

**BCRC: The Table's Top Goals  
& Strategies to Achieve Them  
May 8, 2023**

**The Table's Top Goals**  
*Recommended by the Table in September 2022*

1. Diversify and retain a RECOVER study pool that reflects the diversity of Greater Boston.
2. Educate and engage our diverse community re. Long COVID.
3. Provide equitable Long COVID clinical care to our diverse community.
4. 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.

**Strategies to Achieve the Table's Top Goals**  
*Recommended by the Table on January 27*  
*Recommended by BCRC Forum on March 28*

**1. Diversify and retain a RECOVER study pool that reflects the diversity of Greater Boston.**

**Strategies for Study Recruitment/Retention** -- from the Table

**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 Latinx 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, but 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.

## 2. Educate and engage our diverse community re. Long COVID.

### Strategies for Community Education and Engagement – from the Table

#### 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 LesbianGay Urban 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.**

**Strategies for Community Education and Engagement** – from the Forum

- Learn barriers and gaps that prevent people from learning or knowing about Long COVID.
- **Faith-based leaders are a great entry-point for connecting with the community**, but they need education about Long COVID, support, backup, and connection with each other.
- **Community Health Centers do not prioritize or discuss Long COVID despite being the backbone during the COVID pandemic. We need to re-engage them** in spreading the word.
- It's important to make medical info clear, understandable, multilingual, and physically accessible. Must disseminate information widely and effectively through multiple channels.
- **Better promotion/communication is needed.** We need to be **intentional with the messenger** and **how the message is tailored** to the individual. Meet people where they are, speak their language, be physically in the space, show up authentically with every group.
  - There is a **stigma** – this must be overcome with different resources and stories.
  - How do we reach people who have **given up on accessing care** or **don't know** what Long COVID is or **don't trust** medical institutions or **have preconceptions** that they can't afford it, think it takes too long, and isn't worth the effort?
  - Message should **come from someone trusted** (pastors, family members, places where people gather) to **reach different populations** (by age, gender, role, race, sexual orientation, language, ability, SES, immigrants, housing, young children) **in different ways** (visual, verbally, auditory, QR codes, TV ads, community learning lab, broad communication campaigns)
  - Have **all hospitals come together to make a statement about Long COVID**.

- **Cultural humility** – reach common ground and shared understanding through recognizing differences and equity.
- Need **old-fashioned street outreach**, go to events and pass info to people, novel ways to communicate (bathrooms, sports facilities, T stops), text not email
- **Dismantle the guinea pig mentality**
- Recommendations and action items identified at this forum should be shared broadly in the community. They also need follow-up to build momentum.

### 3. Provide equitable Long COVID clinical care to our diverse community.

#### Major Barriers to Long COVID Clinical Care & Strategies to Address Them

- **Housing status:** *the unhoused and other marginalized populations experience a number of problems receiving care for COVID and Long COVID.*
  - Long COVID *clinics are primarily being used by people with means and time.* The unhoused and other *marginalized populations cannot easily access these resources.*
  - **Look into efforts by Boston-area hospitals to assemble numbers on:**
    - The unhoused and barriers to their accessing care for COVID and Long COVID
    - Other marginalized populations and barriers to their accessing care for COVID and Long COVID
- **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.*
  - **Bundling insurance for Long COVID care would allow patients to get a fuller spectrum of the care they need.**
  - Coordination of care is also complicated because care across multiple specialists can be required. **Sufficient staffing for care coordination is important.**
- **Focus on advocacy for both insurance and housing:**
  - Relevant stakeholders include **policy makers, payers, advocacy groups**, etc.
- **Communications:**
  - **important to make people – including healthcare providers – aware of existing resources!**  
How to get the word out:
  - **Centralization of information is critical:**
    - **Website of resources – difficult to maintain.**
    - **“Hotline” concept with navigators** to assist people with accessing relevant services could be helpful.
  - **Relevant stakeholders: health systems/clinicians**, schools, shelters, religious organizations
  - Possible communications venues: grocery stores, CVS – other types of businesses people frequent.

- *Leverage connections already created by groups working on COVID vaccination efforts.*
- **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 *Train the Ambassador Program*** – was presented by Jai Marathe and Hope White from the MA-Community Engagement Alliance (CEAL)

**Strategies for Equitable Long COVID Clinical Care** – from the Forum

- We need to **acknowledge medical racism**.
  - We need to change the way we care for Long COVID patients. **The onus should be on clinicians to be empathetic, to listen, to trust, to support, to validate. Give scripts to doctors to train them in what to say.**
  - **Set Long COVID protocols for healthcare providers** – understand the **different experiences** with COVID and Long COVID, know the (culturally) **appropriate services**, help people **navigate** the system, **provide information** via printed materials, **listen, validate, and practice empathy** with patients.
    - a. **Meet people where they are**, work treatment and care into their lifestyle.
    - b. There is bio/psychosocial/social stress and **trauma**. (1)
    - c. **Practice trauma-informed care.**
    - d. **Share resources:** lots of hospitals/orgs are doing similar things, consolidate, and share.
  - **More support groups** and in different languages
  - **More mental health services**
- 4. 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.**

**Strategies for Advocacy to Address Long COVID, Advance Health Equity, and Improve the Health of Our Diverse Community** – from the Table

**Policy is at the forefront of mind:**

- ***What 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 do not have -- and we need -- a Long COVID system or infrastructure across our health care institutions to keep accurate data on who's getting Long COVID, including among communities hardest hit by COVID, and to ensure they get the services they need.* We need a Long COVID tracking project just like we had a COVID tracking project – so that this invisible disease becomes visible – to the people who have it and to the rest of us.
- *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 to community members* 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:

- *We need a way to fund these activities.*
- Disseminate information to *raise awareness, find the optimal channels, and stay connected.*

#### Strategies for Advocacy to Address Long COVID, Advance Health Equity, and Improve the Health of Our Diverse Community – from the Forum

- **Long COVID patient self-advocacy:** empower people to advocate for themselves by providing the language and understanding of what they're experiencing.
  - **Listen to people** – people need to be heard. Integrate personal narratives into research agendas.
  - **Encourage people to listen to and “trust” their bodies:** we know our bodies better than anyone else. Also to take care of themselves from day-to-day stress (child care, bills, groceries, errands).

- Contact their elected officials to **advocate for paid time off** for workers with long COVID.
- **Less money to research, more to community** – research says the same thing that disparities exist. Go on the ground to patient-facing grassroots organizations, **de-silo community initiatives** so there is **less double** dipping and ensure all communities are reached.
- **We need to keep momentum and sustain movement for change.**
- **What we need to continue to discuss with others and work on:**
  - COVID is long term, and there's so much distrust and trauma: healing is needed.
  - Build bridges across different institutions.
  - Advocate for resources and policy to move forward.
  - How do different demographic groups experience the pandemic differently?
    - Must go to them rather than they come to us.
    - Consider how equity can be reflected in protocols/policies/etc.
  - Develop guidelines to help people manage symptoms and self-advocate.
  - What is being done for the survivors? People need to tell their stories.
  - There is still resistance to engaging in these conversations, to talk about Long COVID, to gather people – how do we get people to lean in and overcome fatigue in hearing about this?
  - **Get education out to empower patients.**

### Common Themes

1. **Need funding and resources to implement strategies and compensate community partners who work on this effort.**
2. **Need centralized database/website of available Long COVID information and resources. This can help increase visibility, synthesize efforts, and prevent duplication.**
  - Specifically need resources for populations who are unhoused, marginalized, or uninsured/limitedly insured.
  - Examples of information includes: Linda Sprague-Martinez's research funded by MassCPR, the MA-CEAL Ambassador Program, BCRC's community education forum series, the Vaccine Equity Committee.
  - 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.**
  - Social media strategies: Facebook, WhatsApp, email
  - Active strategies: Faith-based leaders, community partners that hospitals worked with on earlier COVID vaccination or testing sites, grocery stores, CVS, MBTA stations

- Passive strategies: posterboards
  - Health systems and their clinicians need to be proactive in informing themselves and their patients about Long COVID, especially ensuring that they inform and equitably serve people from communities hardest hit by COVID. It's important that clinicians learn how to recognize Long COVID, meet patients where they are, and engage them as partners in tailoring plans to manage how Long COVID impacts patients' health, livelihoods, and lives.
  - Stakeholders to connect with: community members, policy makers, payers, advocacy groups, **health systems/clinicians**, schools, shelters, **religious organizations**, etc.
- 4. Support community education, self-advocacy, and political advocacy to empower patients to advocate for themselves and their communities re. Long COVID – with clinicians, at work, and with their elected officials.**
- 5. Write up recommendations for effective recruitment strategies – and share them across health care institutions working together to understand, treat, and prevent Long COVID.**
- 6. Engage in political and institutional advocacy to address Long COVID, advance health equity, and center community leadership in authentic partnership with others to define the problems and the solutions, and to evaluate and learn from the results to hold institutional and government leadership accountable for:**
- Improving the health care and health outcomes of Greater Boston's diverse community
  - Developing and funding an infrastructure within and across institutions and sectors to achieve the following goals:
    - Make working with the community to address Long COVID a priority.
    - Do ongoing data collection and performance review to drive goal setting, action, learning, innovation, and impact to:
      - Address Long COVID.
      - Advance health equity.
      - Improve the health care and health of our diverse community.
      - Strengthen our public health infrastructure so that it is better able to respond to Long COVID as well as respond to, anticipate, and help prevent future health crises.

### **Conclusion**

When we began BCRC, we identified three big goals: 1) supporting the success of RECOVER, including educating our community about Long COVID – what it is, how it operates and impacts our bodies, how to treat it, and how to prevent it; 2) advancing health equity as we address Long COVID; and 3) authentically centering community leadership in figuring out how to achieve



these goals. As we continue to do this work, it's becoming clear to us that we face two other big challenges:

1. ***Our public/private health system – in Boston and our state -- has not yet made Long COVID a priority.*** It's not only patients, families, and communities who don't know what Long COVID is and how debilitating it can be for people who have it: but many doctors and senior hospital leaders are in the dark, too, about this silent, epidemic growing all around us but outside of our consciousness – especially impacting key segments of our country hardest hit by COVID: Black, Latinx, Native American, and immigrant communities.
2. ***Hidden even further from public consciousness is the fact that our public/private health system is not a match for Long COVID or any other new epidemic or serious health challenge we may face: the infrastructure for timely and effective data collection and sharing, including across race, as well as the collaboration needed to drive and accelerate learning, action, and impact across siloes -- institutional, sector, geographic, and community – isn't there.*** This becomes saliently clear as doctors and journalists involved behind the scenes in the early days of COVID reveal just how inadequately prepared our public health infrastructure was to respond to COVID – as well as how much politics kept getting in the way of what key science leaders were advising our country to do: which was to use data, not politics, to drive decision making for public good. As those of us in our city and country who are aware of Long COVID seek to address it, we, too, are faced with a fragmented and inadequate public health infrastructure under-resourced for years and not designed for the collaboration and learning needed to understand and solve big health challenges that impact us all.

***BCRC believes it is both essential and urgent that community, health care, political, faith, workplace, and philanthropic leaders come together to learn about and take both timely and ongoing action to address Long COVID, and to do it in a way that achieves 3 important goals:***

1. Advance health equity.
2. Begin to reimagine and put in place a public/private health infrastructure that not only addresses Long COVID but future public health challenges.
3. Hold us all accountable for the shared leadership, learning, and resources needed to produce these results.

**At its Community Partnership Table meeting on May 25, 4-6pm, BCRC will invite participants to use this report plus what participants learn from updates presented at the meeting to *identify what BCRC's key areas of focus should be to drive partnership development, fundraising, action, and impact going forward.***