

Long COVID Workshop

Massachusetts-Community Engagement Alliance

- [Insert Presenter Name Here]

NIH CEAL
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**Welcome to the MA-CEAL
Long COVID Workshop!**



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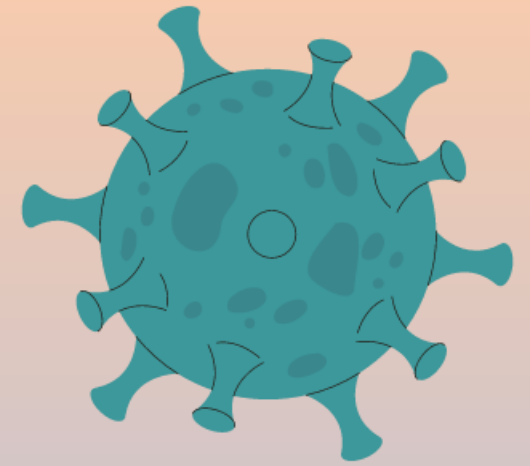
Workshop Objectives

- Develop Basic Understanding of COVID-19
- Understand general guidelines for protection and prevention of COVID-19
- Define and describe symptoms of Long COVID
- Identify impacts of Long COVID and the implications for underserved communities
- Learn about treatment and support for Long COVID

Think back on the COVID-19 pandemic: What is one emotion you experienced?



About COVID-19



COVID-19 (coronavirus disease 2019)

- A disease caused by a virus named SARS-CoV-2
- This virus can be transmitted by both symptomatic and asymptomatic individuals
- Causes respiratory symptoms that can feel like a cold, a flu, or pneumonia
- Older adults and people who have certain underlying medical conditions are at increased risk of severe symptoms
- Heavier burden on Black, Indigenous, and People of Color (BIPOC) and underserved communities

Source: [cdc.gov](https://www.cdc.gov)

How SARS-CoV-2 is Spread

There are **two ways** SARS-CoV-2 spreads :

1. Droplets: Sars-CoV-2 spreads when an infected person releases droplets that contain the virus



2. Airborne (aerosols): Sars-CoV-2 spreads when an infected person breathes out small particles that contain the virus, called aerosols



COVID-19 Prevention

- Wear high-quality masks
- COVID-19 vaccines are **safe, effective and offer the best protection** against becoming seriously ill, being hospitalized, and even dying from COVID-19
- Stay up to date with COVID-19 vaccines and booster shots
 - Immunity can **decrease** or "**wane**" over time
 - Boosters increase or "**boost**" antibody levels even higher than they were after the second dose

WHICH MASKS OFFER THE BEST PROTECTION?

POOR

- any cloth mask without filter
- bandanas
- Gaiter



GOOD

- cloth mask with an extra layer that is a filter (fits well)
- medical surgical mask that does not fit well



BETTER

- double mask
- medical mask fitted using knot technique



BEST

- well-fitting respirator such as N95



2023-2024 COVID-19 Vaccine Recommendations

- 1 dose of either Pfizer or Moderna 2023-2024 COVID-19 vaccine is recommended as a Booster in persons older than 12 years
- For persons 12 years and older who have never been vaccinated, 1 dose is given as primary dose and 1 dose for booster
- Talk with a trusted clinician to find out more about these vaccines

***Note that vaccine recommendations change every year.**


Please refer to CDC website for the most up-to-date information:
<https://www.cdc.gov/coronavirus/2019-ncov/vaccines/index.html>

COVID-19 Testing and Treatment

If you have symptoms of COVID-19, you need to get tested

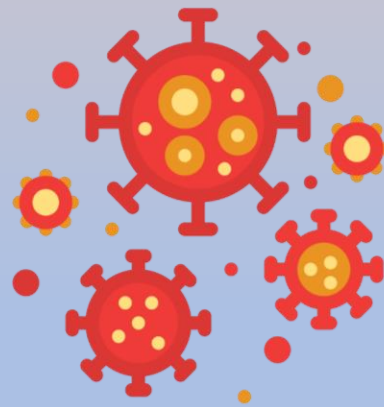
1. Home based testing ✓
2. Facility based testing ✓

If you are diagnosed with COVID-19, treatment is available:

1. Paxlovid (oral tablets) – Preferred
2. i.v. Remdesivir 
3. Molnupiravir (oral)

Source: https://bfscd.ss19.sharpschool.com/district_news/illness_and_mask_update

Some people experience prolonged symptoms after a diagnosis of COVID-19



Long COVID is a patient coined term

- First used in May 2020 as a hashtag on Twitter by Elisa Perego, an archeologist at University College, London

Long COVID Symptoms: 200+ described



Headache



Memory Fog



Coughing



Body ache



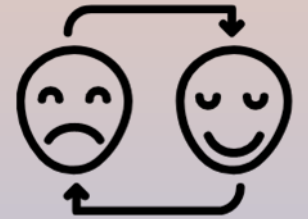
Runny nose



Fatigue



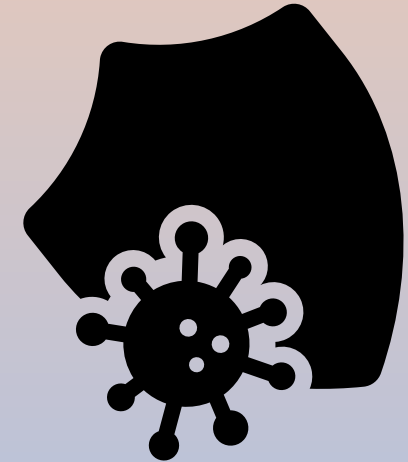
Loss of smell and taste



Depression or anxiety

Symptoms present four or more weeks after SARS-CoV-2 infection that last for at least 2 months and cannot be explained by an alternative diagnosis.

We Don't Know Why Some People
Develop Long COVID!



Long COVID symptoms can appear at different times for different people:

- Some people are symptomatic with COVID-19 and symptoms never go away despite testing (-)
- Some people will be symptomatic with COVID-19 and the symptoms will go away but come back weeks to months later despite testing (-)
- Some people will have no symptoms with COVID-19 and then develop symptoms weeks to months later despite testing (-)

**People with Long COVID are
NOT infectious**

Though Long COVID is a risk, MA-CEAL survey data showed that many individuals did not know what long COVID was

Let's talk about it!

How long do symptoms of Long COVID last?

- A lot of people recover in weeks to months
- Some people report symptoms lasting for longer than 1-2 years (at this time)

Do other viruses cause long-term symptoms?

Yes:

- A number of viruses may cause long-term symptoms
 - E.g. Chikungunya (can cause arthritis), Dengue Fever, etc.

Do other conditions look similar to Long COVID?

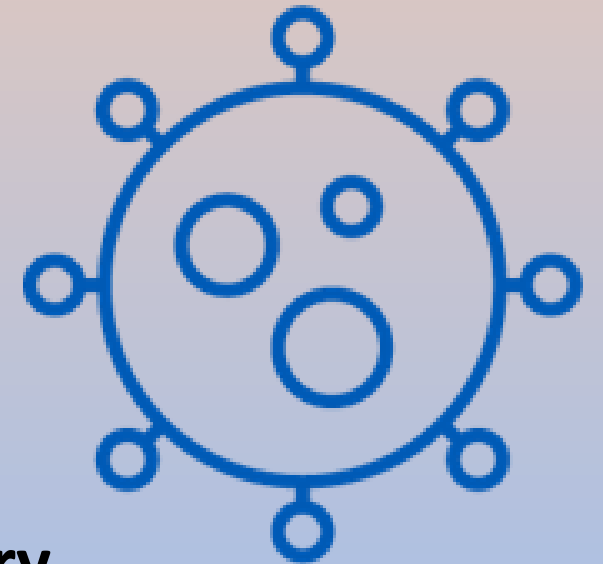
Yes:

- E.g. Chronic fatigue syndrome

CDC. Post-COVID conditions among adult covid-19 survivors aged 18–64 and ≥65 years - United States, March 2020–November 2021. Centers for Disease Control and Prevention. <https://www.cdc.gov/mmwr/volumes/71/wr/mm7121e1.htm>. Published May 26, 2022. Accessed November 29, 2022.

Potential ways Long COVID affects our body

- **Cells** might be infected from COVID-19 infection
- Change in **immune system** response
- Persistent **inflammation** in the immune system
 - For hospitalized patients
 - The condition could be part of '**prolonged recovery phase**' after a critical illness



Implications of Long COVID

- **Health Equity**

- Racial disparity in access to treatment
- Low health literacy in communities of color

- **Economic**

- Decreased work productivity
- More individuals on disability leave
 - Financial concerns/burden for those with post-COVID syndromes

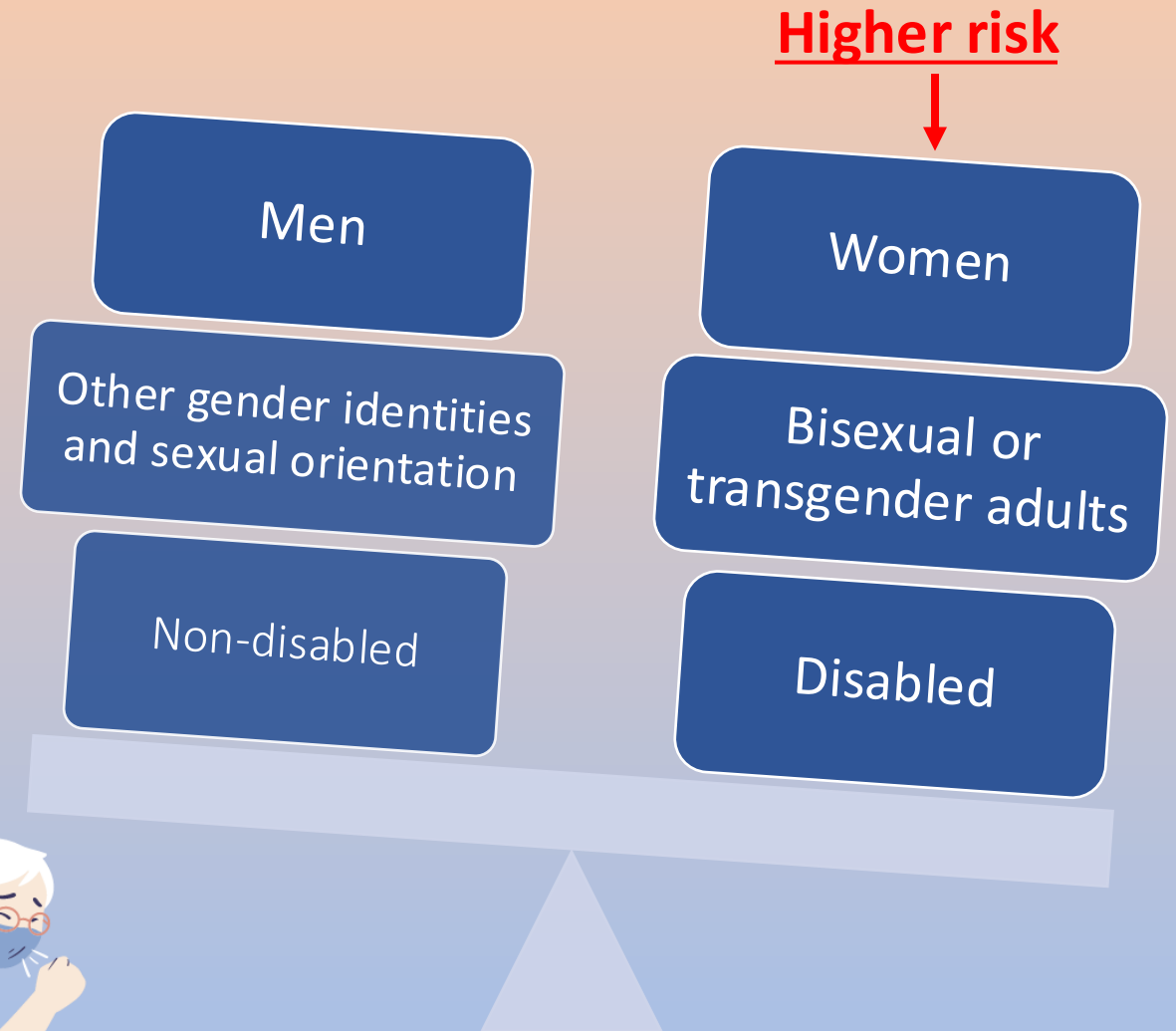
- **Social**

- Education (with higher impact on communities of color)
 - Children and young adults more likely to miss school or college, adults may miss professional development opportunities
- Sense of isolation



Who Is At Risk of Long COVID?

- Women
- Patients hospitalized for COVID-19
 - ICU stay during acute infection
- People with need for additional oxygen during COVID-19 illness
- People with multiple medical comorbidities



Burden of Long COVID is high in women, bisexual, transgender and disabled adults

Martimbianco ALC, Pacheco RL, Bagattini AM, Riera R. Frequency, signs and symptoms, and criteria adopted for long covid-19: A systematic review. International journal of clinical practice. <https://pubmed.ncbi.nlm.nih.gov/33977626/>. Published June 2021. Accessed November 29, 2022.

CDC. Long Covid - Household Pulse survey - covid-19. Centers for Disease Control and Prevention. <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>. Published November 29, 2022. Accessed November 29, 2022.

Other factors predisposing to develop long COVID

- Re-infections of COVID-19
- Socioeconomic risk factors include:
 - Lower income
 - Lack of ability to adequately rest in the early weeks after developing COVID-19

Bowe, B., Xie, Y. & Al-Aly, Z. Acute and postacute sequelae associated with SARS-CoV-2 reinfection. *Nat. Med.* <https://www.nature.com/articles/s41591-022-02051-3>
Williamson, A. E., Tydeman, F., Miners, A., Pyper, K. & Martineau, A. R. Short-term and long-term impacts of COVID-19 on economic vulnerability: a population-based longitudinal study (COVIDENCE UK). *BMJ Open* 12, e065083 (2022).
Ziauddeen, N. et al. Characteristics and impact of Long Covid: findings from an online survey. *PLoS ONE* 17, e0264331 (2022).

COVID-19 and BIPOC Communities

- Burden of COVID-19 is high amongst the BIPOC communities
 - Black/African Americans: **2.2 X** more hospitalization and **1.7 X** higher death rate
 - Latino/a/Hispanics: **1.9 X** more hospitalization and **1.8 X** more death
- Life expectancies shortened by COVID-19
 - Black individuals by **2 years**
 - Latino/a individuals by **3 years**
 - White individuals by **0.7 years**

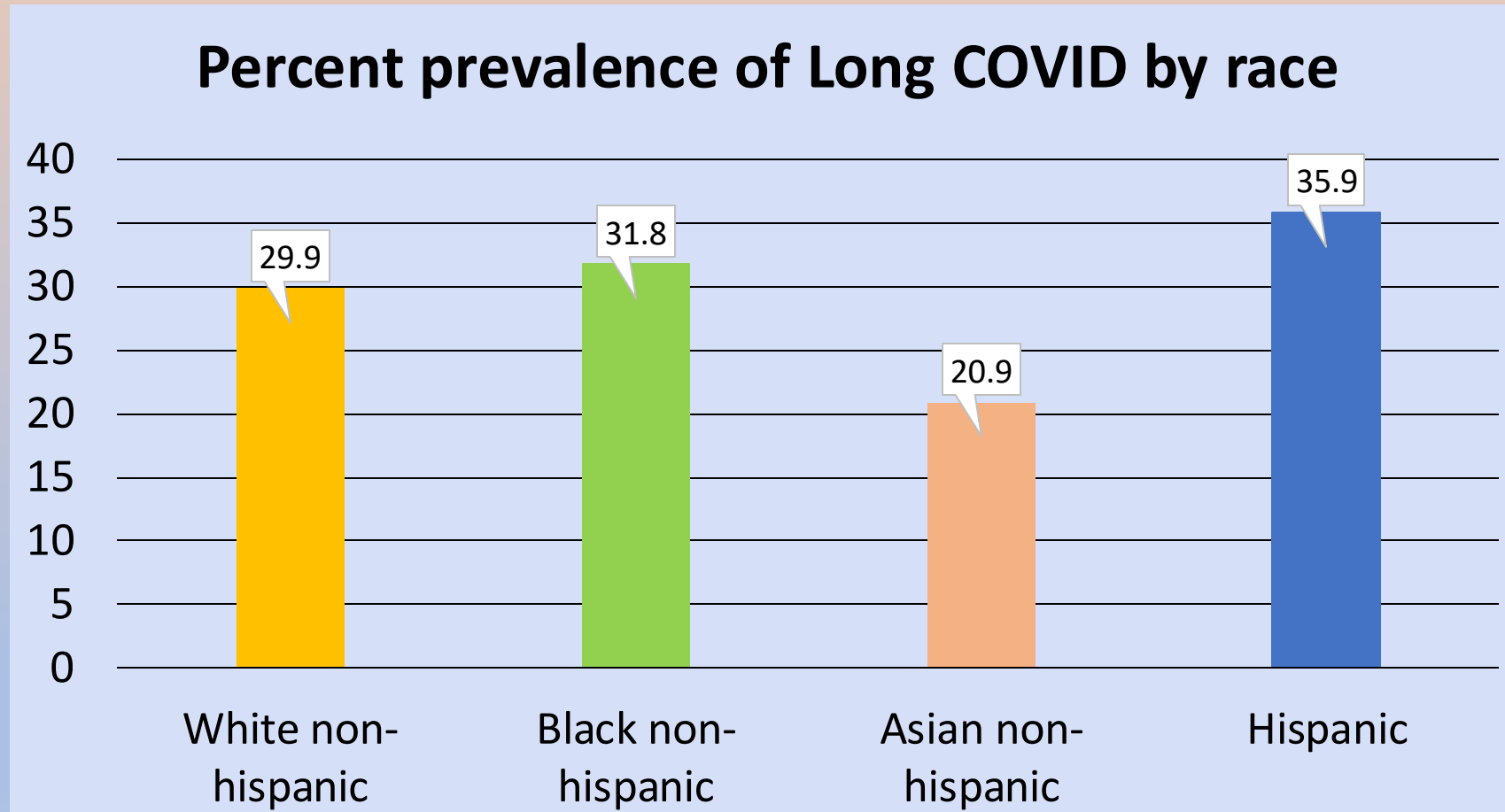


Long COVID rates in the US is decreasing

- Early reports from CDC showed 1 in 5 adults (i.e., 20%) experienced symptoms of long COVID
- In early June 2022, 7.5% Americans aged 18 or older reported symptoms of Long COVID
- In mid-June 2023, this figure has decreased to 6% reporting long COVID symptoms

Source: https://www.cdc.gov/mmwr/volumes/72/wr/mm7232a3.htm?s_cid=mm7232a3_w

Long COVID rate is higher in Latino/Hispanic and Black adults



National Center for Health Statistics. U.S. Census Bureau, Household Pulse Survey, 2022–2023. Long COVID. Generated interactively: from <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>

A different study with a different report:

- Study supported by the NIH RECOVER initiative showed that majority of patients from a sample of 30,000 with long COVID diagnosis were:
 - White, non-Hispanic
 - Female
 - More likely to live in affluent areas with greater access to healthcare

RECOVER= Researching COVID to Enhance Recovery

Source: <https://covid19.nih.gov/news-and-stories/symptoms-long-covid-differ-people-different-racial-and-ethnic-groups>

Something to think about:

- Are BIPOC community members aware of long COVID?
- Is there a difference in who has long COVID and can access long COVID care?
- What are the barriers and how can we overcome these?

Multiple barriers to health equity in care for Long COVID:

Economic barriers:

- Minimal or no insurance
- High co-pays
- Loss of or decreased income due to Long COVID or as a result of the pandemic
- Less job security, less job flexibility and lower entitlement to sick leave or occupational health service



Occupational barriers:

- Higher proportion of BIPOC communities are essential workers
- Sometimes the choice is between prioritizing their health vs ensuring basic family income



Other barriers:

- Housing and food instability



Geographical barriers:

- Vulnerable populations often reside in resource poor settings without easy access to health care services



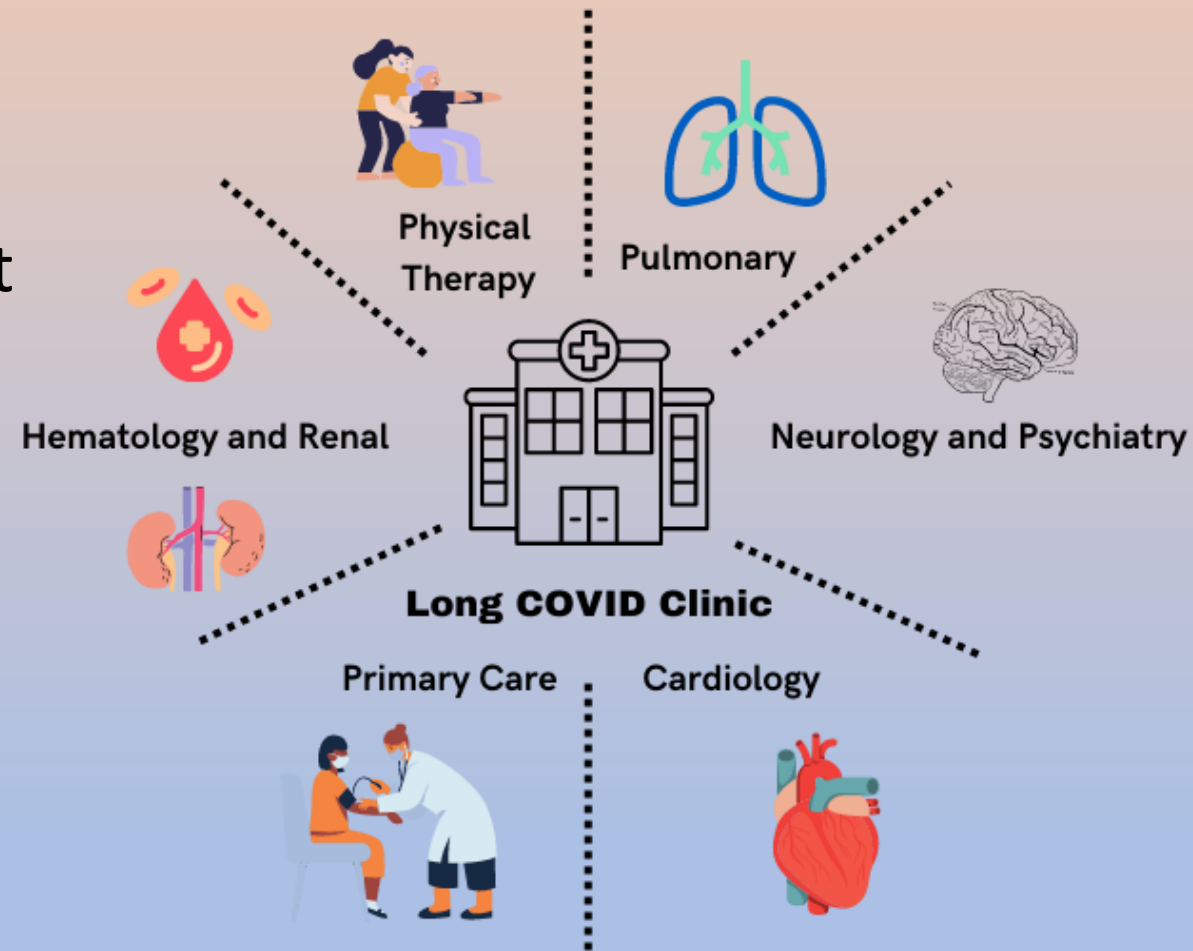
Other reasons leading to Long COVID inequity:

- Mistrust in medical system
- Spread of misinformation
- Lack of awareness surrounding Long COVID
- Systemic disparities within healthcare systems
- Lack of recognition of Long COVID by physicians



Long COVID Clinics

- Multidisciplinary
- The goals are:
 - To understand Long COVID with input and engagement from communities
 - Develop treatment modalities for managing Long COVID
 - Develop strategies to prevent patients who have COVID-19 infection from developing Long COVID



What to expect when you are seen in Long COVID Clinics

Patients receive individualized care, which may include:

- Detailed interview regarding symptoms
- Physical examination
- Blood tests
- Referral to other specialties
- Specialty tests like CT scans, lung function tests, etc. are based on individual assessments and symptoms



When to seek care at Long COVID clinics?

1. Talk to your primary care or trusted physician if you have symptoms after COVID-19 that last for longer than **4 weeks**
2. Care at Long COVID Clinics is recommended if symptoms are:
 - **moderate to severe AND/ OR**
 - **interfering with** work, daily activities, self-care, mental health etc.
3. Most mild symptoms of Long COVID that do not interfere with day-to-day activities are expected to improve with time.
4. All patients are evaluated at Long COVID clinics regardless of symptom severity

How to prepare for Long COVID appointment

Before the appointment, it's important to:

- **Prepare descriptions** of the best and worst days of symptoms
- Make a **list of all current medication** and supplements/over the counter treatments
- Make a **list of questions** for the appointment
- **Take notes** to remember the discussion with your clinician

After the appointment make sure to:

- Keep **track** of your symptoms (symptom log)

What to Do Before the Appointment (continued)

If your appointment is a telemedicine visit:

1. Ensure that you have access to a phone and/or computer with internet access for a video visit
2. Ensure that you are in a private location so you can talk freely with your doctor

Living with Long COVID

- A 2021 study has shown that 6 months after having COVID-19, many adults had:
 - *Anxiety*
 - *Low mood*
 - *Insomnia*
- Along with this, being in the ICU can lead to poor mental health within 6 months (if you become severely ill from COVID-19, you may need to go into the ICU)



IMPORTANT TO KNOW



- About the vaccine:
 - Vaccination **may decrease symptoms** if the patient has Long COVID
 - Vaccination **may prevent the development** of Long COVID
- About treatment:
 - Treatment of COVID-19 infection with Paxlovid **may reduce** the risk of Long COVID

Notarte KI, Catahay JA, Velasco JV, et al. Impact of covid-19 vaccination on the risk of developing long-COVID and on existing long-COVID symptoms: A systematic review. eClinicalMedicine. [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(22\)00354-6/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(22)00354-6/fulltext). Published August 26, 2022. Accessed November 29, 2022.

Xie Y, Choi T, Al-Aly Z. Nirmatrelvir and the Risk of Post-Acute Sequelae of COVID-19. MedRxiv. <https://www.medrxiv.org/content/10.1101/2022.11.03.22281783v1%E2%80%8B>. Published November 3, 2022. Accessed November 29, 2022.

Reminders for patients with Long COVID

- Be patient with yourself
- Get vaccinated + boosted
- For "new" (breakthrough) COVID-19 infections-get treated if you are eligible
- Ask for medical help and follow through with the recommendations
- Be informed and do not hesitate to ask questions

Wrap Up/ Conclusion

- We have now concluded the Long COVID Workshop

Questions?

