RECOVER Community Partnership Table

Meeting #3: Building Relationships, Defining Action

September 22, 2022, 4pm ET – 6:30pm ET

Meeting Summary

Participants:

Name	Organization	Role
Ingrid Bassett	Massachusetts General Hospital	RECOVER site Principal Investigator
Jill Carter	BPS Health & Wellness	Assistant Superintendent
Li Chen	Brigham and Women's Hospital	RECOVER Project Director
Jackie Chu	Massachusetts General Hospital	RECOVER investigator; primary care clinician
Cheryl Clark	Brigham and Women's Hospital	RECOVER Investigator
Barbara Couzens		
Michael Curry	Mass League	CEO
Susan Dargon-Hart	Mass League	Senior Vice President Clinical Health Affairs
Elizabeth Gay	Brigham and Women's Hospital	RECOVER co-Investigator; Long COVID clinic director
Callie Gu	Brigham and Women's Hospital	Health Equity research assistant
Jennifer Haas	Mass General Hospital	RECOVER co-Investigator; primary care clinician
Rosa Hunter	RLH Consulting	Principal
Janice John	Cambridge Health Alliance	RECOVER Site Investigator
Cheralyn Johnson	Community Care Cooperative (C3)	Director of Technology, Integration, and Analytics
Diane Kanjilal	Massachusetts General Hospital	RECOVER co-Investigator and nurse coordinator
Colin Killick	Disability Policy Consortium (DPC)	Executive Director
Ronald Lammy	Total Wellness for Elders	President/CEO
Jacqui Lindsay	Innovation by Design	Director
Rebecca Lobb	Boston University School of Medicine	Assistant Director of Community Engagement
Jai Marathe	Boston Medical Center	RECOVER site Principal Investigator
Atyia Martin	All Aces, Inc.	CEO and Executive Director, Next Leadership Development
Delphene Mooney	On The Rise, Inc.	Executive Director
Janet Mullington	Beth Israel Lahey Health (BILH)	RECOVER site Principal Investigator
Yuri Quintana	Beth Israel Lahey Health (BILH)	Chief of Clinical Informatics
Alice Rushforth	Tufts Medical Center	Associate Dean of Programs and Partnerships
Curtis Santos	The Foundation for Boston Centers for Youth and Families	
Frank Schembri	South Shore Hospital	RECOVER site Principal Investigator
Fitzgerald Shepherd	Boston Medical Center	RECOVER site Principal Investigator

Linda Sprague Martinez	Boston University School of Social Work	Assistant Director of Research and CTSI Community engagement program
Julie Sullivan	Brigham and Women's Hospital	Long COVID Clinic Patient Navigator
Robert Torres	Beth Israel Lahey Health (BILH)	Boston Region Director of Community Benefits
Ann-Marcia Tukpah	Brigham and Women's Hospital	Physician
Anisha Tyagi	Massachusetts General Hospital	RECOVER Research Assistant
Dianne Wilkerson	Black Boston COVID-19 Coalition (BBCC)	Co-Founder
Gloria White-Hammond	My Sister's Keeper	Founder and executive director
Charles Williams	Boston HealthNet (BHN)	Medical Director
Dean Xerras	Massachusetts General Hospital	RECOVER Co-Investigator; medical director of MGH Chelsea and member of Chelsea's Board of Health
Gwill York	Brigham and Women's Hospital	Board of Trustees
Dani Zionts	Massachusetts General Hospital	RECOVER Project Manager

Goals of this meeting:

1. Facilitate building relationships across the Table, study members, and health care institutions
2. Update on key areas of work
3. Support the Table to come together and set its directions and initial priorities

Agenda:

Times are estimates – the actual meeting spent longer on presentations and began discussions around 6pm, with the group ending closer to 6:40pm

4:00pm	Welcome, meeting goals, and overview Introductions & Making space for ourselves as we work together
4:20pm	Your recommendations: Top goals for the Community Table
4:30pm	Presentations: Getting started on Community Table goals - RECOVER study updates, including recruitment - Defining institutional asks of senior health systems leaders re: Long COVID equity - Informing equitable clinical strategies for Long COVID
4:55pm	Small group discussions: Moving work forward on Community Table goals - Group 1: Recruitment strategies to improve access to the RECOVER study - Group 2: Defining asks of institutional leadership for RECOVER sites - Group 3: Informing clinical strategy to make care delivery equitable for people with Long COVID
5:40pm	Reports from small groups
5:55pm	Discussion of next steps, including meeting cadence, communication strategies between meetings, planning group structure, and the next Table meeting

Meeting Minutes:

The presentations are captured in the meeting recording and slides, which should be shared, and relationship building is best captured in the slides and transcripts. Below please find minutes from the small groups, reports, and planning of the next steps.

Group 1: Recruitment

- General Reflections
    - ***Healthcare systems are overburdened and struggling right now***; staffing issues are severe
        - How can we address more than the COVID piece?
        - ***Can we offer something multi-faceted*** to attract people? Examples from other community groups or those who do vaccination and testing are community fairs with education, music, food, on-site social support.
    - There is a ***disconnect between what we can offer*** to health centers and what federally qualified health centers (FQHCs) can offer.
    - Reiterating comments from the chat: ***why are we doing the same thing we've done before and expecting different results***?
    - This space is appreciated; ***what we're seeing regarding distrust isn't new***; much of the data confirms what we already know.
    - Struck by the comments about chronic fatigue syndrome etc. and the stigma associated with Long COVID. We need to have a ***long-term strategy to get ahead of the stigma*** : talk about it, put up signs, and make sure people know it's a real disease and that we are studying it.
- Recruitment
    - ***Intentional communication campaigns*** are needed.
        - We need to explain ***who*** we are seeking to recruit and ***why***; built into the strategy more intentionally, including naming the groups we want to recruit (Black and brown patients and their families, disabled groups, older adults).
        - ***Significant information gap that Long COVID clinics exist*** – if we are primarily recruiting there, we need to address that and increase awareness of them and Long COVID in general.
        - ***Share the health benefits of participation*** such as the ability to get rich clinical labs performed, to learn more about themselves, and to have fuller information to bring to their primary care doctors.
    - What multi-faceted approaches can we consider? Consider health fairs, multi-level approaches, including one-to-one contact and invitation, and marketing campaigns – public radio, buses, state website that connects patients to Paxlovid, etc.
    - We ***need trusted messengers***; similar to what was working during the pandemic, people in the community have not heard of the long COVID clinics.
        - Trusted messengers were helpful; people are encouraged and happy to help.
        - ***Much was learned during the pandemic***: go where people love, laugh, learn, live, work, and play.
    - ***Participants in long COVID studies need to be treated well and with dignity*** – they will be ambassadors in their communities.
    - ***Can we meet people at local markets*** or other places where they naturally go?
    - Is there ***money in the budget to support the trusted messengers***; honor the skills they bring?

- ***Be attentive to the group who does not report race/ethnicity*** – they are usually at the bottom of care outcomes and need support!

Group 2: Asks of Institutional leadership

- General reflections – defining the problem: crucial to target those hardest hit
  - Lack of engagement and recruitment of Black and Latinx communities - ***We know who we need to be recruiting: why aren't we doing it?***
  - It is ***frustrating***: we hear repeated reports of these inequities, and none of it is new.
  - ***What is the infrastructure*** – the one we have and the one we need – to cover the communities that need help the most? All the reports identify that the Black and Latinx populations are the ones at the highest levels of stress: from inequities re. COVID; from inequities re. their other health needs, including mental health; and from inequities re. the social determinants of health. In two years under COVID, ***our institutions keep doing the same things but expecting different result***s. We know we need to recruit people, and the community knows how to do it, but we don't really partner with the community to get this done. We need to partner with community organizations and invest in them to get this done. ***We should be asking hospital leadership to make this investment immediately to get this done so we can diversify our study pool and prioritize those parts of our community hardest hit by COVID and by all the inequities that undermine the health of our communities.***
  - When we do this community outreach to educate our communities about Long COVID and recruit them to participate in the research study, let's also ***make sure we educate the community about what clinical care and support are available***.
  - Has the study hired community health workers? They've been the stars of reaching out to people. People feel heard and cared for by them. They help people feel safe, and they speak the language of their communities. They are human beings who see and speak to community members as other human beings. We need people doing outreach and recruitment who know that it's all about human connection. Let's ***make sure we engage trusted community health workers to help us develop our recruitment strategies and plan as well as reach the parts of our community most in need***.
  - A huge portion of deaths from COVID have been people in nursing homes. The disability community has also been greatly impacted by COVID, and many people who get Long COVID become disabled by it, so ***those with disabilities need to be one of the key groups we target for recruitment*** into the RECOVER study.
  - ***Let's not recruit anyone who's not from communities highly impacted by COVID***. Focus on recruiting groups most in need that we know are missing from the study pool. Who are the groups hardest hit by COVID? ***Community members identified the following key groups: people who are Black, Latinx, elderly, disabled, immigrants, essential workers, living in congregant settings, and un-housed***.
- Recommendations to NIH and senior hospital leaders
  - Adding people to the study pool who are not seen as the hospital's usual targets is more expensive. We ***need to make clear to NIH and hospital leaders that if diversifying our study pool is a priority, then we need to anticipate and fund the expense required to recruit, care for, and retain a diverse study pool*** that reflects the diversity of our community.
  - We want senior hospital leadership to put ***policies in place that ensure and fund the inclusion of communities hardest hit by COVID***, including:

    - Encouraging health care institutions to have ***workforce policies that ensure that study staff is hired from communities most impacted*** by COVID and that study staff match the diversity of the study pool.
    - Making sure that ***community members from target groups hardest hit by COVID and Long COVID are treated well*** when they come to the hospital to participate in the study and to receive clinical care and support for Long COVID.
- Senior hospital leaders and NIH also need ***to invest in a community communication, education, and engagement campaign that is led by community partners*** who are seen as trusted messengers by their communities; and health care institutions and NIH need to invest in community partners to play this role.
- ***Need policy actions if NIH and health care institutions don't want to pay for COVID clinics***. What's the role of the Table to say our communities want change – and to push for change? ***We need to put together a policy action plan that captures the changes the community wants to see.***
- Part of community engagement is organizing – you often have to push back and create new behaviors in our institutional partners. I am hearing the Table say ***something needs to change in the behaviors of our institutional partners: 1) invest in community partners trusted by communities hardest hit by COVID to inform and recruit members of these communities to participate in research on Long COVID and receive clinical care and support; and 2) invest in community health workers to work with these community partners to help diversify our study pool.*** We cannot hold another meeting unless we can say that change is happening, i.e., that BCRC is developing a recruitment plan with and led by our community partners. Time is short and we need to get this done. Do representation well is the clear message from tonight's Table meeting. ***We may need to do social / political work to get this done.***
- We could ***see if we could get PIs across BCRC to agree to recruit those hardest hit; we could try to get national to mandate it; or we could try to do both***.
- Are there infrastructure barriers to how recruitment for RECOVER operates? I don't know that we're all – health partners and community partners -- on the same page re. our stated goals, i.e., re. diversifying our study pool to reflect the diversity of our community. I'm not hearing that conversation at our sites. ***We need to be crisp and concrete to senior hospital leaders that the critical issue is representation: it's an issue of racism and the erasure of Black and Latinx populations.*** If representation in our study pool matters, as well as providing equitable clinical care and support to patients with Long COVID, then our job is to build support for achieving these essential goals. We need to make crisp, specific asks of senior hospital leaders, homing in on what we want them to do, and then we need to work with them to accomplish what we want them to do. We need to be clear with them about what we want and will fight for.
- We ***need to get senior leaders to agree that we will open up our RECOVER study enrollment and will focus like a laser beam on recruiting Black, Latinx, and other communities hardest hit by COVID.*** The message for this needs to come loudly and clearly about this from Bruce and Ingrid. If we don't make progress on this, we can't go anywhere: the community will not believe us, trust us, and will walk. We need to work with sites and PIs to agree that we will all focus on diversifying our recruitment efforts to include those hardest hit by COVID. ***We also need to find out how different hospital sites are currently doing their recruitment.***

- We also ***need to get senior hospital leaders to agree that even though NIH did not prioritize the goals, role, or funding for representation of our diverse community and advancing health equity in the original objectives it set for the RECOVER study, we need to prioritize these goals in Greater Boston's contribution to the RECOVER study.*** Senior hospital leaders, PIs, and staff, not just RECOVER community partners, need to be committed to and own these goals – beginning with diversifying our study pool by recruiting those hardest hit by COVID. Next, ***we need to understand from our RECOVER leaders -- PIs and Long COVID clinic directors -- what the current barriers are to recruiting this target population to our study pool. Then we need to learn from our community partners,*** working in collaboration with our RECOVER leaders, how to overcome these barriers.

<u>Group 3: Improving equitable clinical care for Long COVID</u>

- ***Connect primary care clinicians with information on Long COVID*** to reach our communities – how do we do that education and how do we ensure the information held by specialty clinics is distributed?
- ***Build good relationships with policymakers***: make sure to promote the economic stability of our communities by ***adding Long COVID criteria for unemployment and other care and support.***
- Policymakers to put ***pressure to add resources for Long COVID care and make them institutional priorities.***
- Have to ***blaze the trail to keep the sense of urgency*** around this!
- Create more ***long-standing relationships with communities*** and move forward together in a sustained way, not just during specific projects.
    - Policy advocacy
    - HPC – implementation grants
    - Move care back to community settings

<u>Report-outs</u>

Groups read the highlights from the notes above, additional discussion is captured below

- We should be unflinching in saying we will only target those hardest hit by COVID – that is the priority, nobody else.
- We need to use and invest in known models for recruiting diverse populations.
- If we are centering humanity and human-centered approaches, we need to have that be a priority and need the financial investment from our institutions.
- Potential partnership between institutional leadership group and Long COVID care group on education and advocacy efforts.
- Solution for consideration for meaningful impact: get the institution executives to take accountability for a humanistic response to Long COVID and engage outsiders to guide staff in bringing cross-functional attention to the systemic structures that sustain the failing conditions.
- Our role is to take the stand to center community and make sure it's done – that is the biggest role we can play in creating change.

Next steps

- We commit to keeping our next steps to be very action focused. The planning committee will put this information together and then reach back out to the Partnership Table to get feedback on how to take these large priorities and break them into actionable pieces and schedule our next meeting.

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 in the coming weeks.