

RECOVER - BCRC Community Partnership Table

Meeting #4: Progress Reports, Building Relationships, and Defining Action

January 27, 2023, 1 – 3pm ET

Meeting Summary

Goals of the Meeting

1. Provide a progress report on enrollment numbers and working with community partners to diversify our RECOVER study of Long COVID in Greater Boston.
 - Long COVID support groups for patients
 - MA-CEAL “Train the Ambassador” Program – Dr. Jai Marathe and Hope White
2. Introduce two proposed strategies to support Community Education and Engagement re. Long COVID:
 - A community education forum series – to be launched in 2023
 - A newsletter – to be issued quarterly
3. Form working groups to recommend next steps for action re. the Table’s top goals, i.e., *collaborate with our healthcare and community partners to:*
 - Diversify and retain a RECOVER study that reflects the diversity of Greater Boston.
 - Educate and engage our diverse community re. Long COVID.
 - Provide equitable Long COVID clinical care to our diverse community.
 - Advocate for research, institutional and public policy, and funding to center community leadership in addressing Long COVID, advancing health equity, and improving the health of Greater Boston’s diverse community.

Meeting Minutes

The meeting presentations are captured in the meeting recording and slides, which have been shared. In the second half of the meeting, Table members went to breakout rooms to form initial working groups around the following topics: Recruitment/Retention, Community Engagement/Education, Clinical Care, and Data/Research. Below please find minutes from the working group breakout rooms, their reports, and discussion of next steps to inform action.

Common themes from working groups

1. **Need funding and resources to implement strategies and compensate those who worked on this effort**
2. **Centralized database of available Long COVID resources and efforts in. This can help increase visibility, synthesize efforts, and prevent duplication**
 - a. Specifically need resources for populations who are **unhoused, marginalized, or uninsured/limitedly insured**
 - b. **Examples of efforts include:** Linda Sprague-Martinez’s research funded by MassCPR, The MA-CEAL Ambassador Program, the community education forum series, Vaccine Equity Committee

- c. Make sure healthcare providers are aware of resources in addition to community members
- 3. **Need new strategies to connect with people and meet them where they are to help them learn about Long COVID and Long COVID resources and support.**
 - a. **Social media strategies:** Facebook, WhatsApp, email
 - b. **Active strategies:** Faith-based leaders, COVID vaccination or testing sites, grocery stores, CVS, MBTA stations
 - c. **Passive strategies:** posterboards
 - d. **Stakeholders:** community members, policy makers, payers, advocacy groups, **health systems/clinicians**, schools, shelters, **religious organizations**, etc.
- 4. **Write up recommendations for effective recruitment strategies**
(Recruitment/Retention WG + Data/Research WG)
- 5. **Political advocacy** (Clinical Care WG + Data/Research WG)

Group 1: Study Recruitment/Retention

Facilitator: Dani Zions (MGH), and **Notetaker:** Robert Torres, (BILH)

Attendees: Sharon Scott (Union of Minority Neighborhoods), Elmer Freeman (CHEERS), Gloria White-Hammond (Bethel AME Church), Gladys Vega (La Colaborativa), Diane Wilkerson (Black Boston Health Coalition), Li Chen (BWH), and Neil Gilbert (Mass Sickle Cell Association of Boston)

General Reflections:

- **Attendees want to help their communities learn about Long COVID and about resources so they can advocate for themselves.**
 - We need to **learn about Long COVID.** We helped with vaccination, and we want to continue helping.
 - We want to help the Black community **learn about resources so Black people can advocate for themselves and feel more comfortable with the medical community.**
 - We need to **create a global way to identify resources** that will help communities of color.
 - We want to **learn about what we haven't done well during our study recruitment process to date.**

Recruitment:

- We've had the **same discussion every time we meet (BCRC)** which is very frustrating. **Why haven't we met the goal for Black and Latino numbers?** I meet every day with people whose Black family is struggling with COVID and the aftermath.
- **Not sensing the same sense of urgency in the community** as during the height of the pandemic: this will affect recruitment.
- We need **paid employees from the community who can work on this effort.**

- Sites may not have funding left.
- We (Boston Black Health Coalition must have touched 3-4K people. So how are we behind the goal of recruiting 175 Black people?
- We need to ***think about the connections that people have.*** No one wanted to get vaccinated in Chelsea until I got on Facebook and started convincing people.
- Two people offered to get at least 10 more people enrolled each.

Group 2: Community Education and Engagement

Facilitator: Jacqueline Rodriguez-Louis (BWH), and **Notetaker:** Anisha Tyagi (MGH)

Attendees: Gwill York (MGB Board), Darian Leta (Mass League), Hope White (BMC), Nathalie Bazil (DPH- Technical Coordinator for COVID response), Mary W, RonAsia Rouse (BWH), Ronald Lammy (Total Wellness for Elders), Curtis Santos (Boston LesbiGay Foundation)

General Reflections:

- ***Attendees described what they are already working on, what their communities need to know, and what strategies work to effectively communicate with communities:***
 - The Boston LesbiGay Foundation has a one-stop van program in Dorchester to meet people where they are. They teamed up with a community health center to provide services. They are ***looking at what services are available in these communities and giving them more visibility.***
 - ***Nothing more powerful than meeting people where they are.*** Working class, immigrant families don't know that they have Long COVID because they don't have time to ask these questions.
 - ***Partnering with organizations in our communities is key.***
 - ***We need a different way of talking about COVID.*** It is so repetitive. Many programs are paying people to take the COVID shot or the booster shot, but they do not realize that ***people need more education about Long COVID.***
 - ***We need new language and words to describe these issues;*** my experience with the elder community is that I have heard repeatedly presentations being made about health subjects and hearing, "oh I've heard that before, so I don't want to go," but these are some of the same individuals who have these issues, and they are tired of hearing the same issues.
 - ***We need information and communication in multiple languages*** (like info sheets).
 - ***We also have to think about the cultural component that impacts who's learning about Long COVID and who's not.*** All communities and their members are not equally aware of Long COVID, how it affects us, + whether they have it.
 - ***We need faith-based leaders to have conversations about Long COVID,*** especially with communities hardest hit by COVID; and we need to ***have***

- conversations about Long COVID on WhatsApp.* Even I get confused about the booster, and bivalent booster.
- I want to emphasize the visuals. *We need poster boards around Boston with influencers who are talking about Long COVID.*
- *We should also go back to basic communications* -- including reaching out directly, e.g., through direct mail -- and update people on these issues.
- We have to *communicate with and engage our community using an intergenerational lens.* We agreed that trusted community sources are key.
- Another key strategy is *providing basic things like tangible resources people need to survive COVID and Long COVID.*

Next Steps:

We will send an email out to all of the attendees to see how we are connected, what we are working on, and who is willing to work with us to help identify what we can do now to begin to implement the strategies recommended by this and other working groups, including securing the funding needed to implement them.

Despite their enthusiastic, soul-level interest in this Table goal, members expressed concern and chose not to commit to devoting more meeting time to this working group because they were overwhelmed by their current job responsibilities – and cannot take on new responsibilities without the resources needed to carry them out.

Group 3: Long COVID Clinical Care

Facilitator: Tracy Battaglia (BMC), and **Notetaker:** Alice Rushforth (Tufts)

Attendees: Amberly Ticotsky (BILH), Fitzgerald Shepherd (BMC)

Major Barriers to Long COVID Clinical Care:

1. **Housing status:** *the unhoused and other marginalized populations experience a number of problems receiving care for COVID and Long COVID.*
 - a. Long COVID *clinics are primarily being used by people with means and time.* The unhoused and other *marginalized populations cannot easily access these resources.*
 - b. ***Look into efforts by Boston-area hospitals to assemble numbers on:***
 - The unhoused and barriers to their accessing care for COVID and Long COVID – ***what is the status of this work?***
 - Other marginalized populations and barriers to their accessing care for COVID and Long COVID – ***what is the status of this work?***

2. ***Insurance: patients hit insurance limits quickly and have to make difficult decisions about what care to pursue and what care they cannot follow up on.***
 - a. ***Bundling insurance for Long COVID care would allow patients to get a fuller spectrum of the care they need.***
 - b. Coordination of care is also complicated because care across multiple specialists can be required. ***Sufficient staffing for care coordination is also important.***
3. ***Communications: important to make people aware of existing resources – including healthcare providers!***

Additional Strategies for Tackling Barriers:

1. ***Focus on advocacy for both insurance and housing:***
 - a. Relevant stakeholders include **policy makers, payers, advocacy groups**, etc.
2. ***Communications - how to get the word out:***
 - a. ***Centralization of information is critical:***
 - i. Website of resources – difficult to maintain.
 - ii. “Hotline” concept with **navigators** to assist people with accessing relevant services could be helpful.
 - b. ***Relevant stakeholders: health systems/clinicians***, schools, shelters, religious organizations, etc.
 - c. Possible communications venues: grocery stores, CVS – other types of businesses people frequent.
 - d. ***Leverage connections already created by groups working on COVID vaccination efforts.***
3. ***General approach: Identify others working in these spaces and coordinate and collaborate so efforts are not siloed and to prevent duplication/gaps.***
 - a. Two relevant ongoing efforts for the clinical care working group:
 - i. **Research conducted by Linda Sprague-Martinez** and colleagues through Long COVID key informant interviews. Work was funded by Mass Consortium Pathogen Readiness (CPR).
 - ii. **The Ambassador Program** – was presented by Jai Marathe and Hope White from the MA-Community Engagement Alliance

Group 4: Long COVID Research

Facilitator: Yuri Quintana (BILH) and **Notetaker:** Cheryl Clark (BWH)

Attendees: Rebecca Lobb (BMC); Jai Marathe (BMC); Janice John (CHA); Maryka Lier (BPS); Linda Sprague-Martinez (MassCPR); and Gyana Srivastava (BILH)

When it comes to Long COVID, what do people want to focus on? What are most people worried about? What kind of information are people looking for? What kinds of question are people looking for? How do we hope to answer those questions? At a top level, what are you hearing from colleagues, patients, other investigators about research questions that are high priority?

Policy is at the forefront of mind:

- **What additional strategies are needed to change policy** including and apart from data/evidence – **what moves policy?**
- **We need an understanding of who is getting access to resources and who is not** (e.g., on the disability side, there may be less pediatric outreach)
- **We need access to mental and physical healthcare interventions and information/public health campaigns**
 - A shared communication outreach network across hospital networks could be helpful

Proposed Research Topics:

- Having **research on perceptions of what Long COVID means** could help with research hesitance.
- Study **how clinicians engage patients** re. Long COVID
 - Often patients feel **dismissed**
 - How to get supports to avoid a sense of **isolation** for patients
 - Having leadership perceptions for **how to approach new conditions** that are not known well
- Collect data on **effective strategies for recruitment**
- Research on **effective outreach to groups** would be important, and to **share a network and resources**
 - Can draw from **Vaccine Equity Committee**
- Huge **absenteeism in schools** since the pandemic; would be interesting to know if Long COVID is related to any of this
- **Misinformation and mistrust of providers**

Next Steps:

- **Need a way to fund these activities**
- Disseminating information to **raise awareness, finding the optimal channels, staying connected**

Thank you all for your time, attention, and care in advancing these topics and we look forward to working with you further in the months ahead and to seeing you at our next Table

meeting. Please keep an eye on your inboxes for further communications to schedule those meetings in the coming weeks.