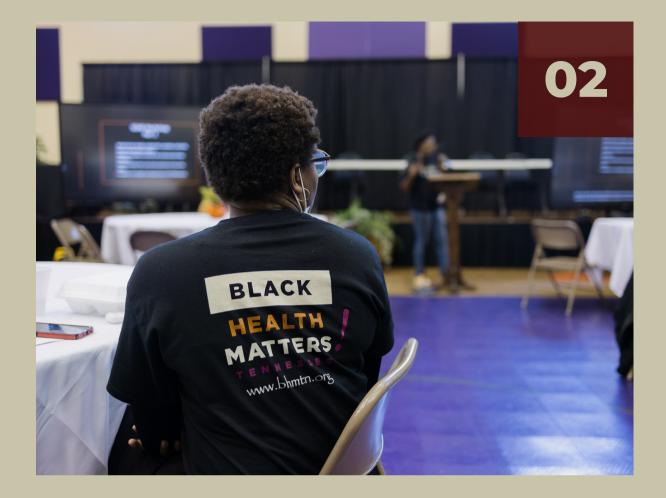
# LONG COVID TOWN HALL REPORT

## 2023

The findings in this report are from the town hall and listening session held on November 2, 2023 at St. James Missionary Baptist Church



www.bhmtn.org



## ABOUT OUR TOWN HALL

The Tennessee Justice Center and Black Health Matters TN collaborated to host a listening session in partnership with Community Catalyst. The purpose of the listening session was to understand the needs of the community in addressing Long COVID or Post-COVID symptoms. Our goal was to facilitate meaningful conversations among community members that included health providers, faith leaders, and community organizations in order to develop community-driven recommendations to address the impact of this condition.

## BACKGROUND ON LONG COVID

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## What is Long COVID?

Long COVID is the condition where some people who are infected by COVID continue to experience symptoms that can last weeks, months, or years, even after recovering from COVID. These symptoms can be ongoing, or they can be recurring, meaning symptoms start appearing again.

### What are the symptoms of Long COVID?

- Extreme fatigue
- Coughing
- Difficulty breathing or shortness of breath
- Aches and pains
- Pins-and-needles feelings
- Anxiety or depression
- Fever

- Brain fog (trouble thinking or remembering things)
- Fast-beating or pounding heart
- Changes in menstrual cycle
- Sleep problems
- Stomach pain or diarrhea
- Loss of smell or change in taste
- Lightheadedness or dizziness

## Why is this important?

People with Long COVID may experience challenges in getting diagnosed. There is no test to diagnose Long COVID; rather, medical providers must rule out other possible causes or diagnoses. In addition, some Long COVID symptoms may not seem related to COVID. This can result in a medical provider misunderstanding unexplained symptoms, making it difficult to diagnose.

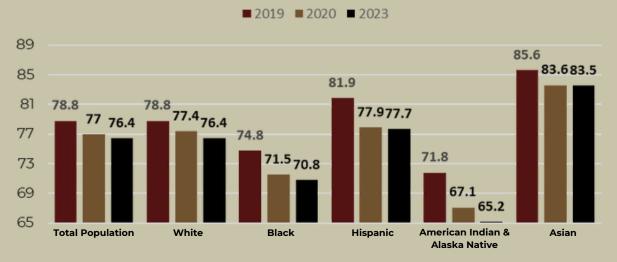
## LONG COVID IN TENNESSEE

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### **34000** OF TENNESSEANS WHO HAD COVID ALSO SUFFERED FROM LONG COVID SYMPTOMS.

### **HEALTH INEQUITIES**

The COVID-19 pandemic triggered a decline in <u>life expectancy for Black</u>, <u>Hispanic, and American Indian populations</u>. Since 2019 the life expectancy of these populations <u>has declined by 4+ years</u>. Additionally, Tennessee has refused to expand Medicaid resulting in negative health impacts for these communities.



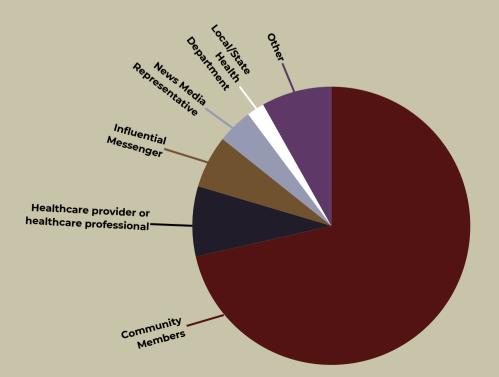
Source: Pandemic to Prosperity



### THE POWER OF YOUR VOICE

We called on our community to share their stories and experiences. Our community showed up to be heard with over 70 people participating in the survey and/or town hall! We gained insight on the Post-COVID symptoms people were experiencing, the impact it had on their lives, and the support our community needs.

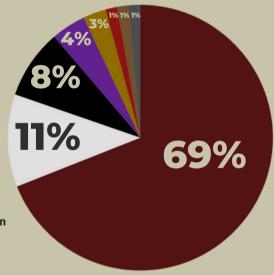
### **The Voices Represented**



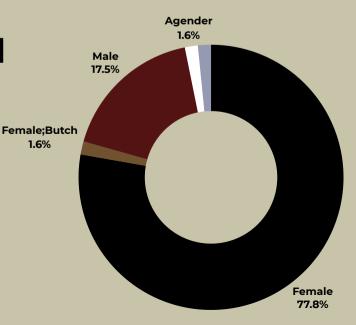


### THE DIVERSITY

- Black or African American
- Other/Choose not to identify themselves
- White
- Hispanic
- Asian or Asian American
- Middle Eastern
- Biracial: Black or African American and White
- Native American



## Self-Reported Gender of Participants



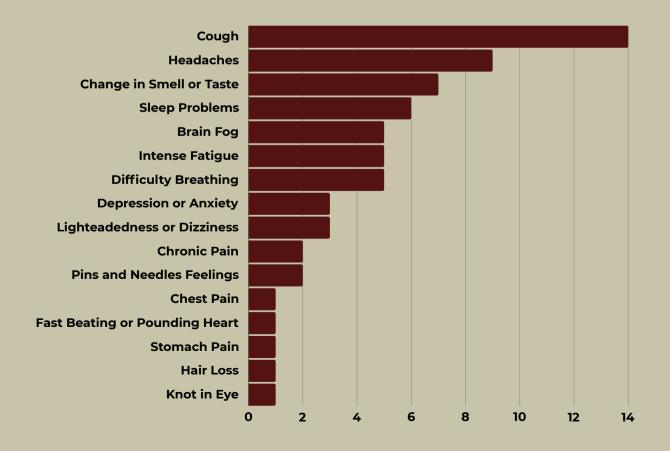
## THE LONG COVID EXPERIENCE



**OF THOSE WHO TESTED** POSITIVE FOR COVID CONTINUED TO EXPERIENCE SYMPTOMS AFTER THE INITIAL DIAGNOSIS.

### Long Lasting Symptoms

Below you will find the symptoms that people continued to experience even after they no longer symptomatic.







### THE CONVERSATION AT THE TOWN HALL

The town hall had 4 groups and each group had someone to facilitate the conversation around COVID and/or health disparities. The discussion focused on the strengths, opportunities, aspirations, and results (SOAR) in our community. The SOAR process allowed us to understand our current strengths and envision a future that addresses our needs.

#### STRENGTHS

- What strengths does your community have to address COVID and/or health disparities?
- What is working in the community?

#### ASPIRATIONS

- Which opportunities excite and inspire you?
- How can we build on them more?

#### **OPPORTUNITIES**

- What resources do we want available to support COVID and/or address health disparities?
- How can we make the most of our strengths?

#### RESULTS

- What will the community look like when your top 6-10 opportunities and aspirations are realized?
- What will look different and how will it change your community?





## **STRENGTHS IN OUR COMMUNITY**

Access to Free COVID Vaccines and Test Kits

• We are more likely to get vaccinated if they are free and at community events or churches. We are also more forthcoming if trusted providers like Meharry, local health clinics, and health department are within walking distance of our neighborhood. It used to be easier to access vaccines and test kits but since the end of the public health emergency and the commercialization of the COVID vaccine it has been more difficult to find resources.

#### **Community Support**

• When in need we can rely on family members, friends, and church members to help. Many of us had our community provide transportation to receive medical care or drop off groceries and food when we were sick.

**Education Through Trusted Resources** 

 We are most likely to trust educational information if it's coming from a trusted resource. Trusted resources include spiritual and/or faith leaders and local community organizations. In addition, culture plays a large role in getting up-to-date information. A lot of us rely on "word-of-mouth" communication from trusted community members or from culturally relevant media like radio stations and Spanishspeaking news outlets.





## **OPPORTUNITIES IN OUR COMMUNITY**

#### Community-Based Events and Education

 We want to learn and have more in-depth conversations at events. The opportunity to attend the events should be held at convenient times to the working class and at trusted locations like churches, parks, libraries, and health departments. We want our advocates and influencers to have up-to-date information. They would spread accurate information to the community through social media and "word-of-mouth."

#### Healthcare Coverage and Medicaid Expansion

 "Healthcare for all" would improve the lives of our community. We wouldn't have to worry about not being able to afford the medical care we need. Currently, many of us are uninsured or underinsured which impacts our ability to seek healthcare. Medicaid expansion would ensure we have equitable access to the care we deserve.

#### Having Trusted Health Professionals

 Many of us have had negative experiences with healthcare professionals. We believe that there needs to be trust between healthcare professional and the patient. This first starts by giving medical providers more information and training on how to diagnose Long COVID. We also want there to be more opportunities for minority populations to be connected with culturally competent healthcare providers. More minority populations should also be given the opportunity to participate in clinical trials.





### **ASPIRATIONS FOR OUR COMMUNITY**

#### Sharing our Truth

• Our stories and testimonies are powerful. We must be transparent about our experiences and push for changes.

#### Healthcare Coverage

 No one should be without health coverage! As a community, we must vote in our best interests to make sure Medicaid is expanded and that there aren't cuts to our coverage.

#### Safe Spaces

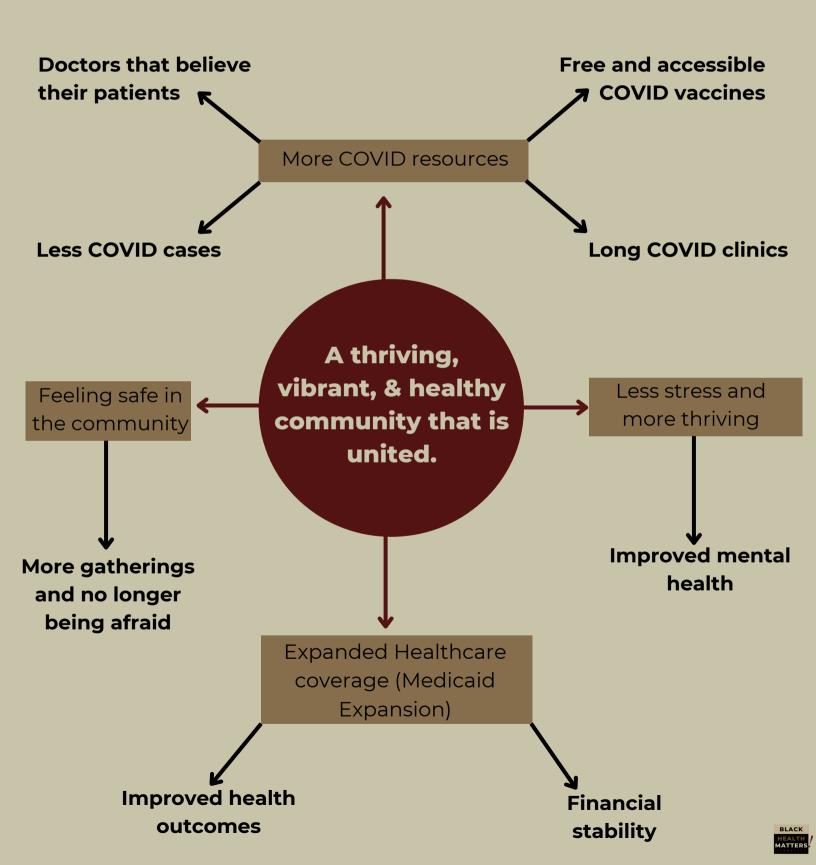
• Our communities should have the funding needed to create safe spaces. The funding would go towards creating community projects to improve the neighborhood and enhance safety.

#### Health Hubs and Mobile Clinics

• Our communities should have "health hubs" or mobile clinics that offer wraparound services to food, shelter, educational material, healthcare, and vaccines. Having these resources at trusted locations will allow the community to openly talk about their concerns and have their basic needs met.



## RESULTS WE WANT IN OUR COMMUNITY 12



## BHM TN's Dedication to Health Justice

Black Health Matters TN is dedicated to eradicating the health disparities that exist as a result of racism. This racist history impacts our present-day policies and health outcomes. At Black Health Matters TN, we know that it is up to us to demand an end to racial health disparities that cause the suffering and deaths of Tennesseans. We use our platform to amplify Black and Brown voices to demand health justice.

## Join us in making "good trouble!"







Townhall sessions which was very informative. Although, I Always tested negative affect being exposed nound frankly t Palendys that Actually caught Covid (some hospitulised on a respirator. When my God-notice contracted Govie while in the numsing Home, I was so hart ful be charse I was restricted from visiting the numsing home went on lock down. I plumas stayed up to ate with any vectorations given in an effort to keep from to help support MY Community with

LONG COVID

I hope everyone would get Vaccinated + BoosteD. I truly Believe of I had not Been Fully Vaccinated I would not Be here today with ME Being immunal Compression with Rhuematoid Aetha. His, Type 2 Diabots and heart trouble. COUID did A wamber on Ma but Not as Bad

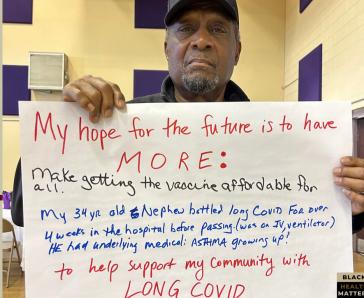
> - Michelly Hubson



My Hope That More People will Get The Vaccine

I hope more people will get the varcine. I have seen many people who did Not get The vaccine infect others. The people they infect become extremely : 11. I have tried to motivate people toget the raceine.

## OUR HOPE



HEALTH





### My long COVID story is ...

After receiving a "Negative" Could 19, Ihad hair loss offer several months.

I had a bad coush, but didn't feel bad- I have a new grand baby, so I didn't want to go ad sochim. I went and got tested and was the I did have COVID.



My Story --I took all my vaccines + boosters last year but still got covid a few months later. I was down to days. I still feel a lot of my fatigue is a result of could (even a year later).

## **OUR STORIES**





## My long COVID story is ... After receiving a "Negative" Covid 19, Thad hair loss offer Several months.

I had abad coust, but didn't feel bad. I have a new grandbaby, so I didn want to go and save him. Twent and extracted and manufer T did have down and southing. I went and got tested and une a new grandback, so a

after CovID the third Time I devolved a knot in my lefy that causes me not to see Clearly Sometimes. It does not nort but it is visible. Hopefully It will go a way soon. SOON.



"These glossy commercials I see now make me feel like it's about greed and money more than health. I understand people need to make money, but at what cost. I shouldn't have to decide between rent and getting my vaccine. In this country you can't afford to live, and you can't afford to die. It's greed."

## **YOUR VOICE MATTERS!**

"Doctors wouldn't listen to me about my Long COVID symptoms. I don't know if that's because I'm a woman or because they don't have all the information on Long COVID. I was able to find a doctor, my husband's PCP, who was a good listener and respected me."

## **SHARE YOUR STORY WITH US**



