WEBINAR
LONG COVID

January 20, 2023
12:00pm - 1:00pm

FEATURING

Bruce Levy, MD
Brigham and Women's Hospital |
Harvard Medical School

Linda Sprague Martinez, PhD
Boston University, School
of Social Work

HOSTED BY

Rep. Mindy Domb

Jessica Collins

PUBLIC **HEALTH** INSTITUTE
OF WESTERN MASSACHUSETTS
PARTNERS FOR HEALTH EQUITY

Long COVID

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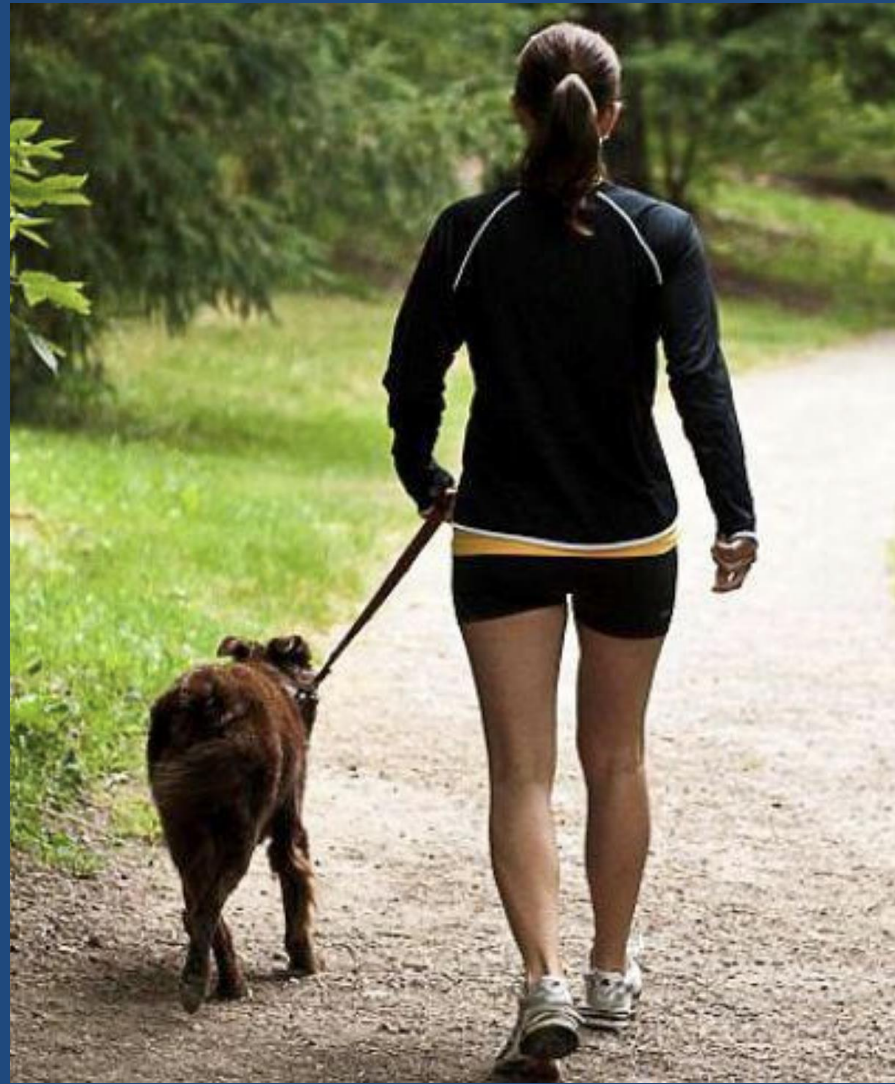Brigham and Women's Hospital/Harvard Medical School

Public Health Institute of Western Massachusetts

January 20, 2023

BWH BRIGHAM AND WOMEN'S HOSPITAL | The Lung Center |

PARTNERS ASTHMA CENTER
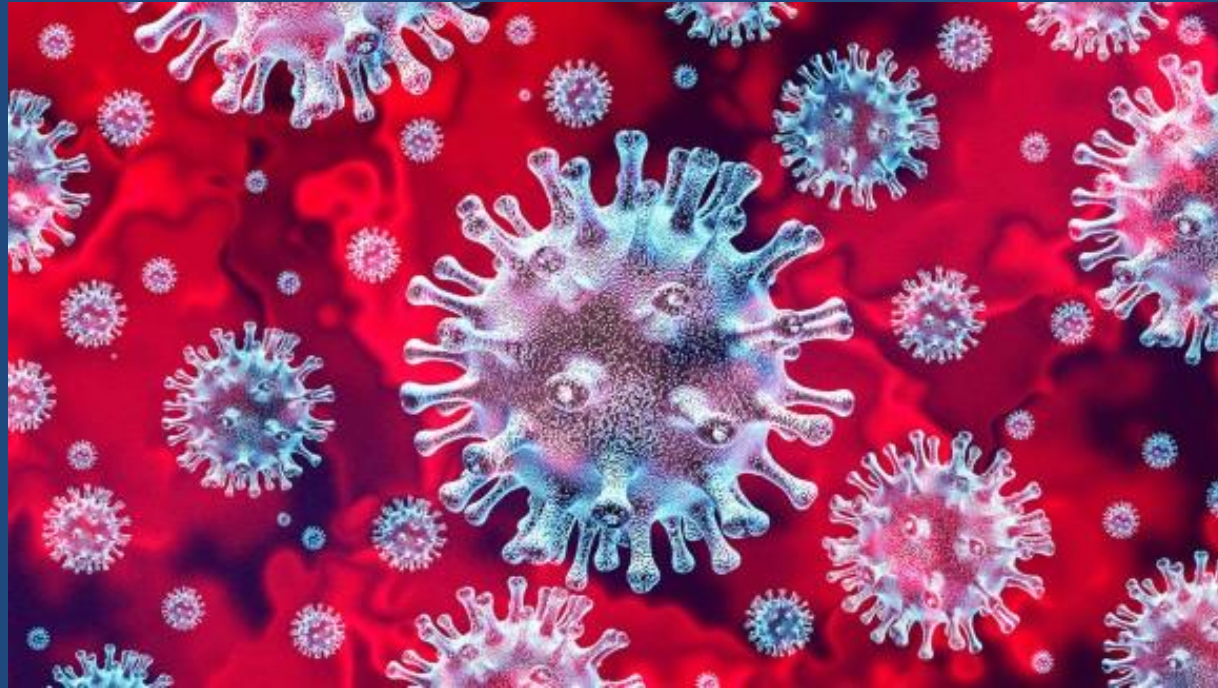
HARVARD MEDICAL SCHOOL *TEACHING AFFILATE*

Understanding COVID-19

Treatments for COVID-19

Vaccines

Intravenous medications

Anti-viral medications

Therapeutic anticoagulation

Long COVID/PASC – "A Post-Pandemic" Pandemic

Persistent Symptoms in Patients After Acute COVID-19

Angelo Carfì, MD[1]; Roberto Bernabei, MD[1]; Francesco Landi, MD, PhD[1]; et al

Author Affiliations | Article Information

COVID-19'S LASTING MISERY

Months after infection with SARS-CoV-2, some people are still battling fatigue, lung damage and an array of other symptoms. By Michael Marshall

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Long-term Health Consequences of COVID-19

VIEWPOINT

Carlos del Rio, MD
Division of Infectious Diseases, Department of Internal Medicine, Emory University School of Medicine, Atlanta, Georgia.

Lauren F. Collins, MD
Division of Infectious Diseases, Department of Internal Medicine, Emory University School of Medicine, Atlanta, Georgia.

Preeti Malani, MD, MSJ
Division of Infectious Diseases, Department of Internal Medicine, University of Michigan, Ann Arbor; and Associate Editor, JAMA.

With more than 30 million documented infections and 1 million deaths worldwide, the coronavirus disease 2019 (COVID-19) pandemic continues unabated. The clinical spectrum of severe acute respiratory syndrome coronavirus (SARS-CoV) 2 infection ranges from asymptomatic infection to life-threatening and fatal disease. Current estimates are that approximately 20 million people globally have "recovered"; however, clinicians are observing and reading reports of patients with persistent severe symptoms and even substantial end-organ dysfunction after SARS-CoV-2 infection. Because COVID-19 is a new disease, much about the clinical course remains uncertain—in particular, the possible long-term health consequences, if any.

Epidemiology
Currently, there is no consensus definition of postacute COVID-19. Based on the COVID Symptom Study, in which more than 4 million people in the US, UK and Sweden have entered their symptoms after a COVID-19 diagnosis, postacute COVID-19 is defined as the presence of

tion among a random sample of 292 adults (≥18 years) who had a positive outpatient test result for SARS-CoV-2 by reverse transcriptase–polymerase chain reaction, 35% of 274 symptomatic respondents reported not having returned to their usual state of health 2 weeks or more after testing, including 26% among those aged 18-34 years (n = 85), 32% among those aged 35-49 years (n = 96), and 47% among those aged 50 years or older (n = 89).[4] Older than 50 years and the presence of 3 or more chronic medical conditions were associated with not returning to usual health within 14 to 21 days after receiving a positive test result. Notwithstanding, 1 in 5 individuals aged 18-34 years without chronic medical conditions had not yet achieved baseline health when interviewed at a median of 16 days from the testing date.

Manifestations
The most commonly reported symptoms after acute COVID-19 are fatigue and dyspnea. Other common symptoms include joint pain and chest pain.[3] In addition to these general symptoms, specific organ

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Symptom Duration and Risk Factors for Delayed Return to Usual Health Among Outpatients with COVID-19 in a Multistate Health Care Systems Network — United States, March–June 2020

Mark W. Tenforde, MD, PhD[1]; Sara S. Kim, MPH[1,2]; Christopher J. Lindsell, PhD[3]; Erica Billig Rose, PhD[1]; Nathan I. Shapiro, MD[4]; D. Clark Files, MD[5]; Kevin W. Gibbs, MD[5]; Heidi L. Erickson, MD[6]; Jay S. Steingrub, MD[7]; Howard A. Smithline, MD[7]; Michelle N. Gong, MD[8]; Michael S. Aboodi, MD[8]; Matthew C. Exline, MD[9]; Daniel J. Henning, MD[10]; Jennifer G. Wilson, MD[11]; Akram Khan, MD[12]; Nida Qadir, MD[13]; Samuel M. Brown, MD[14]; Ithan D. Peltan, MD[14]; Todd W. Rice, MD[3]; David N. Hager, MD, PhD[15]; Adit A. Ginde, MD[16]; William B. Stubblefield, MD[3]; Manish M. Patel, MD[1]; Wesley H. Self, MD[3]; Leora R. Feldstein, PhD[1]; IVY Network Investigators; CDC COVID-19 Response Team
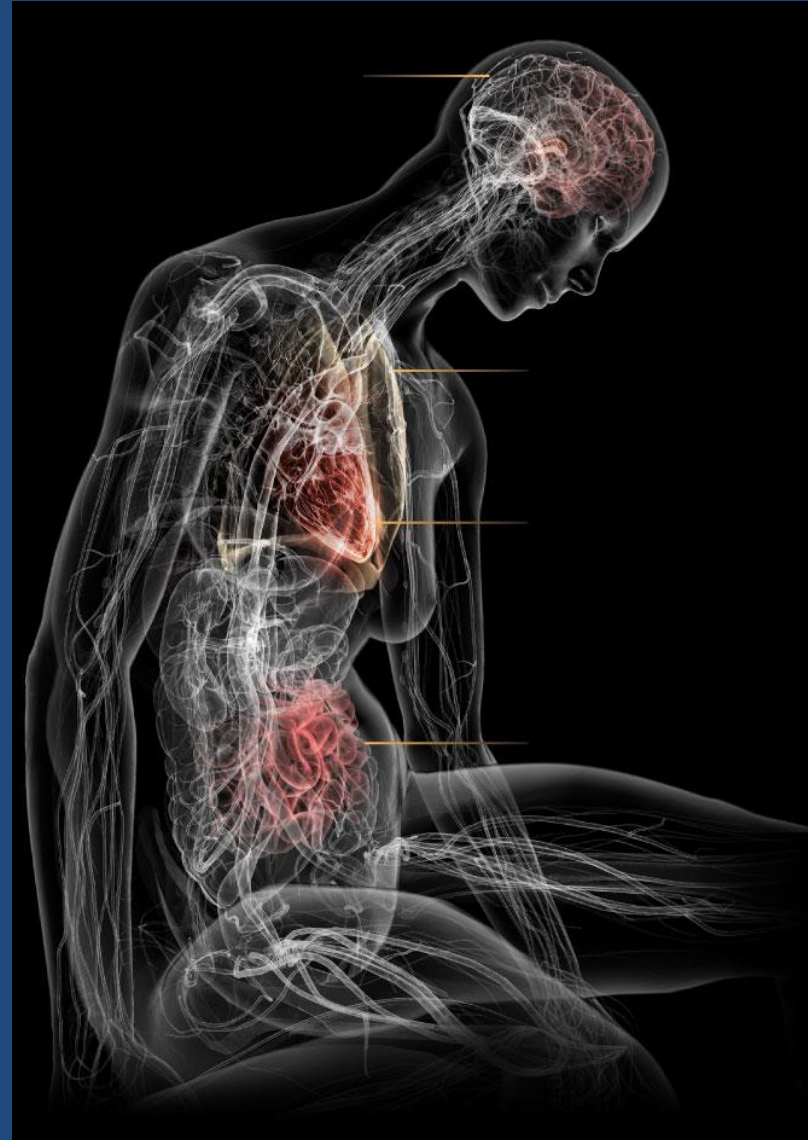

COVID Symptoms, Symptom Clusters, and Predictors for Becoming a Long-Hauler: Looking for Clarity in the Haze of the Pandemic
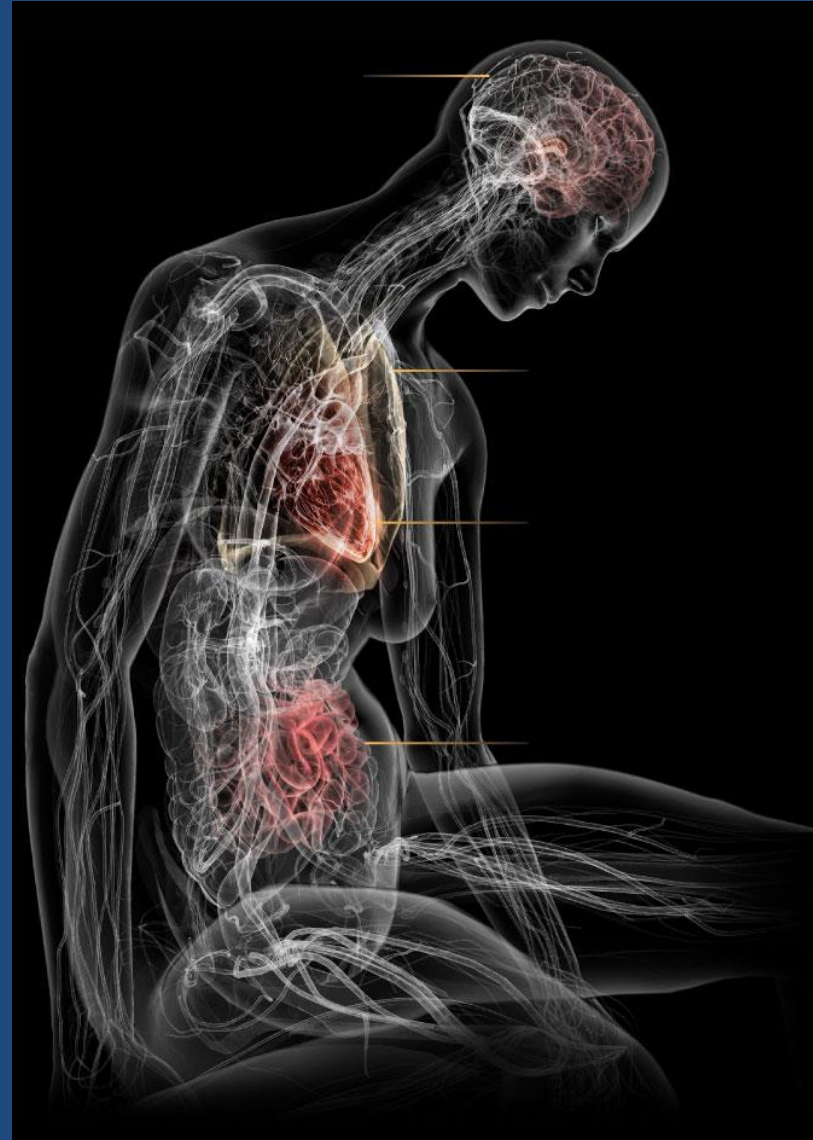
Yong Huang, Melissa D Pinto, Jessica L Borelli, Milad Asgari Mehrabadi, Heather Abrihim, Nikil Dutt, Natalie Lambert, Erika L Nurmi, Rana Chakraborty, Amir M Rahmani, Charles A Downs

Post-Acute Sequelae of SARS-CoV-2 Infection

Long COVID

Long COVID Symptoms

Fatigue

Muscle weakness & joint pain

Brain fog & headache

Anxiety & depression

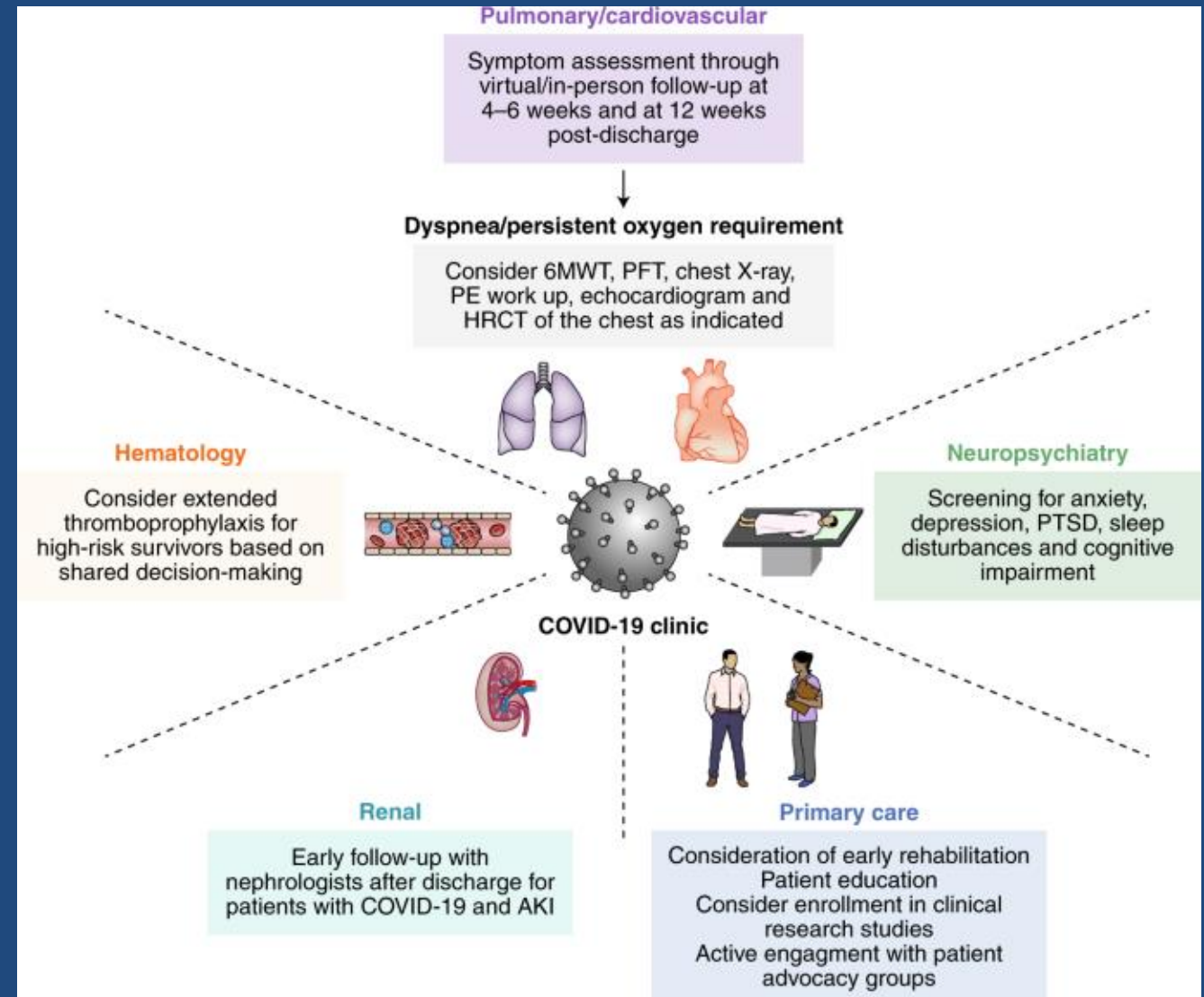Long-term loss of smell & taste

Long COVID Patient Impact

Women

to

Men

Proposed CARE is COSTLY and not easily accessible

Brigham launches COVID Recovery Center

BWH CRC Analysis - 2022

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, not utilize interpreter services, and have commercial insurance

	Cluster			P-value
	1	2	3	
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

BWH CRC Analysis - 2022

Compared to Cluster 2:

- Cluster 1- more ICU stays and symptoms, but less likely to access support groups, care coordination and mental health education

- 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
ICU Admission	3.87 (1.84 - 8.14) *	<.0001	1.5 (0.674 - 3.33)	0.32
Symptom Report				
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
Type of Social Services Support				
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

MASSACHUSETTS GENERAL HOSPITAL

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BOSTON MEDICAL CENTER
EXCEPTIONAL CARE. WITHOUT EXCEPTION.

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BWH BRIGHAM AND WOMEN'S HOSPITAL

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The Greater Boston Covid-19 Recovery Cohort (BCRC)

- >16,000 Covid inpatients
- >123,000 Covid outpatients

CHA Cambridge Health Alliance

Site Lead:
Janice John

The national COVID recovery effort

The Boston Globe
1872 · 2022
Serving our community for 150 years

Boston hospitals to participate in national study of long COVID

By Felice J. Freyer Globe Staff, Updated March 7, 2022, 10:20 a.m.

BRIGHAM AND WOMEN'S HOSPITAL

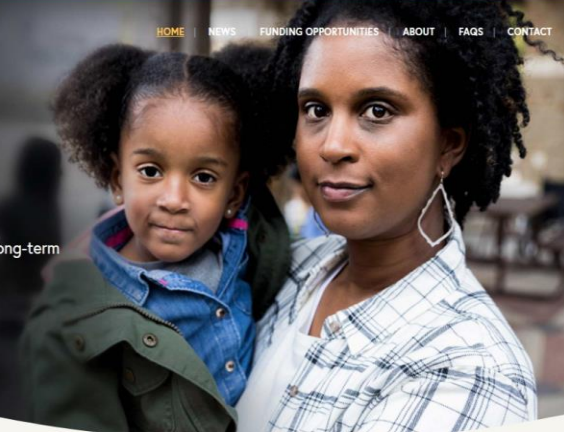Interested in volunteering for RECOVER studies? Sign up and be notified when studies open for enrollment.

RECOVER
Researching COVID to Enhance Recovery

HOME | NEWS | FUNDING OPPORTUNITIES | ABOUT | FAQS | CONTACT

RECOVER: Researching COVID
to Enhance Recovery

We're building a nationwide study population to support research on the long-term effects of COVID-19. Join the search for answers.

LEARN MORE

RECOVER, a research initiative from the National Institutes of Health (NIH), seeks to understand, prevent, and treat PASC, including Long COVID. PASC stands for post-acute sequelae of SARS-CoV-2 and is a term scientists are using to study the potential consequences of a SARS-CoV-2 infection.

RECOVER Adult Cohort

RECOVER
Researching COVID to Enhance Recovery

An Initiative Funded by the National Institutes of Health

What is the case definition?

What is the prognosis?

What is the right care?

Who is at greatest risk?

What is caused by the virus vs severe illness?

What are the disease driving mechanisms?

Graphics credit: Isabel Healthcare
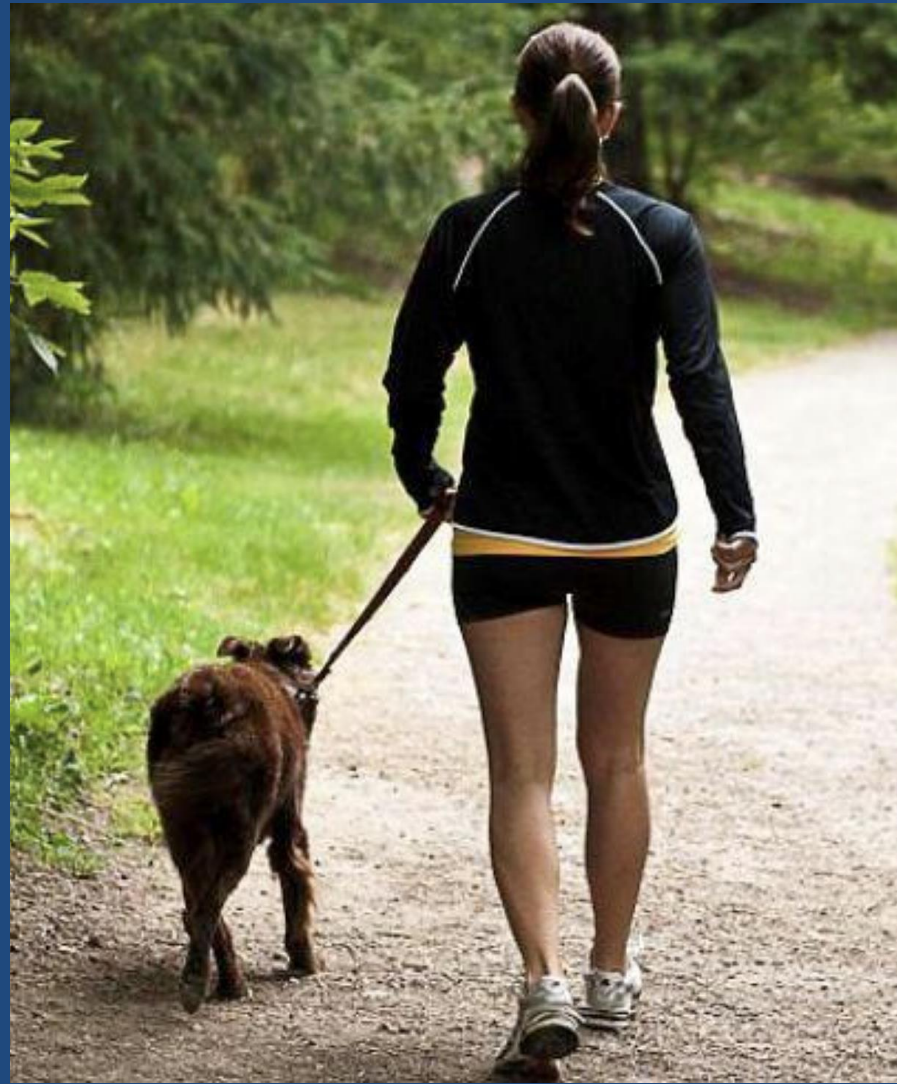
OUR NEXT PUBLIC Health Disaster?

- 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.

Fischer, Kai, J. James Reade, and W. Benedikt Schmal. No. 368. DICE Discussion Paper, 2021.

Cutler, David M. *JAMA Health Forum*. Vol. 3. No. 5. American Medical Association, 2022.

Keeping equity at the center of COVID recovery

Long Covid Impacts on Diverse Communities in Massachusetts

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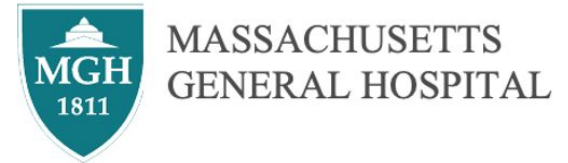
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Rebecca Lobb, *Boston University School of Medicine, Clinical and Translational Science Institute*

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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

Current Scope: Focus on Diverse Black and Latinx communities, with the plan to expand and engage other minoritized and marginalized groups in Massachusetts

Long Covid Care Site Assessments

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

Layer 1 Legend: Confirmed COVID cases per 100k population by MA county

- 0 - 16,732
- 16,732 - 20,091
- 20,091 - 22,330
- 23,930 - 25,524
- 25,524 - 27,300
- 27,300 - 29,913

Layer 2 Legend: Long COVID Resources in Massachusetts

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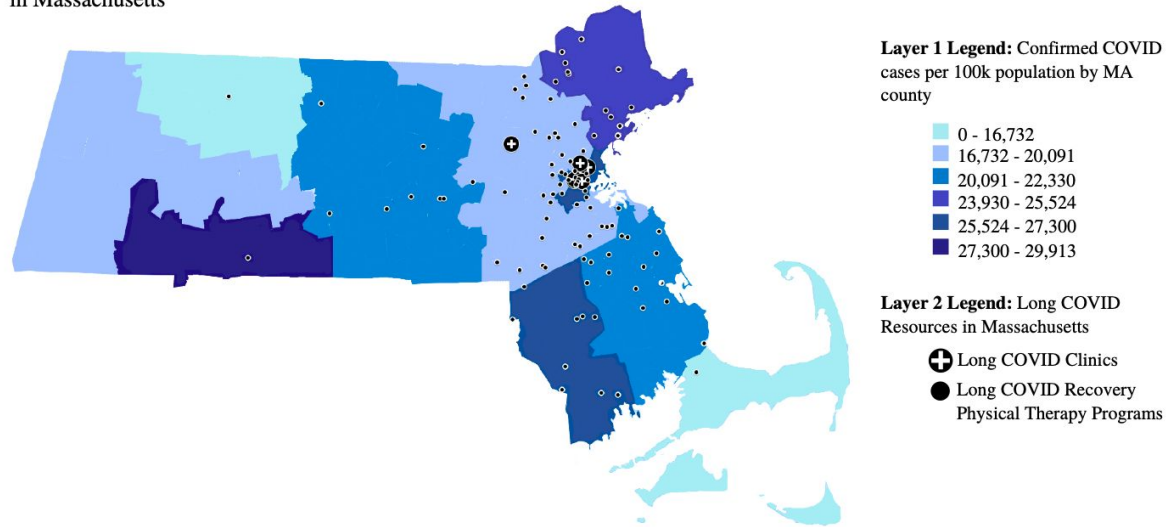
Note. Data source: Coronavirus COVID-19 Global Cases by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University; the Census American Community Survey; the Department of Health and Human Services; and the Bureau of Labor and Statistics. Retrieved from https://coronavirus.jhu.edu/us-map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

- **Conducted Zoom interviews** with clinic directors (n=5), 30-45 minutes via Zoom with a prepared set of questions
- Spoke with **all currently operating clinics** in the state (excluding physical therapy-only sites) focused on **adult care**

Site Assessment Findings: Patient Demographics

Themes from clinics where data was captured (many don't have the administrative capacity to track this information)

- An estimated 70-90% of patients at academic medical center clinics are white

- 80-90+% speak English as their primary language
  - Only small percentage list Spanish as their primary language; huge shift from the population that was seen in the ICU during the first surge

- Majority of patients at academic medical center clinics have private insurance

- Median age ranges from 40-60

Site Assessment Findings: Care Delivery Models

- Only one program had an emphasis on long-term follow up through primary care providers; all other programs had **limited contact with PCPs**

- Most programs could only see patients for **one to two** visits (excluding intake)

- All program directors emphasized the importance of having **social workers** to support patients with resource navigation and mental health challenges

Long Covid Impact Assessment

- Goal: to explore the impact of Long Covid on diverse communities across MA

- 8-10 participants per focus group, either individuals experiencing Long Covid themselves or caring for someone with Long Covid

Methods:
- Sampling
- Recruitment
- Procedures
- Data Management
- Analysis

Thematic Analysis

| Immersion in data to identify meaningful patterns | → | Code Development & Text labeling | → | Identification of meaningful themes |

| Refinement of themes | → | Identification of the the larger story | → | Selection of illustrative quotes |

Braun & Clark, 2006
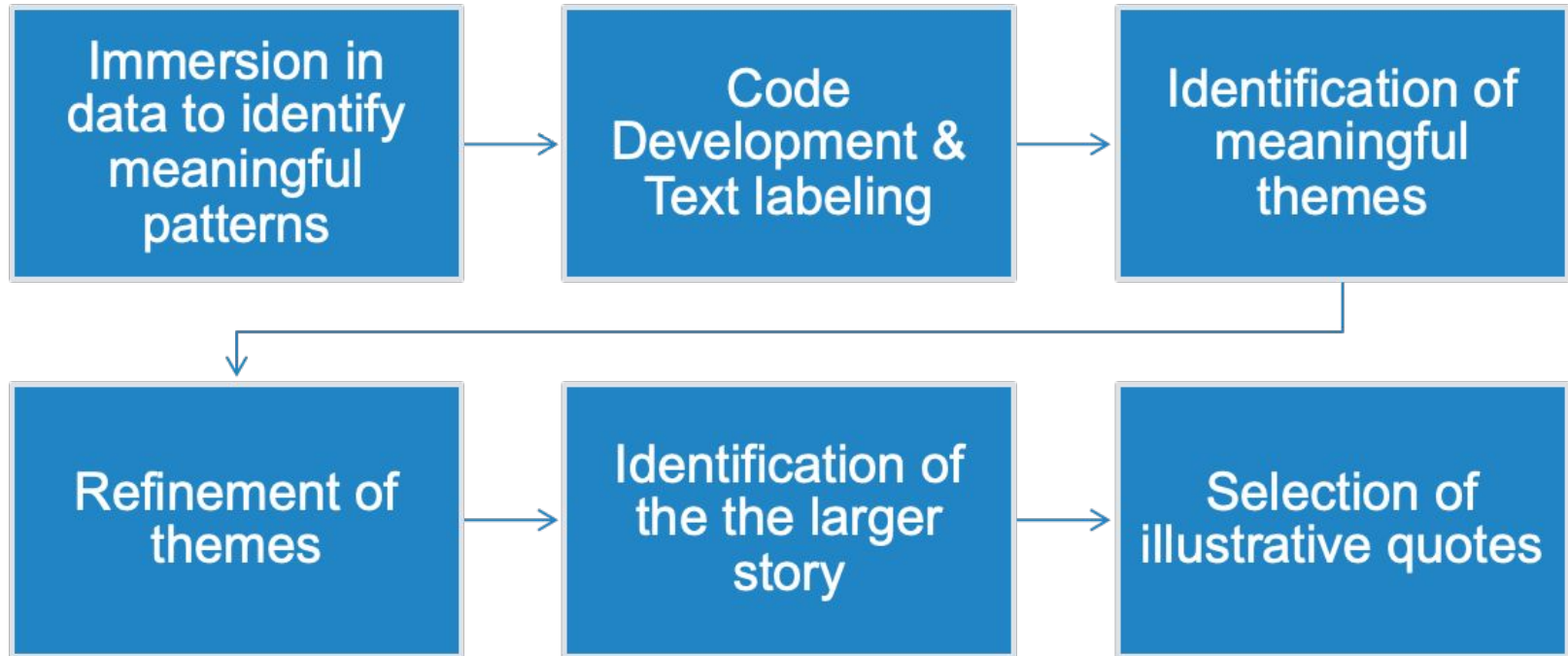
Participant Demographics
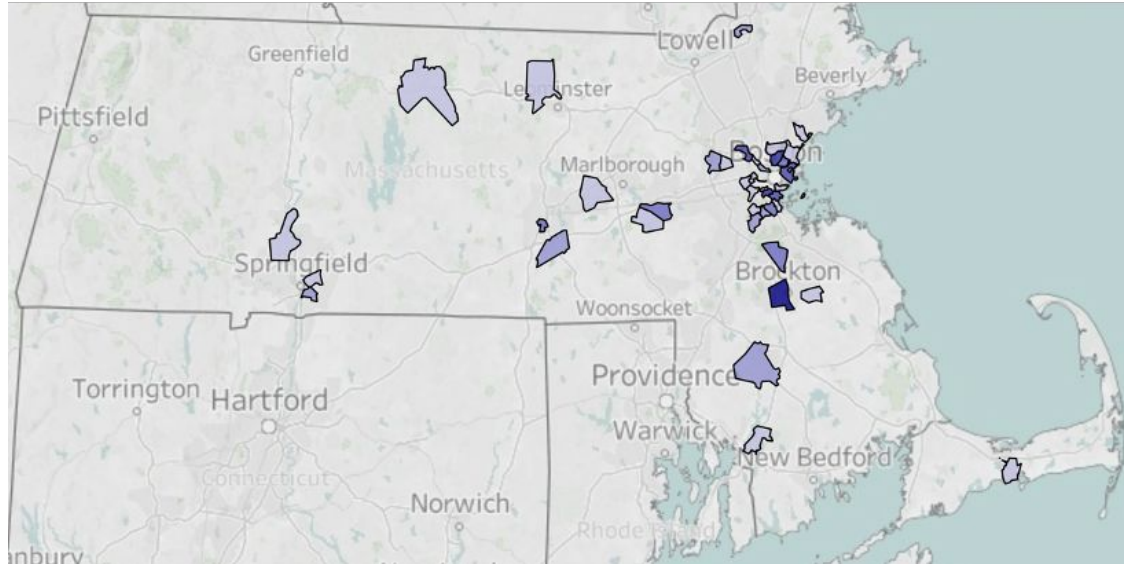
11 groups in five languages:
- 2 in English
- 2 in Haitian Creole
- 1 in Portuguese
- 6 in Spanish

99 participants
- 30 identify as Black
- 69 identify as Hispanic/Latinx and more than one race

Long Covid Symptoms Reported

Fatigue	Chest pain	Dizziness
Exhaustion	Vomiting	Vertigo
No stamina	Muscle and joint pain	Spinning sensation
Inability to feel rested	Spasms	Floating sensation
Headaches	Body aches	Inner ear pain
Hair loss	Memory Loss	Difficulty concentrating
Cloudy, foggy mind	Forgetfulness	Loss of sense of smell
Shortness of breath	Depression	Loss of appetite
Cough	Anxiety	Weight loss
Excess phlegm	Inability to regain balanced sugar levels	

Findings: Lack of Awareness of Long Covid

- In nine of the 11 groups the **majority of participants had not heard of Long Covid**, but appreciated having language to describe what they were experiencing.
- In the two English language groups participants had heard of Long Covid, but felt that it was **not part of the mainstream discourse**.

"So 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."

"Sometimes I think I'm being crazy"

Yes, after Covid, I went to my primary care doctor many times and my primary care doctor said you have long Covid, because your signs and symptoms after Covid haven't gone for a long time. 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, for the whole 2021 year, I was hearing about Covid. It was this year that I began feeling better, but 2021 was a bad year for me with Covid.

"...a constant tiredness..."

... I did not know the term Long Covid, it seems quite appropriate, because effectively one is stuck in that [cycle], ... In the case of what happened with my father-in-law who is an elderly person, he is also a diabetic and with my niece, who is younger person, much younger, she is 20 years old, without any medical condition. ... I noticed both my father-in-law and my niece, who were left with a permanent fatigue. I mean, whatever they did, it was "I'm exhausted", "I'm tired", no matter how much they slept, it doesn't matter if they took vitamins, it doesn't matter, a constant tiredness ...my niece said, "I have no appetite", ..., "I do not want to eat anything" for more than a month and a half. Which led her, obviously to lose a lot of weight. And in the case of my father-in-law, who is diabetic, because there was the issue of insulin levels that even though he followed a strict diet no matter how much medicine he took constantly those levels are much higher than it usually has ever been.

"Like I am here but I am not here"

"…I do not know if that is normal, but I do not know if it has happened to you guys, but I feel like I am walking on air. Like I am here but I am not here. And suddenly I was going to do something, the other time I was going to make tortillas, I took the sugar out to make tortilla and I said to myself, like what is wrong with me?"

Findings: Language Barriers Prevent Utilization of Covid Resources

Across all nine groups conducted in non-English languages, **language was cited as a major barrier**

- Lack of language-accessible information online and in the news
- Poor translator services at healthcare facilities

Even if there were translators present or information was available in their language, it was not necessarily understandable or accessible

"When I tested positive in 2020, I was not able to get a doctor. I had a high fever of 110 and I wasn't able to get to the hospital. They were turning us all away, I literally had to call a translator company so they explain what was wrong with me. For me, the barrier was language and not being able to explain what is wrong."

"They don't know themselves..."

I've given up. Honestly, I don't. 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 clinic at BMC. 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 serve?

Community Resources

Clinics	South End Community Center	ABCD - Rent Overage/Utility Support	Food Delivery Services
Long Covid Clinic at BMC and Brigham and Woman's Hospital	Mass General and Tufts Pain Management Center for symptoms longer than 3 months	Informal community supports that provided free hand sanitizers, tests, and food	Medical Outreach Team once you test positive for Covid-19
Local non-profit organizations	Social Workers in hospital settings	Mortgage Company forebearnce options	BMC Support group
La Collaborativa (community based organization)	The focus groups	Vaccination Campaigns	Phone Helplines

Participant Recommendations: Information

- Using social media sites, local news, channels in peoples' languages

- Using a mix of online and offline avenues to share information about what Long Covid is and what resources are available

- Flyers and events at community centers like churches, schools, housing complexes

- Support groups so people can both learn from and support one another

- **More information for doctors so they can support patients who have Long Covid**

Recommendations: Policy

- Better guidance for employers and workplaces– **reinstating paid time off for Covid, including for impacts of Long Covid**

- **Faster processing of long term disability** requests, revisiting requirements to "prove" disability as there are no straightforward diagnostic tests for many Long Covid symptoms

- **Economic supports** for housing payments, utilities, food

- Policies around **inclusive health insurance coverage to span a range of wellness options**, including physical therapy, acupuncture, Eastern and traditional medical services, etc.

- State-led **incentives to encourage resource sharing between healthcare institutions**; there is a huge need for services and only a few providers with long waitlists