEPRESSION? YOU MAY HAVE LONG COVID.**

LONG COVID IS REAL.  
You are not alone.



**FATIGUE, HAIR LOSS, HEADACHES, COUGH, FOGGY MIND, DEPRESSION? YOU MAY HAVE LONG COVID.**

LONG COVID IS REAL.  
You are not alone.



# IMPACTS OF LONG COVID

## A PATIENT PERSPECTIVE

NETIA MCCRAY

EXECUTIVE DIRECTOR, MBADIKA

MA | Part II

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MBADIKA

# IMPACTS OF LONG COVID

## A PATIENT PERSPECTIVE

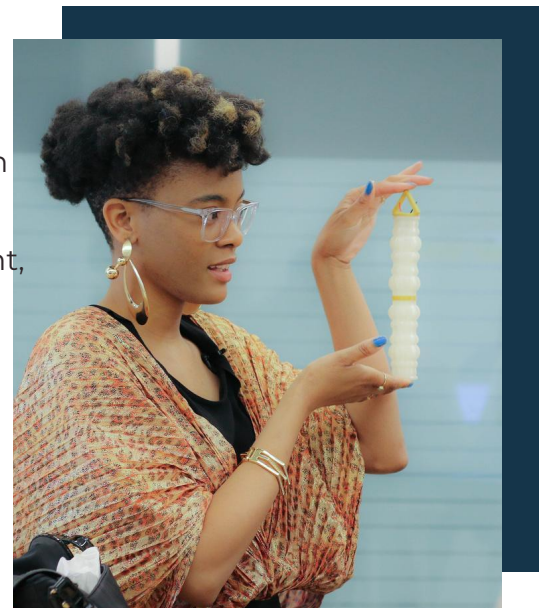
**NETIA MCCRAY**

**EXECUTIVE DIRECTOR, MBADIKA**

Focus on making STEM (Science Technology Engineering Mathematics) education accessible to learners of all ages, including socioeconomically disadvantaged communities, which have been disproportionately affected by various employment, disability, educational, and developmental outcomes.

### Experience

- Executive Director, Mbadika [2010 - Present]
- B.S. Political Science, Massachusetts Institute of Technology (MIT), Class of 2014





MARCH 2020 - PRESENT

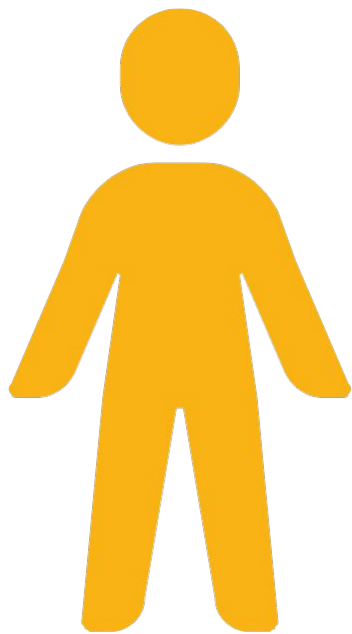
abc NEWS

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**12.2 MILLION**

**WORKING-AGE AMERICANS  
WITH LONG COVID, WHO WERE  
IN LABOR FORCE PRE-COVID.\***

**B** | Brookings Metro

\*New Data Shows Long COVID is keeping as many as 4 million people out of work, Katie Bach, Brookings METRO,

August 24, 2022

<https://www.brookings.edu/research/new-data-shows-long-covid-is-keeping-as-many-as-4-million-people-out-of-w>



15%

**PERCENTAGE OF THE LABOR  
SHORTAGE THAT COULD BE  
EXPLAINED BY WORKING-AGE  
ADULTS WITH LONG COVID.\***

**B** | Brookings Metro

\*New Data Shows Long COVID is keeping as many as 4 million people out of work, Katie Bach, Brookings METRO,

August 24, 2022

<https://www.brookings.edu/research/new-data-shows-long-covid-is-keeping-as-many-as-4-million-people-out-of-w>



**57%**

**PERCENTAGE OF AMERICANS  
WITH LESS THAN \$1,000 IN  
SAVINGS.\***

Survey finds more than half of Americans can't afford a \$1,000 emergency, Shirin Ali, The Hill, January 19, 2022  
<https://thehill.com/changing-america/respect/poverty/590453-survey-finds-over-half-of-americans-cant-afford-a-10>

**FUNCTIONAL LIMITATION  
AND CURRENT [LONG COVID] SYMPTOMS  
WHICH IMPACT DAY-TO-DAY LIFE  
WERE ASSOCIATED WITH  
HIGHER PREVALENCE OF HOUSING INSECURITY.**

\*Association of Long COVID with housing insecurity in the United States, 2022-2023,  
Samuel E. Packard, Ezra Susser, <https://doi.org/10.1101/2023.06.05.23290930>

# \$3,047



## **2024 AVERAGE COST OF A 2-BEDROOM APARTMENT IN BOSTON**

Average Rent for Boston Apartment now over \$3,000, report says, June 21, 2023

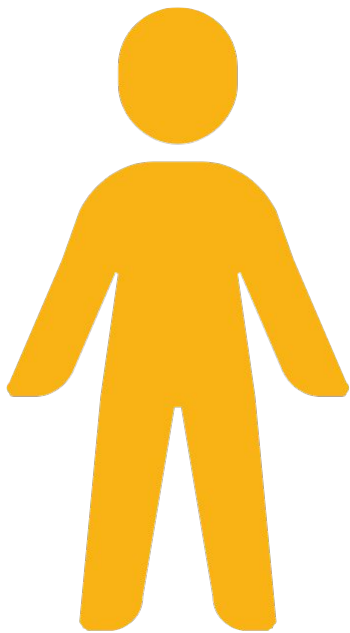
<https://www.wcvb.com/article/average-rent-for-boston-apartment-now-over-dollar3000-report-says/44280426/>

# 4 in 5



**Americans reporting "long COVID" symptoms at least three or more months post infection reporting activity limitations.\*\***

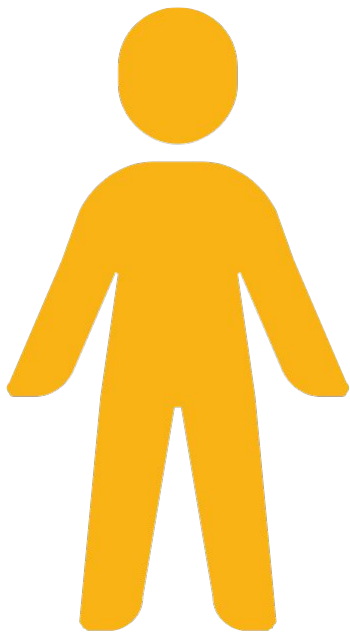
**\*\*U.S. Census Bureau and National Center for Health Statistics, Spring 2023**



2 X

**SIGNIFICANT  
DIFFICULTY WITH  
HOUSING PAYMENTS**

\*Association of Long COVID with housing insecurity in the United States, 2022-2023,  
Samuel E. Packard, Ezra Susser, <https://doi.org/10.1101/2023.06.05.23290930>



2 X

**TO FACE  
EVICTION OR  
FORECLOSURE**

\*Association of Long COVID with housing insecurity in the United States, 2022-2023,  
Samuel E. Packard, Ezra Susser, <https://doi.org/10.1101/2023.06.05.23290930>



# 30 MONTHS



## TIME FROM COVID-19 INFECTION TO DIAGNOSIS

\*From an Anonymous Long COVID Patient. African American Female. Age 30. Bachelor of Science.

**\$435,678**



**TO DATE COST OF  
LONG COVID SYMPTOM DIAGNOSIS,  
MANAGEMENT, AND CARE**

\*From an Anonymous Long COVID Patient. African American Female. Age 30. Bachelor of Science.



**WHAT**

**CAN**

**SHE**

**DO?**

**WHAT**

**CAN**



**SHE**

**DO?**

**WHAT**

**CAN**

**WE**

**DO?**

# 30 MONTHS



## TIME FROM COVID-19 INFECTION TO DIAGNOSIS

\*From an Anonymous Long COVID Patient. African American Female. Age 30. Bachelor of Science.

**MBADIKA**

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# IMPACTS OF LONG COVID

## A PATIENT PERSPECTIVE

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**NETIA MCCRAY**

### LONG COVID PATIENT | ADVOCATE

Focus on making knowledge regarding post-infectious disease and chronic illness accessible to all, including socioeconomically disadvantaged communities, which have been disproportionately affected by COVID and yet remain underrepresented in Long COVID care and treatment.

#### Experience

- Education Director, COVID-19 Longhaulers Advocacy Project
- Patient Advocate, Rep. Ayanna Pressley's TREAT Long COVID Act
- Member, Mount Sinai/Polybio Center for Recovery from Complex Chronic Illness (CoRE) Advisory Board





**WHAT**

**CAN**



**WE**

**DO?**

**WHAT**

**CAN**

**YOU**

**DO?**

**THANK YOU**

**VIRTUAL BRIEFING**

**Long COVID and  
Health Equity  
in the Commonwealth:  
Finding a Path Forward**

**Part 2  
March 11, 2024  
10:00 a.m. – 11:30 a.m.**