Boston COVID-19 Recovery Cohort:
Community Partnership Table Meeting
Thursday, April 4, 2024 from 4-6pm

Link to recording: https://vimeo.com/930853938?share=copy

Forum Summary: Overview

Agenda

4:00   Welcome and Meeting Overview – *Jacqui Lindsay*
4:03   Review the Table's Top Goals – *Jacqui Lindsay*
4:05   Briefings with MA Legislators: focus, results, next steps – *Jacqui Lindsay*
4:10   Clinical Trials: Overview – *Dr. Lindsey Baden*
4:25   BCRC Forums – *Jackie Rodriguez-Louis*
4:40   Community Engagement Process Manuscript – *Dr. Marisha Palm*
5:00   Large Group Discussion: 2024 Goals and Plan
5:55   Closing Reflections & Next Steps – *Jacqui Lindsay*
6:00   **Close**

Attendees

Planning group members: Peter, Jacqui, Aya, Cheryl, Li, Jackie, Bruce Levy, Dani Zionts, Ingrid, Robert, Mara

Speakers: Lindsey Baden

Attendees: Alice Rushforth, Curtis Santos, Cheralyn Johnson, Darris Jordan, Dean Xerras, Yuri Quintana, Humberto Licona, Jennifer Haas, Jon Gothing, Jonathan Garlick, Kathryn Hall, Katie Friedman, Natalie Izaguirre Webster, Ronald Lammy, Janet Mullington, Charlie Williams

Attendees during discussion: Charlie Williams, Cheralyn Johnson, Jonathan Garlick, Ron Lammy, Alice Rushforth

Key Points

Clinical Trials

- VITAL is underway, SLEEP and NEURO are launching, and AUTONOMIC and ENERGIZE will launch later this year.
- Each clinical trial is co-designed by patient, community, research, and clinical feedback and built on each other. So if there is community input on emerging symptoms, a new clinical trial can be created. Community input is needed at all stages of the clinical trials, from design, to conduct, to dissemination

Community Education Forum Series

- Reviewed the past four forums of 2023 and provided a summary of the April 2024 Forum on anti-racist institutional change in healthcare settings
- The Table agrees that the forum is heading in the right direction with the forums, wishes to emphasize trustworthiness during a time of uncertainty, and agreed to help with promoting events

Community Engagement Process Manuscript

- The planning group discussed **writing BCRC's CE model into a manuscript** to document our work for other institutions to incorporate and is currently exploring authorship models to include Table members' perspectives
- **Authorship**: If you are interested in learning more or becoming involved, please contact bcrc@mgb.org and marisha.palm@tuftsmedicine.org

Large Group Discussion re. Top 4 goals

- Goal #1 **Research:** Engage CHWs to support retention in RECOVER observational study and to share information about clinical trials
- Goal #2 **Community Education**: Increase *access* and think of new ways of outreach
- Goal #3 **Clinical Care:** Support different systems related to health (SDOHs) and include CHWs
- Goal #4 **Advocacy**: Continue to build partnerships

Meeting Presentations

Briefings with MA Legislators

- Briefing on January 30th on what **we know and don't know about Long COVID** (link to Jan 30th recording)
- Second briefing will be in the Spring on what priorities are important to the community to **address Long COVID**

Clinical trials overview

Presentation by Dr. Baden

- Clinical trials study to see if we can **treat and reverse Long COVID conditions** by first identifying the major and most debilitating symptoms to study
- Pathology: direct viral effect on biological systems on immune system
- Major symptom clusters: viral persistence, neurologic/cognitive, autonomic dysfunction, sleep disorders, cardio-pulmonary/exercise intolerance/fatigue
  - **Patient perspectives informed symptom and intervention prioritization**
- Clinical studies (Vital, Neuro, Sleep, Autonomic, Energize) were **designed in a similar way** to build on each other using **patient, community, clinical feedback** and to **integrate multiple studies** to share information with each other enabling results to be reported as soon as possible/in a timely matter.
  - Ex. Trial designs shared some endpoints, controls, and approach to patient inclusion; data analysis; and mechanistic studies to inform new targets
- **VITAL** – alleviating Long COVID symptoms by treating viral persistence in patients using Paxlovid (antiviral drug) for 15-25 days. Measuring symptom and objective improvement using questionnaires.
  - Using placebo group to understand natural history of LC, if Paxlovid can improve LC outcomes (perhaps for a subgroup)

Q&A:

- **Does community engagement have a role in these clinical trials? If so, what role does it play?**
  - Community members and Long COVID patients were included during the design of the study. Now, input is needed while the study is being conducted and communicated to the public. A future need could require input to how outcomes can be translated to the broader community
- **Can people interested reach out to enroll?**
  - ABSOLUTELY, active in the Brigham and soon at BILH. Can reach out to bwhlongcovid@bwh.harvard.edu to be connected
  - Two studies (Sleep and Neuro) are launching now and Autonomic and Energize will launch later this year
- **Are there other therapeutic responses beyond Paxlovid?**
  - Paxlovid may not work on all symptom clusters, need multiple shots
- **Which symptoms are most plaguing our community?** This way we can connect communities to particular studies
  - Long COVID has different dominant symptoms (cardio vs. neuro) for different people
  - Clinical trials are designed in a way that allows for branching or other elements to be created. If there is community input regarding emerging concerns, additional studies can be created.
- **As the work evolves, will it be possible to create profiles of how Long COVID is impacting particular communities?**
  - Will be doing blood/cytokine/other profiles. Primary question is if we can help patients based on their symptoms
  - Anchor this on a clinical basis. Paxlovid could work for certain symptoms, but not for others
- **How can we more deeply apply an equity lens to clinical trials?**
  - Dr. Baden welcomes community engagement because the more we can engage our communities, the better the research will serve us

Community Education Forum Series

2-hour long sessions bring speakers and community together to spark discussion around the Table's Top 4 Goals

Forums in 2023:

- Achieving Racial Equity
- Long COVID Clinical Care and Social Support
- The Power of Belonging: from Loss and Grief to healing, Resilience, and Recovery
- Policy Priorities to Address Long COVID in our Country and Advance Health Equity in Our State

April 2024 Forum: Raising the Bar on Advancing Health Equity in Healthcare Institutions and Our State

- **From IARA's report**: There are several levers of change that are crucial to the successful implementation of anti-racist strategies in healthcare institutions of varying sizes.
- **From BMC**: Committed senior leaders + dedicated working groups defined and supported practices to close gaps in healthcare delivery.
- **From Health Equity Compact**: There must be state-level policy change to support and integrate health equity

Discussion:

- **Are we on the right track?**
  - On the right track, forum suggestion – trustworthiness in the face of uncertainty
  - Trust is a critical component of engagement, so much uncertainty around diagnoses/pathobiology. Need to find ways to explain what trustworthiness means in time of diagnostic uncertainty and stigmatization. How do we hold ourselves accountable to build trustworthiness in a way that won't be abused or exploited? How do we stay transparent?
  - The April forum's range of speakers, the presentations, and research were wonderful!
- **How do we continue to grow our network, increase attendance, and foster engagement?**
  - Identifying venues where you can post events in Boston (billboards, flyers, etc)
    - Reaching out to people who aren't in our immediate network
    - Handing out flyers in libraries
  - Alice Rushforth can send list of places she posted events online

Process manuscript

- The planning group discussed **writing BCRC's CE model into a manuscript** to document our work for other institutions to incorporate. Includes
  - 1) Early network building, 2) co-developed goals and priorities, 3) achievements to date, 4) lessons learned, and 5) next steps towards community leadership
- The writing team is committed to **engaging everyone involved** (make key decisions, understand scope, etc) through newsletter, survey, Table meetings
- **Authorship**: Highlighting an **inclusive approach** to involving partners in the writing process
- If you are interested in learning more or becoming involved, please contact bcrc@mgb.org and marisha.palm@tuftsmedicine.org

Large Group Discussion

Goal #1: Recruit and retain diverse study pools and center community voices in research.

Objective: Support **retention** of a diverse study pool in RECOVER research (which observes participants over 4 years).
Objective: Support our diverse community to learn about RECOVER **clinical trials** to discover possible solutions to address Long COVID; and to learn how to participate in them, if interested.
Objective: Center community voices in research.   **Proposed Strategy: Write a paper** to share BCRC's Community Engagement model and to help others learn from it.

- Engaging community health workers network as a strategy for each of these objectives
    - CHWs are from the communities we're engaging and trusted by the patient more than us
        - Multiply reach of study enrollment
- Centering community voices takes a lot of skill to know how to equitably center and engage portions of marginalized and disadvantages communities. i.e. need language to name sources of inequities, communicators also need training and support (unpack their positionality, personal biases, culturally humble) to be able to engage.
    - Objective to center community voices is good, but need training and accountability
    - Key targets: Clinicians that hold mainstream/evidence-based knowledge but not diverse/experiential knowledge,
        - Inclusive science communication movement (Dr. Garlick as a resource)
- Need goals that move the needle and get us the desired outcome, not goals that just sit there/aren't actionable

Goal #2: Support community education and engagement to address Long COVID and health equity.

Objective: Increase turnout to community education forums and community partnership table meetings.
Objective: Increase overall community **engagement** with the BCRC.   **Proposed Strategy:** Use **bidirectional dialogue** at community education forums to increase community engagement.

- Edit turnout objective to "increase **access** to community education forums and community partnership table meetings" and make a measure of success turnout (attendance and views of recordings)
- Strategies to remove barriers and increase access to meetings include:
    - Leverage social media to access younger generation
    - Thinking of time, weather, and technology
    - Technology may also be a barrier for some to join a webinar. Do we have the resources to bring this conversation *to* the communities we want to reach in person? - Cheralyn Johnson
    - Outreach: are we extending invitations to the people we'd like to see
    - In Community Health Centers: Are you interested in solving Long COVID? Here are three ways!
        - Callie reach out to Charlie afterwards re. building a stronger relationship with community health centers and inviting patients and CHC staff to our events
- Bi-directional dialogue
    - Set expectations and boundaries when engaging in bi-directional dialogue

- o   Structuring spaces to make sure both sides are safe (discomfort is different from feeling unsafe)
- o   Requires intentionality
- Accessibility
  - o   Technology as a barrier for some to join the webinars
  - o   Can in person conversations be introduced into our work?

Goal #3: Provide effective and equitable clinical care and social supports.

Objective: Inform and educate clinicians about Long COVID and advancing health equity. 　　**Proposed Strategy: Circulate** relevant **clinical grand rounds** to health system partners + ensure COVID, Long COVID, and health equity presentations are included. 　　**Proposed Strategy:** Do a **pilot project** that supports PCPs to learn from the community and each other re. how to address Long COVID and advance health equity as they seek to improve the 　　healthcare and health of our diverse community.
Objective: Elevate the need for a stronger **primary care infrastructure** to provide equitable care - not exclusively pertaining to Long COVID. 　　**Proposed Strategy:** Carry the message -- in **forums and legislative briefings** -- that a strong primary care infrastructure is necessary for health equity and Long COVID recovery.

- Supporting different systems (more to health than healthcare)
  - o   Understanding SDOH, providing equitable clinical care
  - o   Pilot project to support PCPs (primary care providers) and community health workers will include (physicians, physician assistants, CHWs)

Goal #4: Advocate for policy and institutional change to address Long COVID and advance health equity.

Objective: Identify **shared priorities** for change. 　　**Proposed Strategy:** Structure Table meetings to involve **discussions** re. quarterly progress on Table's top goals and proposed annual objectives and strategies
Objective: Identify and **build partnerships** needed to create change. 　　**Proposed Strategy: Support briefings** to inform BCRC partners - community members, policymakers, & equity leaders - about the issue and to advocate for priorities that improve community health care and health. 　　**Proposed Strategy:** Organize a space for **senior equity leaders** from each health institution to share their strategies and learnings with each other to inform their own work and to charter a collaborative, cross-institutional initiative.

- -   BCRC is interested in building partnerships and supporting collaborations between partners we develop
  - o   Working in institutions and across (to push forward the needle)
- -   Potentially change wording of "Identify shared priorities for change"
  - o   Changing wording to "improvement" or "positive change"

Next Steps

- -   Feature key work of community partners during Table meetings
  - o   Table can also help shape this work
  - o   Discussing how to move all of this work forward to benefit community
- -   What worked
  - o   Jacqui's facilitation

- o   Informative, specificity of information
- Next steps
    - o   Inviting community organizations nationally for the movement to advance Long COVID work