

VIRTUAL BRIEFING

Long COVID and Health Equity in the Commonwealth

Part 2: Moving to Policy Solutions

Tuesday, June 25, 2024, 12:00 p.m. – 1:30 p.m.

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

Learn about actions the legislature can take to best support our constituents experiencing Long COVID.

Open to legislators, staff, and members of the public.

Sponsored by

Rep. Mindy Domb
Sen. Jo Comerford

Rep. Marjorie Decker, House Chair, Joint Committee on Public Health

Sen. Julian Cyr, Senate Chair, Joint Committee on Public Health

The MA Black and Latino Legislative Caucus

Register Here!



Speakers: Long COVID

Cheryl Clark, MD, ScD,

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

Michael Curry, Esq.,

President and CEO, Massachusetts League of Community Health Centers

H. Dawn Fukuda, ScM

Assistant Commissioner, Department of Public Health; Director, Bureau of Infectious Disease and Laboratory Sciences (BIDLS)

Jacqui Lindsay

Consultant, Boston COVID Recovery Cohort; Co-Chair of National Community Engagement Group of NIH's national RECOVER research initiative, President, Innovation by Design

Dr. Larry Madoff, MD

Medical Director, Bureau of Infectious Disease and Laboratory Sciences (BIDLS), Department of Public Health

Linda Sprague Martinez, Ph.D.,

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

Netia McCray,

Executive Director, Mbadika

Rep. Mindy Domb



IMPACTS OF

MA



LONG COVID

A PATIENT PERSPECTIVE

NETIA MCCRAY

EXECUTIVE DIRECTOR, MBADIKA

MA

JUNE 2024

MBADIKA

IMPACTS OF LONG COVID

A PATIENT PERSPECTIVE

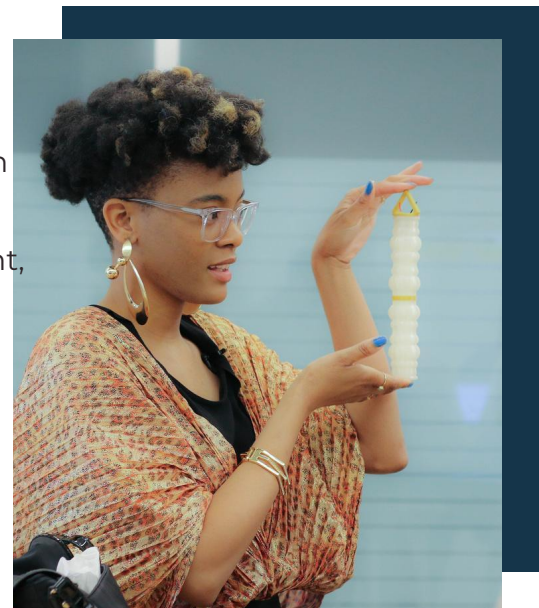
NETIA MCCRAY

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



MAY 2023

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

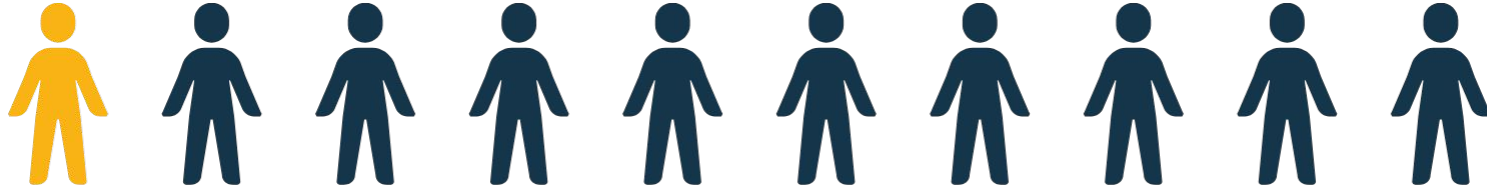
1 in 2



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**

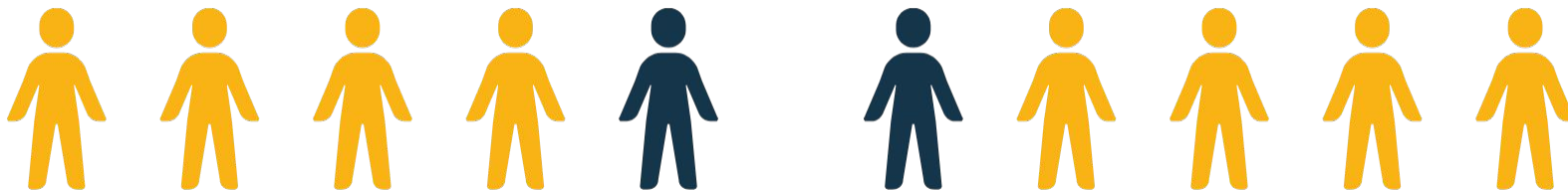
4 in 5



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

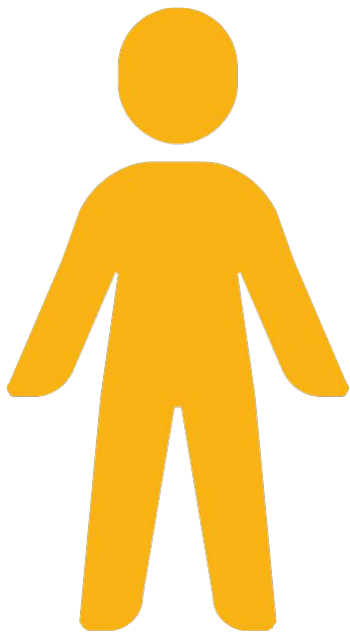
EDUCATION



SOCIOECONOMIC

STATUS

INCOME



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

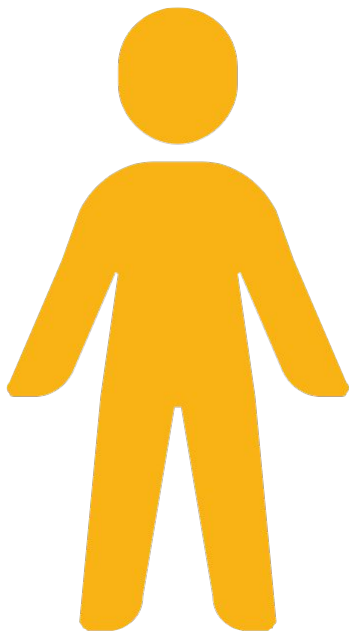
<https://www.wcvb.com/article/average-rent-for-boston-apartment-now-over-dollar3000-report-says/44280426/>

4 in 5



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

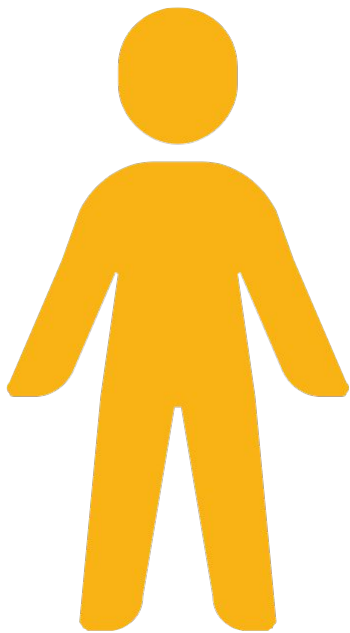
****U.S. Census Bureau and National Center for Health Statistics, Spring 2023**



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?

MBADIKA

IMPACTS OF LONG COVID

A PATIENT PERSPECTIVE

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



SHE

DO?

OCCUPATION

EDUCATION



A diagram with the word "SOCIOECONOMIC" in the center. Two lines extend upwards from its top center to the words "OCCUPATION" and "EDUCATION". A vertical line extends downwards from its bottom center to the words "STATUS" and "INCOME".

SOCIOECONOMIC

STATUS

INCOME

WHAT

CAN

WE

DO?

WHAT

CAN



WE

DO?

WHAT

CAN

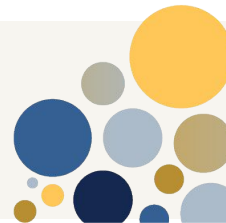
YOU

DO?

THANK YOU

6 Community-Driven Policy Priorities for Systems Change: To Address Long COVID and Advance Health Equity in MA

Recommended by the Boston COVID
Recovery Cohort (BCRC) Community



Overview of 6 Community-Driven Policy Priorities for Systems Change



Develop **a shared definition** of Long COVID



Invest in a **quantitative data infrastructure**



Invest in **qualitative data and stories**



Invest in **clinical care and social support**



Invest in **educating the public & primary care providers**



Invest in a **community-building infrastructure**

1. Develop a shared definition of Long COVID



To inform efforts to address Long COVID and advance health equity, including:

- Continued research
- Clinical care and social support
- Public and community education and engagement
- Advocacy for policy and institutional change

2. Invest in a quantitative data infrastructure



To support statewide data collection, coordination, monitoring, and learning about Long COVID and health equity.

- Support collaboration among public, private, and community-based health care systems.
- Collect and coordinate information across these systems.
- Use this data to monitor how Long COVID is evolving, and to identify whom it impacts and how, across the diverse demographic and geographic communities of our state.

Invest in a quantitative data infrastructure (cont.)



- Use this data to help do ongoing performance review to understand:
 - What testing, mitigation strategies, and equity approaches are working, not working, and for whom.
 - Where and what improvement is needed, and how, to strengthen the health care and health of our diverse communities.

3. Invest in capturing qualitative data and stories from diverse patients and families living with Long COVID



Use their lived experience, knowledge, needs, and priorities to inform:

- Research
- Statewide data collection on Long COVID and health equity
- Public and community education and engagement
- Clinical care and social support
- Advocacy for policy and institutional change
- Advancing health equity

4. Invest in an infrastructure to provide effective and equitable clinical care and social support



Informed by quantitative and qualitative data, clinical care and social support will:

- Address Long COVID.
- Advance health equity.
- Strengthen our primary care system, especially Community health Centers, to integrate and continuously improve the health care and health of the diverse community of our state.

5. Invest in educating the public & PCPs about Long COVID and advancing health equity

To inform effective and equitable clinical care and social support for all.



6. Invest in a community building infrastructure to help achieve these policy priorities for systems change

To improve the health care, health, and participation of our diverse communities in defining and shaping what's needed to achieve these priorities.



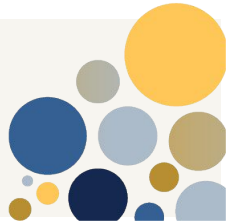


An Initiative Funded by the National Institutes of Health

recoverCOVID.org

Long COVID and Health Equity in the Commonwealth Part 2: Moving to Policy Solutions

June 25, 2024



What are the policy priorities for equity in clinical care and social supports?

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

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

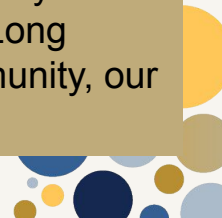
Learn about Long COVID, health equity, and how to better address them.

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.



2024: A **New** Definition for Long COVID

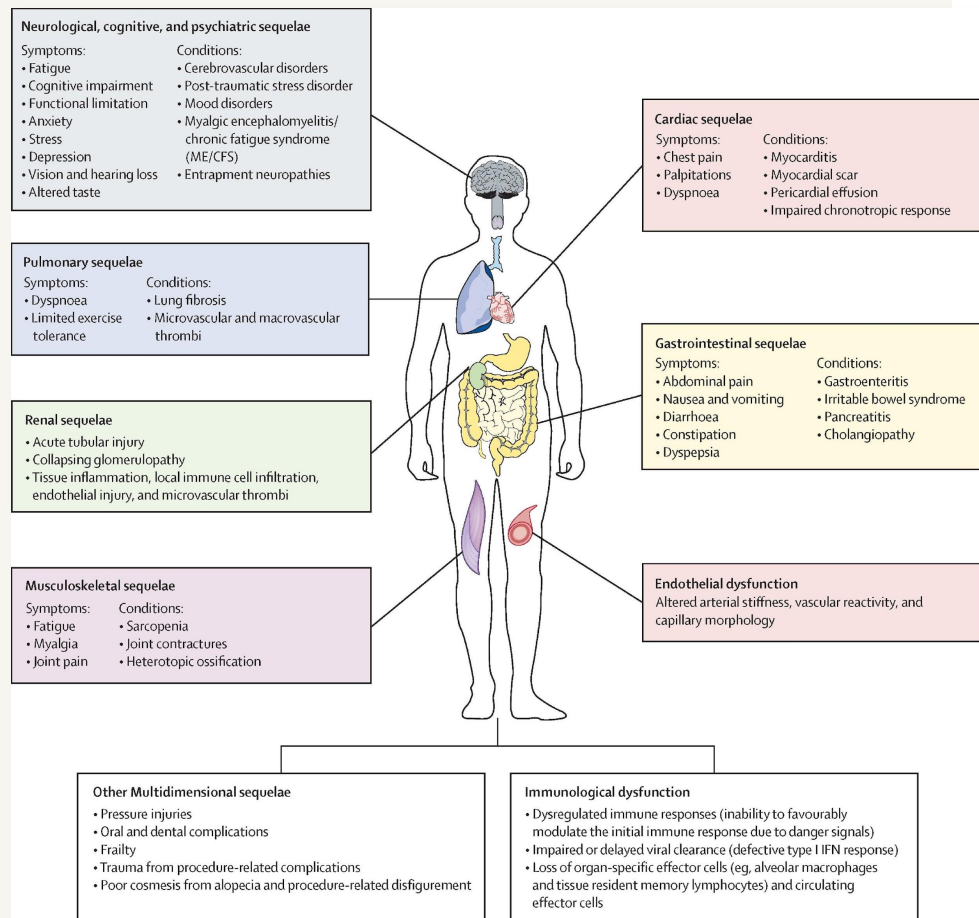
“Long COVID (LC) is an infection-associated **chronic condition** (IACC) that occurs after SARS-CoV-2 infection and is present for at **least 3 months** as a continuous, relapsing and remitting, or progressive disease state that affects **one or more organ systems**.”

- **Timing:** can be *continuous* or delayed after initial infection
- **Involvement:** (Multi)system. With new conditions, or worsen existing conditions
- **Progression:** Can relapse, remit or progress (get better or worsen)
- **Severity:** Possible severe and life-threatening events even months or years after infection. Can affect ability to work and perform self-care



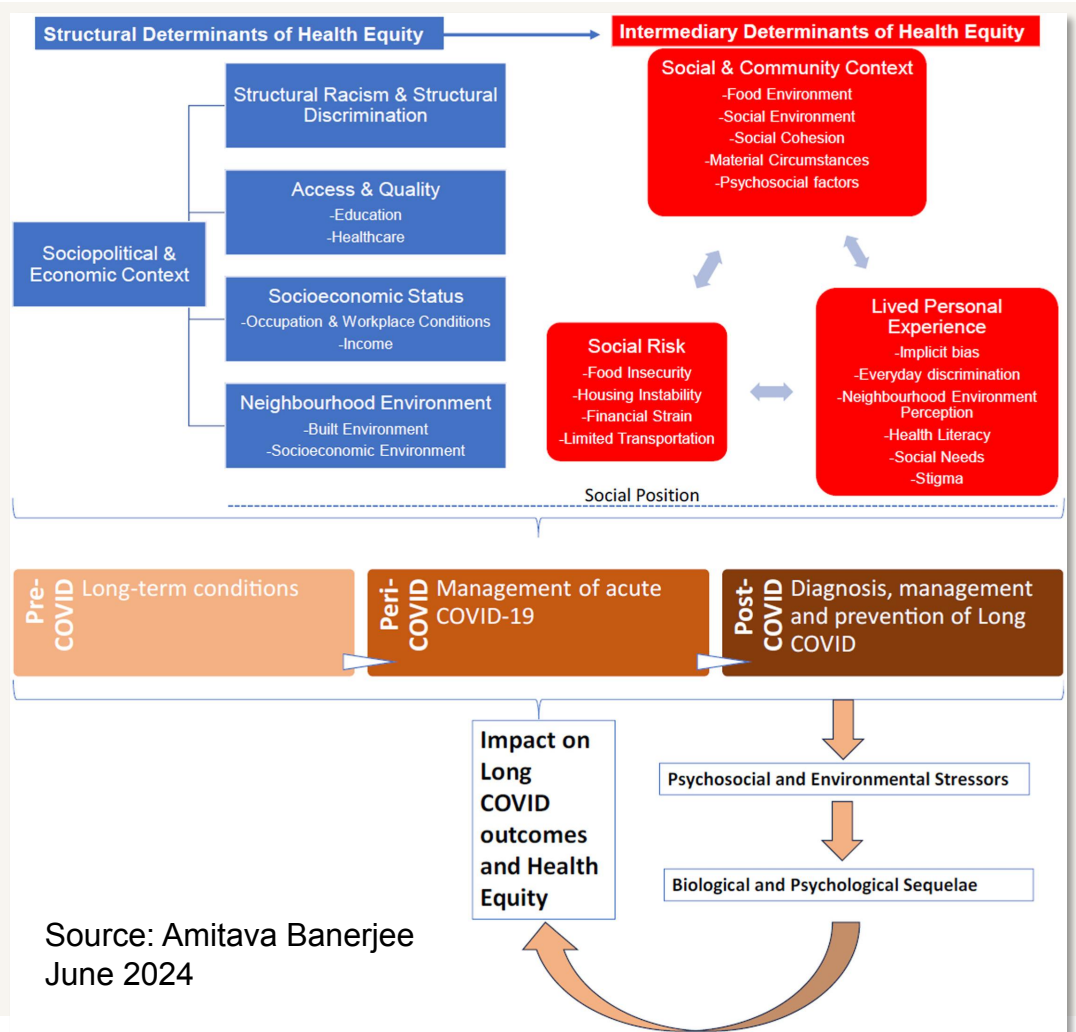
Chronic, multisystem condition: Clinical Implications

- Longitudinal care
- Multi-disciplinary care
- Coordinated, integrated care



Source: Parotto et al
Lancet Resp. Med 2023

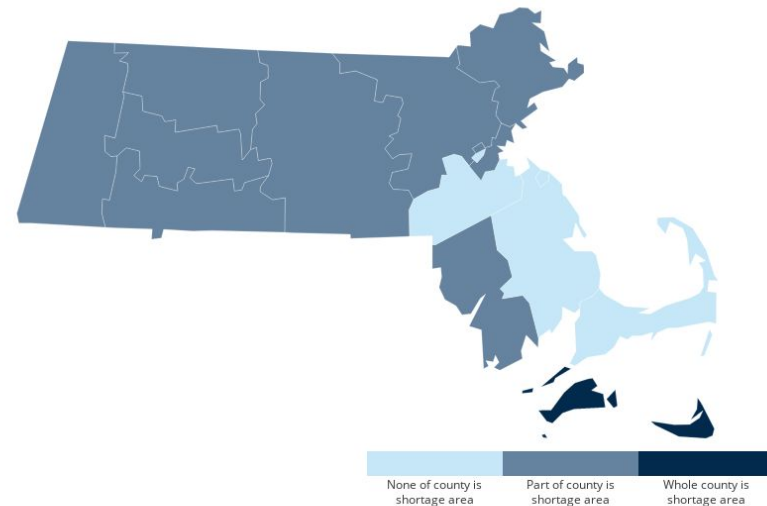
Chronic, multisystem condition: social implications



Priority #1: Invest in Primary Care Access in Massachusetts

- Geographic access
- Demographic disparities
- Socioeconomic access
 - Community Health Centers

Health Professional Shortage Areas: Primary Care, by County, April 2024 - Massachusetts



Source: data.HRSA.gov, April 2024.

Primary Care Access Matters for Equity



EQUITY

Metrics focused on assessing inequities in the system



FINANCE



CAPACITY



ACCESS



CARE

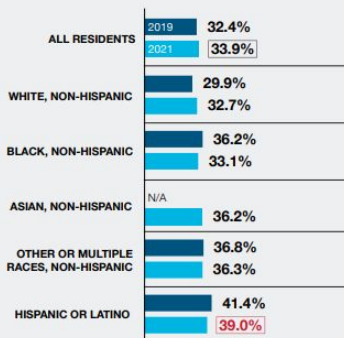


EQUITY

Difficulty Obtaining Necessary Health Care, by Race/Ethnicity

Percentage of Massachusetts residents who reported that they had difficulty obtaining necessary health care in the past 12 months, stratified by resident race/ethnicity.

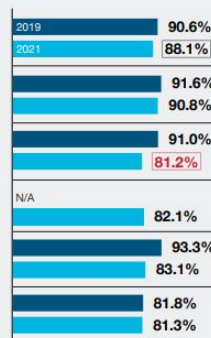
Lower is better.



Usual Source of Care, by Race/Ethnicity

Percentage of Massachusetts residents who reported that they have a usual source of care, stratified by resident race/ethnicity.

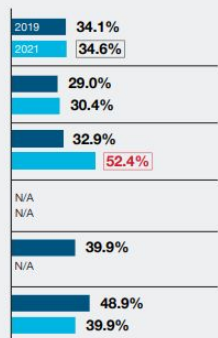
Higher is better.



Avoidable Emergency Department (ED) Use, by Race/Ethnicity

Of Massachusetts residents who had at least one ED visit in the past 12 months, percentage who reported that their most recent ED visit could have been treated by a general doctor if one had been available, stratified by resident race/ethnicity.

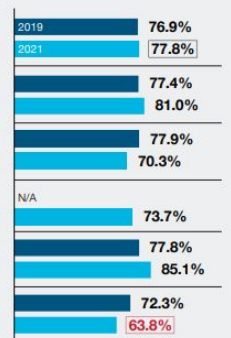
Lower is better.



Preventive Care Visit, by Race/Ethnicity

Percentage of Massachusetts residents who reported that they had a visit to a general doctor, nurse practitioner, physician's assistant, or midwife for preventive care in past 12 months, stratified by resident race/ethnicity.

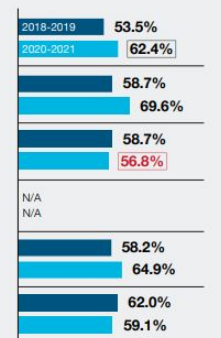
Higher is better.



Adult Influenza Vaccinations, by Race/Ethnicity

Percentage of Massachusetts adult residents (18+) who received the seasonal influenza vaccination in the past 12 months, stratified by race/ethnicity.

Higher is better.

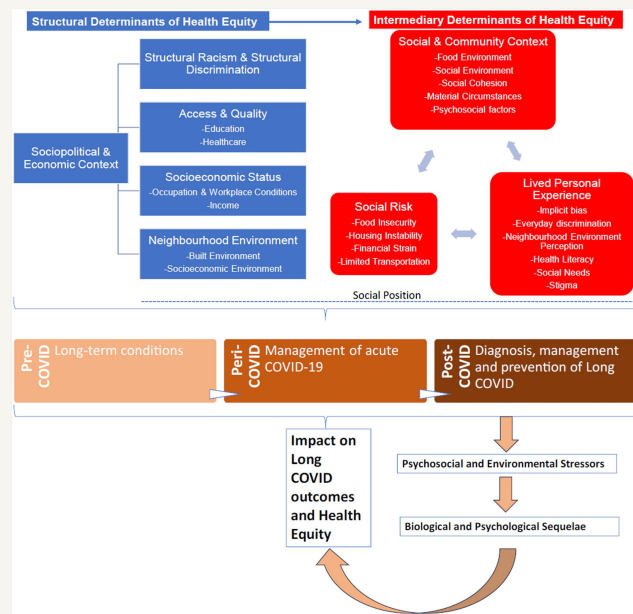


For at-a-glance health outcomes measures in Massachusetts, see the [context page](#). For additional information on the metrics displayed above, including data sources, see [technical appendix](#) and [databook](#).

Note: Red boxes identify worst performing percentage for each metric compared with percentages for all residents (gray boxes) for each metric in 2021. In 2019, "Asian, non-Hispanic" residents were reported as part of the "Other or multiple races, non-Hispanic" group. 2021 values for "Asian, non-Hispanic" and "Other or multiple races, non-Hispanic" were suppressed due to small sample size.

Priority #2: Promote a Diverse Primary Care Workforce

- Community Health Workers
- Mental Health workforce
- Multicultural workforce



SDOH: Community Health Workers in COVID

\$340M
investment from
Centers for
Disease Control
and Prevention*

- **787,000** referrals made to health care services and social services
- **16.9 million** people served by education and messaging



**Community Health Workers for
COVID Response and Resilient
Communities (CCR)**

***Boston, Brockton, Chelsea, Everett, Lowell, Malden, Revere,
Springfield, Worcester**

Recommendation #2: Promote a Diverse Primary Care Workforce – Mental Health

Investments to watch:

- City of Boston -\$21 Million (American Rescue Plan Act, ARPA funds)
 - City school support
 - Training behavioral health clinicians
- Scale successful strategies

Persistent Sadness Among Boston Public High School Students (2021)

43%

Recommendation #2: Promote a Diverse Primary Care Workforce – Multicultural Workforce

Investments to watch:

MA Repay loan repayment

- Behavioral Health and primary care
- Continuous skilled nursing
- Department of Mental Health
- Human Service/Home Health Workers



Summary: Equity in Long COVID requires equity in healthcare and social care

Three take home points:

- **New Definition**
 - Chronic, multisystem condition with clinical and social implications
- **Priorities** in healthcare
 - Primary care access, sustainability and workforce diversity
- **Interventions** to watch in Massachusetts
 - Community health worker investments
 - Mental health training for child mental health
 - Multicultural workforce investments, loan repayment



An Initiative Funded by the National Institutes of Health

recoverCOVID.org



UConn HEALTH

HEALTH DISPARITIES
INSTITUTE

Long COVID Policy Recommendations: An Equity Approach

A presentation for the
Massachusetts Legislature
by

Linda Sprague Martinez, PhD
Professor of Medicine and Public Health Sciences
Director of the UConn Health Disparities Institute

Champion Justice

Dismantle Racism

*Advance Health
Equity*

Develop a shared definition of Long COVID

Good News! June 11th NASEM released the definition.

- Adopt the proposed definition that includes the equity framing from the report.
- Develop and distribute the definition and guidelines for ensuring Long COVID equity to professional organizations and health care delivery organizations across Massachusetts.

2024 NASEM LONG COVID DEFINITION

Long COVID is an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.

1. Attribution to Infection



No laboratory confirmation or other proof of initial SARS-CoV-2 infection required.

Can follow SARS-CoV-2 infections of any severity, including asymptomatic.



2. Onset and Duration



Must be present for at least 3 months.

Can be continuous from or delayed in onset following acute SARS-CoV-2 infection.



3. Symptoms

More than 200 symptoms and conditions possible, including exacerbation of pre-existing conditions.

Can affect one or more organ systems.

Can range from mild to severe and resolve over a period of months or persist for months or years.

No symptoms or conditions included in the definition are required or exclusionary.



4. Equity

Can affect children and adults, regardless of health, disability, or socioeconomic status, age, sex, gender, sexual orientation, race, ethnicity, or geographic location.



5. Functional Impairment

Can have profound emotional and physical impact and affect ability to work, attend school, take care of family, and practice self care.



Invest in educating the public plus primary care providers (PCPs) about Long COVID and advancing health equity

- Establish shared leadership Long COVID communications working group that this intergovernmental, cross sector and community led.
 - Develop a state Long COVID webpage.
 - Launch a multilingual educational campaign to share and promote the definition as well as information about Long COVID among the public and providers.
 - Evaluate and monitor the campaign.



Invest in an infrastructure to provide effective and equitable clinical care and social supports

- Pass legislation guarantees all MA residents paid time off.
- Develop and disseminate guidelines for supporting MA residents with Long COVID with specific messaging directed to:
 - Employers
 - School Districts
 - Health Professionals
 - Insurers
 - Other relevant state offices
- Establish a mechanism for reporting barriers to treatment and supportive services (Long COVID 311).
- Monitor and evaluate all activities.
- Assess racial and ethnic as well as geographic variation in access to treatment and supportive services.



Long COVID: A Guide for Health Professionals on Providing Medical Evidence for Social Security Disability Claims



Invest in data infrastructure

- There is a need for qualitative as well as quantitative data.
- These data systems need to be integrated.
- Ensure data collection systems established provide opportunities for patients to share their experiences.



Massachusetts Department of Public Health

Public Health Efforts and Opportunities Long COVID Response in Massachusetts

June 25, 2024

H. Dawn Fukuda, ScM, Bureau Director
Larry Madoff, MD, Medical Director

**DPH Bureau of Infectious Disease and Laboratory Sciences
Massachusetts Department of Public Health**

Long COVID – Definition from National Academies of Science Engineering Medicine (NASEM)

Long COVID (LC) is:

- an ***infection-associated, chronic*** condition (IACC)
- that occurs ***after*** SARS-CoV-2 infection* and
- is present for ***at least 3 months***
- a ***continuous, relapsing and remitting, or progressive*** disease state
- that affects ***one or more organ systems***.

(*) The definition does not require laboratory confirmation or other proof of initial SARS-CoV-2 infection.

Assessing Responsive Services

Long COVID Manifestations (partial list)

Respiratory

Shortness of breath, cough, interstitial lung disease and hypoxemia

Neurological

Difficulty concentrating, memory changes, problems with taste or smell, cognitive impairment, mood disorders, anxiety

Cardiac

Fast heart rate, cardiovascular disease and arrhythmias, blood clots, stroke,

Gastrointestinal

Bloating, constipation, and diarrhea.

Metabolic

Diabetes, hyperlipidemia

Autoimmune disorders

Lupus, rheumatoid arthritis, and Sjogren's syndrome

Other organ systems

Chronic kidney disease, postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), mast cell activation syndrome (MCAS), fibromyalgia, connective tissue diseases..

General

persistent fatigue, post-exertional malaise, sleep disturbance, recurring headache, light headedness, migraines

Rationale for public health study and action

- It is important for public health authorities to monitor the burden of Long COVID, as it likely has massive **social, economic, & health** impacts.
- This requires development of a **case definition**.
- However, **there is no standardized medical definition of Long COVID**.
- Additionally, **algorithms to classify cases of Long COVID in clinical datasets are highly heterogenous**.
- Given that Long COVID is defined by ongoing symptoms (and currently no lab tests), algorithms based on symptoms can be utilized.
- Further, the data leveraged for this surveillance should be **timely, cover a large, representative population**, and be **inexpensive**.

Partnership is foundational to implement Long COVID response

DPH efforts are one of multiple parts of the Long COVID response, alongside:

- Clinicians (adult and pediatric)
- Advocates
- Researchers
- Educators
- Legal Experts
- Community Members
- Federal, state, and local government/agencies
- Others

Current DPH Activities—COVID Response

- COVID Community Impact Survey (CCIS)
- Research to establish surveillance of Long COVID
- Long COVID Education and information (new webpage coming soon)
- COVID-19 Respiratory Dashboard
- Clinical guidance and recommendations
- Access to PPE from State Warehouse
- Vaccination (community-based, mobile, and in-home)
- Vaccine Equity Initiative (VEI)
- COVID-19 tests
- Telehealth/Medical Consultation
- Partnerships with Community Health Centers, Local Boards of Health, and Community-Based (CBO), Faith-Based (FBO), and Tribal Indigenous People Serving Organizations (TIPSO).

Building Long COVID Response Capacity

Estimated 350,000 Massachusetts residents may have Long COVID

Up to 3 in 10 adults who had COVID, report Long COVID

Highest rates of Long COVID are reported in adults who are transgender and those with disabilities

Long COVID has socioeconomic impacts including food insecurity, difficulty paying rent or mortgage, and interruptions in employment

Specialized state and federal resource base for COVID response is declining

Options for Long COVID Response

Prevent COVID infection through prevention and vaccination

Raise awareness

Inventory and promote supportive resources

Facilitate access to clinical/medical care and treatments

Include psychological interventions

Share information and educational resource

Specialized benefits advocacy and counseling

Disability Entitlements, when applicable

Models for Long COVID response

- Disability communities
- Specialized foundations
- Ryan White HIV/AIDS Program
- Veteran's Administration
- Family Planning Clinics
- Hemophilia Treatment Centers
- Substance Use Treatment Programs
- Community Health Centers
- State and Local Public Health agencies
- Local, State, and Federal Funding

Discussion



Connect with DPH



@MassDPH



Massachusetts Department of Public Health



mass.gov/dph