Attendees

Name	Organization	Role
Tracy Battaglia	Boston Medical Center	Primary care physician researcher, co-investigator on RECOVER
Ingrid Bassett	Massachusetts General Hospital	RECOVER site Principal Investigator
Li Chen	Brigham and Women's Hospital	RECOVER Project Director
MyDzung Chu	Tufts Medical Center	ADAPT Director
Cheryl Clark	Brigham and Women's Hospital	RECOVER Investigator
Carline Desire	Association of Haitian Women	Executive Director
Elmer Freeman	CCHERS	ED, Member of BBCC
Barbara Gottlieb	Brookside Community Health Center	Physician
Jennifer Haas	Mass General Hospital	RECOVER co-Investigator; primary care clinician
Janice John	Cambridge Health Alliance	RECOVER Site Investigator
Diane Kanjilal	Massachusetts General Hospital	RECOVER co-Investigator and nurse coordinator
Ronald Lammy	Total Wellness for Elders	President/CEO
Maryka Lier	BPS Health & Wellness	Director
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
Thaddeus Miles	MassHousing	Director of Community Services
Delphene Mooney	On The Rise, Inc.	Executive Director
Caitryn McCallum	Boston Medical Center	RECOVER Project Manager
Yuri Quintana	Beth Israel Lahey Health (BILH)	Chief of Clinical Informatics
Joan Reede	Harvard Medical School	Dean for Diversity and Community Partnership
Linda Sprague Martinez	Boston University School of Social Work	Assistant Director of Research and CTSI Community engagement program
Gyana Srivastava	Beth Israel Lahey Health (BILH)	Research Assistant
Robert Torres	Beth Israel Lahey Health (BILH)	Boston Region Director of Community Benefits
Honorine Ward	Tufts Medical Center	Prof of Medicine and researcher in Geographic Medicine and Infectious Diseases; Site-co-Principal Investigator
Dianne Wilkerson	Black Boston COVID-19 Coalition (BBCC)	Co-Founder
Dean Xerras	Massachusetts General Hospital	RECOVER Co-Investigator; medical director of MGH Chelsea and member of Chelsea's Board of Health
Dani Zionts	Massachusetts General Hospital	RECOVER Project Manager

Group Discussion Questions:
Do you have any questions about the proposed charter?
What are the strengths of the charter?
Are there ways it could be strengthened?
What criteria would you recommend be used to bring on community partners to co-create this project?
Using those criteria, who else would you recommend we invite to join us?

Themes from Discussion:

1. Key needs and next steps: Transparency and to recruit POC and especially Black patients into RECOVER (mentioned implicitly):

- **TRANSPARENCY: How RECOVER works:**
  - **Protocol**:
    - Recruitment processes/outreach approach,
    - Timeline,
    - Budget categories and breakdown,
    - Study protocol/IRB, and
    - What does a visit look like
  - **Priorities and decisions:**
    - Study priorities,
    - Decisions we have made and that we are trying to make,
    - What has changed since the original application was approved,
    - What are our targets, and
    - What variants are we focused on
  - **Study challenges**:
    - What have been the barriers?,
    - How can we make it easier for incoming participants?,
    - What have been the process bottlenecks (e.g., NYU and local IRB approval)
  - **Organizational/oversight process**:
    - Map the study operations – NIH/NYU/hubs/sites/community, cohorts, etc.,
    - Process for changing the protocol,
    - Process for revisiting enrollment goals (esp acute v pasc) with NIH/NYU,
    - What can we control (locally, nationally),
    - What are the boundaries of the study,
    - What can we influence (locally, nationally), and
    - Status of institutional buy-in
  - **How are we providing feedback** to the clinics/clinical care re: Long Covid?

- **LIT REVIEW: What do we already know about community engagement:**
  - Let's not reinvent the wheel – what have other groups done? Best practices for community engagement?
  - What questions did folks raise in first meeting and community listening – answer those!
  - Demonstrate the impact that community partners will have on successful recruitment
  - Have community partners involved in the science
- **CLINICAL DATA**
  - Present data on what long covid is (what symptoms it may cover)

- Demographics of who got covid in Boston so we can try to map our recruitment to that
- Disability data (for Boston covid patients? Or RECOVER enrollees?)
- Vaccination status of folks recruited

- **OBJECTIVES FOR THE TABLE: How the Table will work:**
  - Concrete objectives the table can carry out
  - Where do community partners fit into this initiative?
  - Overall plan for transparency with the community and regular sharing of data
  - Who are we beyond this grant? What can we do beyond the grant?
  - How to make the transition from institutionally led to community led
  - How can we sustain community research engagement?

2. Recruitment and engagement strategy:

- **Partner with community organizations that service the populations we want to enroll**
  - How can community partners help leverage resources to reach key cohorts (e.g., substance use disorder)
  - Review recruitment materials with the Table
  - Bring in community leadership – given them all the information on the study that they need and in writing so they can understand then then disseminate
    - Have individual meetings with leaders from different groups – African American, Haitian American, Cape Verdean, Hispanic
    - Need trusted community leaders on our side, and need to give them the information and resources for them to 1) trust us and 2) advocate for us and answer questions they might get. Should include doctors but not rely on them, not everyone is connected to health care
  - How to best collaborate with community organizations:
    - Consider/learn: What does equity mean to different people? What about trust?
    - Make people feel valued and like they belong – to bring them in, and then throughout with engagement
    - Engage out outreach outside of clinical spaces
    - Different tactics for different groups
    - Bring your authentic self – we only have one shot to make that first impression
  - Deliberately partner with patient reps and bring them to the table, not just clinicians/providers
  - Need to tailor the protocol to the needs of each individual outreach institutions – adaptation necessary for success
- Build trust
  - Get 1-2 leaders at least from the communities you want – more is good, people will trust more if they hear that a group of leaders has lent their weight
  - Peer to peer engagement that is high touch, one-on-one
  - Culturally appropriate training for people collecting data
  - Use real language
  - Consider the real psychological factors that some communities have towards hospitals, medical centers, or research – valid reasons why folks might be anxious or feel negatively about medical research

    - Folks still need housing, food, job security like early pandemic – think about how we can help provide those things – non-health care needs should be part of the package
    - Remember that it is a privilege to be able to socially isolate – ensure our messaging is correct to who we're talking to
- Go where people are
    - Bring research to gathering spots to leverage social capital and build trust (go to where people are and where they feel safe and earn the trust of their leadership)
    - Need to be everywhere and often (multichannel approach)– people need to hear messages repeated over and over from a number of sources, esp trusted sources (think: tv, radio, buses, internet, video – from community members, community reps, peer to peer, high touch)
    - Social media
    - Target health and assistant programs and certified nursing assistant programs targeted towards the elders
    - Labor unions, hotel unions
    - Letter/email followed by a call
- People need to see themselves in the messaging
    - Personal vignettes - Put folks who had covid, are from these communities, and can speak to what it is and how it affected them front and center in marketing materials – esp good if they are a study participant!
    - Don't just recruit, educate- what long covid is, what research participation is, dispel myths
    - Get the message out that research is happening, we want the folks most affected to be part of the knowledge base because otherwise the knowledge that comes out won't include their experience
    - Socializing – BBCC funded a summer program
- Reserve spots for POC or other communities we want to target so they can't go to anyone else
- Specific populations:
    - Involve the younger populations – leaders in homes/communities
    - Link to CAB/PFAC in hospitals
    - Practice-based research networks
    - Specific groups we can link to: housing partners, local broadcasting (Java with Jimmy), VP of the resident service programs, Mass Association of Resident Housing, Boston Health Net
    - Groups who have a strong sense of the RECOVER protocol
    - Dialogue/community meeting in Spanish through some of the Spanish-speaking teams, Spanish-speaking media