

Boston COVID-19 Recovery Cohort: Community Partnership Table Meeting
Tuesday, December 12, 2023 from 4-6pm

Link to recording: <https://vimeo.com/893928954?share=copy>

Agenda

- 4:00 Welcome - *Dr. Ingrid Bassett*
- 4:03 Review Agenda and Table's Top Goals - *Jacqui Lindsay*
- 4:05 RECOVER study updates - *Dr. Ingrid Bassett*
- 4:10 Understanding Social Determinants of Health as Risk Factors for Long COVID
Dr. Candace Feldman
- 4:50 Research re. sharing Black and Latinx community members' experiences with Long COVID
Curtis Santos
- 5:20 Digital Health Program - *Dr. Beth Karlson*
- 5:30 BCRC Community Education Forum Series - *Dr. Marisha Palm*
- 5: 45 Briefing for MA legislators re. Long COVID and Health Equity - *Rep. Mindy Domb*

RECOVER Study Updates

- While RECOVER enrollment is closed, clinical trials are starting at many BCRC study sites
- Retention rates are consistent across all racial and ethnic groups

Understanding Social Determinants of Health as Risk Factors for Long COVID

- Data presented is preliminary and unpublished, thus will be kept confidential at this time
- Questions from the community include:
 - Can you explain how your analysis accounts for the fact that these social determinants of health were known risk factors for acquiring COVID infection? (A person can't get long COVID without having COVID)
 - Could other variants have predisposed patients to Long COVID? RECOVER only looked at Omicron variant.
 - How does repeat exposure affect risk for Long COVID? Vaccination status? Number of shots/boosters?
 - Crowded housing? Unhoused populations? Chronic conditions?

Research re. sharing Black and Latinx community members' experiences with Long COVID – Boston Lesbigay Urban Foundation and FenwayHealth collaboration

- Surveyed BIPOC living in Boston about **beliefs of, knowledge of, and access to** COVID-19, vaccines, and other forms of care and **the impact of COVID-19** on income, business, food security, housing stability, employment, childcare, long-term effects.
 - Loss in income (51.3%), businesses suffered (60.2%), and food security (49.5%) due to COVID-19 were most frequently experienced
 - 85.8% of respondents and their families have been educated on COVID-19, COVID-19 boosters and vaccines
 - **1.3% have been educated on long-term COVID effects**
- **Respondents seek care at institutions that don't have Long COVID clinics or clinical care**
 - Where is Dorchester Health Center or Upham's Corner?
 - Boston Children's pediatric long COVID clinic has a long backlog.

Key Priorities	Communities to engage with next
<ul style="list-style-type: none"> • Economic mobility • Housing • Education on COVID and Long COVID, Vaccines (development, effectiveness, and implementation), prevention + treatment 	<ul style="list-style-type: none"> -Men, Trans, and GNC/NB folx -Latinos and other POC -Aging and older adults -Ppl who have not received vaccine -Ppl who believe the vaccine is not effective -unhoused population and youth (Table Rec)
<p>Connections and collaboration with the Table:</p>	
<ul style="list-style-type: none"> • ROCA: https://rocainc.org/ <ul style="list-style-type: none"> ○ Dean Xerras, dxerras@mgh.harvard.edu – Chelsea CBOs working with at risk youth • Massachusetts Community Education Alliance (Mass CEAL) – leads a Train the Ambassador Program <ul style="list-style-type: none"> ○ Shaquera Robinson, maceal@bmc.org • District 7 puts out a newsletter and can add resources: http://eepurl.com/hw06EL <ul style="list-style-type: none"> ○ Angie B, angelique.brutus@boston.gov ○ Councilor Tania Anderson, tania.anderson@boston.gov • Housing=Health <ul style="list-style-type: none"> ○ Lady Lawrence, Housing.equals.Health@outlook.com or call/text 857.247.6551 • To engage with youth use CHCs and Inter-city mentoring spaces (Level Grounds, Field’s Corner, Missionsafe, Project Right) <ul style="list-style-type: none"> ○ Darian Leta, dleta@massleague.com • Dr. Heather Hue, heather.hue@me.com – using social media to engage with communities 	

- Questions from the Table:
 - Have you asked where or how your patient population would like to be educated on your identified topics? *Not yet!*
 - Is outreach to people currently experiencing homelessness planned? especially with unhoused youth Trans are overrepresented in unhoused population. Anecdotally, there are many who do not believe in efficacy of vaccination. *Would love to connect!*
 - What have you learned about who or what is a “trusted” source of information that is “educating” people?
 - *Did not specify with participants about where and how they were educated about COVID-19 and Long COVID*
 - *Education experience conducted at Curly Middle School and community spaces (Scope)*
 - Curious if you can expand upon the youth/children demographic as the parents are controlling what the folks under 18 do/not do?
 - *Fenway Health recruited folks younger than 18 to be ambassadors to educate children about COVID-19 and Long COVID, yet experienced push back/hesitancy from parents. Looking to connect with more youth organizations!*

<p>Help Curtis Santos and Adrianna Boulin engage with BIPOC living in Boston re. Long COVID. Email lesbigayurbanfoundation@gmail.com and bcrc@mgb.org with your answers</p>
<ol style="list-style-type: none"> 1. Do YOU offer services that support these key priority areas? 2. How much of an issue/challenge is navigating COVID in your communities today? 3. Do you have initiatives aimed at engaging these communities?

Digital Health Program

- **Objectives:**
 - Promote participant engagement and retention
 - Collect and analyze information complementary to the RECOVER cohort studies
- RECOVER participants interested in the program get a free Fitbit and an app where participants can track their symptoms over time, new COVID-19 infections, uploading EHRs, and collecting biosensor data (heart rate, basic activity, sleep, respiratory)
- Equity First: **Fitbits** were offered to populations underrepresented in biomedical research **first**
- **Racial, Educational, and Income diversity in Digital Health Program does not reflect that of the RECOVER cohort** – largely due to pending IRB approval in New York, Chicago, and San Francisco (diverse sites) and perhaps due to education of new technologies and apps
- Biosensor data can detect new COVID infections early, which can help people get treated early
- Questions from the Table (to be answered in the January Newsletter)
 - Maybe barrier to joining is more trust level/not knowing what will happen with the data collected than not understanding what a Fitbit is/does?
 - **BK:** You make a very good point. We are inviting people who have already joined RECOVER, but its possible that some are worried about being monitored or tracked on a Fitbit. We're hoping to get input into educating potential participants around all of the security and privacy protections and ways we remove all information that identifies them from the data that researchers use. Thank you.
 - **LL:** Yes ... thinking that could be the basis for a trust gap, And getting people in community who are trusted as Curtis did with local retailer to communicate usage of data and protections against misuse might help
 - Do participants need a SSN to join? Some studies (NIH) require SSN, but it can pose a barrier
 - **BK:** I don't think that a SSN is required to join RECOVER. I have not seen this in any of the data that we collect in the Data Resource Core for researchers. Ingrid can tell you if the BCRC collects this information. Sometimes it is needed in order to pay participants for their efforts.

Community Education Forum Series

- Forums topics and speakers are shaped by the 4 Table Goals (Research, Community Education, Clinical Care and Social Support, and Institutional and Policy Change)
- See slides for more in depth summaries of each Forum's presentation and discussion
 - **March:** Overview of Dr. Linda Sprague Martinez's research of Black and Latinx community experiences with Long COVID
 - **June:** Long COVID Clinical Care, Resources, and Services and research towards a definition of Long COVID
 - **September:** The Power of Belonging: from Loss and Grief to Healing, Resilience, and Recovery – How to create a Long COVID movement
 - **October:** Policy Priorities to Address Long COVID in Our Country and Advance Health Equity in Our State
- **Outcomes**
 - Congresswoman Ayanna Pressley's letter to Congress in support of a Long COVID Moonshot (\$1B+ in funding)

- Positive feedback from forum attendees re. the value, information, and community importance of the forums

Help improve the Community Education Forum Series!

Email bcrc@mgb.org with your answers and visit www.longcovidmoonshot.com to contact your legislators re. Long COVID

- How do we continue to grow our network, increase attendance, and foster engagement?
- Of the upcoming forums, what are the top priority areas for you? Are there any gaps or forum topics you would like to see?
- Are we on the right track?

Virtual Legislative Briefings in the MA State House w/ Rep. Domb

- **January 30th: Long COVID 101 – What we know and don't know**
 - Those living with Long COVID, medical providers, and researchers will give an overview
- **March 11th: How to apply this knowledge to respond to this challenge?**
 - Some people have heard from constituents, some believe they have Long COVID constituents but haven't heard from people, some don't know much about Long COVID
- Table members priorities for each briefing:
 - **JK: The best "treatment" of long COVID is to prevent it.** —We are currently at the beginning of a COVID surge (of unknown coming dimensions) , due to cold weather and holiday gatherings. Air filtration and masking are effective preventive measures including for vaccinated and boosted people. — Are you advocating for these protective measures e.g. in hospitals, schools, and other workplaces?
 - **School (Youth) AND environmental concerns**
 - **CC:** Reaching the **Trans community**
 - **IB:** Innovative ways to be sure **providers have up to date information** about long COVID.
 - **CW:** how do we move toward **making it "cool" to stay home when sick and wear masks** at the tail of recovery for any respiratory illness. **Shift the norm toward using MA FMLA** without getting grief from peers and bosses. Prevention prevention prevention
 - **Changing cultural framing** from me to we can help -- in much of Asia there is peer pressure to mask and not sneeze on a bus that predates COVID
 - **JG: Recognizing the impact on care providers** who manage and treat Long COVID in the face of diagnostic dilemmas, medical uncertainty and trauma they experienced during the pandemic.
 - **HH:** For Session 2: For those patients whose health is impacted by LongCOVID, **how to help them return to the workforce and/or re-enter or integrate back into society?**

What else would you like to see in the Jan and March briefings?

Email mindy.domb@mahouse.gob and bcrc@mgb.org with your answers

Rep. Domb to connect with maceal@bmc.org