Boston COVID Recovery Cohort (BCRC)
Community Education Forum: June 28, 2023, 6-8pm

Long COVID Clinical Care and Supports: What We Have + What We Need

Forum Notes

Panelists:
- **George A. Alba**, MD, Associate Director, Coronavirus Recovery (CORE) Clinic, Division of Pulmonary and Critical Care, MGH; Assistant Professor of Medicine, Harvard Medical School
- **Tanayott (Tony) Thaweethai**, PhD, Associate Director, Biostatistics Research and Engagement, MGH Biostatistics, Instructor in Medicine, Harvard Medical School, Instructor, Department of Biostatistics, Harvard T.H. Chan School of Public Health
- **Sarimer Sánchez**, MD, MPH, Medical Director of Infectious Diseases Bureau, Boston Public Health Commission
- **James “Jimmy” Hills**, Host of Java with Jimmy

Agenda:
- 6:00   Welcome and BCRC Mission – Dr. Bruce Levy and Dr. Ingrid Bassett, Co-Lead PIs, BCRC
- 6:02:   Forum Overview and Introduction of Panel – Jacqui Lindsay
- 6:05:   An Overview: The Data + Clinical Care & Supports We Have to Address Long COVID – Dr. George Alba
- 6:15:   “First Look”: Key Findings from RECOVER Study re. Adult Cohort – Dr. Tanayott (Tony) Thaweethai, PhD
- 6:30   Panel Discussion: The Data + Clinical Care & Supports We Need to Address Long COVID + How Community Members Can Help
- 7:00:   Q&A Session: Panelists Respond to Questions from Forum Participants
- 7:30:   Q&A: Forum Participants Respond to 3 Questions to Focus and Drive Action
- 7:55:   Reflections, Next Steps, and Close

Key Highlights from the Presentations:
- **The spectrum of symptoms re. Long COVID is varied**, which has made defining Long COVID and understanding how it operates difficult.
- **New research from RECOVER has developed a working definition of Long COVID** that can be used to inform clinical trials and continued research on Long COVID.
- Based on patients’ symptoms, the **research team has developed an equation to identify people with Long COVID.**

Final takeaways

1. Reinfections and not being vaccinated before infection are associated with higher rates of long COVID
2. Look out for key symptoms of long COVID for yourself, your family, and your neighbors

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Score</th>
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<tbody>
<tr>
<td>Loss of smell/taste</td>
<td>8</td>
</tr>
<tr>
<td>Post-exertional malaise</td>
<td>7</td>
</tr>
<tr>
<td>Chronic cough</td>
<td>4</td>
</tr>
<tr>
<td>Brain fog</td>
<td>3</td>
</tr>
<tr>
<td>Thirst</td>
<td>3</td>
</tr>
<tr>
<td>Heart palpitations</td>
<td>2</td>
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<tr>
<td>Chest pain</td>
<td>2</td>
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<tr>
<td>Fatigue</td>
<td>1</td>
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<tr>
<td>Change in sexual desire/capacity</td>
<td>1</td>
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<tr>
<td>Dizziness</td>
<td>1</td>
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<tr>
<td>Gastrointestinal problems</td>
<td>1</td>
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<tr>
<td>Abnormal movements</td>
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</tbody>
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**Definition of post-exertional malaise:** Symptoms worse after even minor physical or mental effort

**Definition of brain fog:** problems thinking or concentrating

**Definition of dizziness:** Feeling faint, dizzy, "goopy"; difficulty thinking soon after standing up from a sitting or lying position
There is now a diagnostic ICD-10 code for Post COVID-19 conditions, unspecified, which enables physicians to indicate Long COVID using electronic medical records.

To Provide Effective and Equitable Care and Support for Our Diverse Community:
Priorities We Need to Address in Partnership with Our Community:

- **Build a data tracker of Long COVID across the state and nationally.**
- **We don’t yet have a clinical agreement on how to diagnose Long COVID, which makes it more difficult to build a data tracker.** Do continued research to develop a clinical agreement so that the data we capture can more accurately track the scale and evolution of Long COVID, who’s impacted by it and how, and what clinical care and social supports and resources they need -- and that our society needs to invest in -- for people to live with and recover from Long COVID.
- **Providing increased and widespread education of PCPs and other health care providers about Long COVID is urgent** -- including the impacts of Long COVID on patients and their families, and what care, support, and resources are available to help them.
- **Messaging to build widespread understanding about Long COVID needs to be prioritized and targeted to reach three key audiences:** 1) all segments of our diverse community, including and especially those hardest hit by COVID, 2) the leadership of our health care institutions, and 3) policy makers at the local, state, and national levels. What is the message, who needs to see the message, and how can we best get the message out to those who need to see it, and those who need to do something about it?
- **Build a diverse workforce and culture of care across health care and other systems serving our diverse community** – a workforce and culture that centers our shared humanity and is guided by the value of life beyond the economic output of people.

Panel Discussion:

- **What data are you aware of about the scale of Long COVID – in Greater Boston, our state, and nationally – and of who has it?**
  - There is no data collection infrastructure to track Long COVID, thus there is no coordinated data around Long COVID.
  - The state tracks disease trajectory to understand and share what it knows about COVID.
  - Long COVID data exists in siloes.
  - Right now:
    - Diagnosis of Long COVID relies on self-reported symptoms to physicians who support and are trusted by community members. This requires the community and physicians knowing what the symptoms are, and physicians building space for trust and support.
    - There is no Long COVID test like there was for COVID, so it is more difficult to know who has Long COVID.
      - Clinical risk scores help and can be applied to electronic medical records to flag those with Long COVID risk. However, this can be fraught with bias.
      - Patient or physician reported cases must be screened.

- **What is needed to create a comprehensive Long COVID data tracker?**
  - We need “overaggressive intentional investment to do proper outreach and get the proper data needed” to represent our communities of color
• Informing those who are seeing patients with Long COVID (primary care physicians and physicians at Long COVID clinics) about Long COVID symptoms, diagnosis, treatment, and resources
  • Dr. Alba works at a Long COVID clinic but is unsure about what other Boston Long COVID clinics are seeing re. Long COVID cases, or what resources exist at these clinics to address Long COVID.
• Informing the community of what Long COVID is so people can self-report symptoms
• Making sure that those flagged for Long COVID are representative of the population.
  • Language is a barrier. “We’re seeing fewer Hispanic patients in Long COVID clinics despite similar referral rates to White patients.
• A Long COVID data tracker requires buy-in on the state level to coordinate all the health systems and requires community buy-in to inform intentional marketing and outreach.
• How aware are communities about Long COVID? What kind of coordinated communication strategy is needed to build widespread awareness?
  • Follow the work that Diane Wilkerson did with education and outreach for COVID testing and vaccination
  • Use social media to inform younger generation
  • Aunties, Uncles, barbershops, churches are good entry points. They also need to be compensated for the outreach they do
  • Using incentives to get communities to get out there and learn
  • What do we want to say? – Dr. Sprague-Martinez is launching a campaign to teach community what Long COVID is and where to go for more info
    • Be transparent about not knowing
• What efforts are there to inform primary care physicians about Long COVID?
  • There is a working definition, but no clinical agreement yet.
  • There are continuing medical education courses. For example, Dr. Alba teaches PCPs about Long COVID. He shares with them that because there are many unknowns, he’s learned to sit in that discomfort.
    • Unsure what other health institutions do. We need to break down siloes between institutions and collaborate instead to share knowledge of what each institution is doing and learning about Long COVID.
  • Important for PCPs to listen to and learn from the lived experiences of their patients.
• Given all you’ve learned from each other this evening, what priorities most need to be addressed to ensure our communities receive the effective and equitable clinical care and resources they need to address and live with Long COVID and improve their health?
  • The pandemic shed light on the unattended medical needs of our community. We need to prioritize investment in our healthcare infrastructure to support providers to effectively and equitably care for our communities – including addressing these unattended medical needs.
  • Invest in our primary care community.
  • Diversify the workforce of our healthcare system.
  • We need state investment in community health centers so that community needs and priorities inform research and care.
  • Provide support for disability – Long COVID is protected as a disability under ADA.
    • The value of a person in society is more than their economic output.
  • Focus on equity in prevention – continue vaccinations (which protects against Long COVID) and also Paxlovid uptake.
• **Invest in health promotion overall**, to prepare us for the next infectious diseases.

• Multiple infections worsen conditions of Long COVID.

• Important to continue testing to help with diagnosis of Long COVID.

Forum participants discussion

• **Given all you’ve learned from each other this evening, what priorities most need to be addressed to ensure our communities receive the effective and equitable clinical care and resources they need to address and live with Long COVID and improve their health?**
  
  • More access to info
  
  • “Outreach by trusted messengers and education”
  
  • “Public health and academic institutions should develop an intentional curriculum, sites, and new staff to address Long COVID, because healthcare is already overwhelmed.”
  
  • Grand rounds for PCPs “with life stories of those impacted by Long COVID... to help physicians connect with the humanity of patients and families impacted by Long COVID.”
  
  • “I love the idea of making humanity more of a centerpiece in medicine. It seems like Long Covid can also be a vehicle to help practitioner training (for doctors, nurses, social workers & other public health practitioners) evolve to help meet this need. As mentioned, this should be a partnership that community helps leads, design & practice at each point.”
  
  • “Priorities- Communities need local and state funding to provide Long COVID resources and education.”

• **What specific actions would you like to see each of our speakers take to help achieve the priorities most important to you?**
  
  • “I’d like to see them advocate for greater basic community communication regarding symptoms of Long COVID and how to access care.”
  
  • “I would like to see our speakers commit to the cause long term – over the course of people’s lives and changes in the workplace – because Long COVID is long term. Are the speakers able to commit long term or have a predecessor to continue for them?”
  
  • “I would like to see the medical research related to Long COVID conducted in communities – in churches, mosques, synagogues, and especially in affordable housing complexes.”
  
  • “I’d like to see our speakers advocate for social supports in the community to maintain those who are experiencing Long COVID.”
  
  • “I like to see the speakers help us get the results of what is being done and what is actually working.”

• **What actions could you take?**
  
  • “Keep informed. Educate and be open to education. Spread the word to inform others in my community.”
  
  • “Collaborate with you all on this forum and share my challenges in the community.”
  
  • “Continue to educate the communities I serve through community-based workshops. Inform my community partners, family members, and friends about the prevalence of Long COVID, especially in communities of color.”