



Presents

**Long COVID: Focusing on the long-term effects of
COVID-19 on CHW work and the communities CHWs serve**

August 25th, 2022

We Will Begin Shortly





translation controls

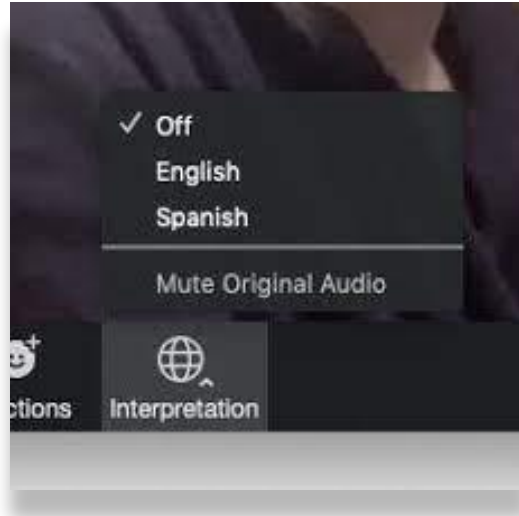
For spanish translation:

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Click the language that you would like to hear.

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Para traducción al español:

Haz clic en “Interpretación” en la configuración/controles de la reunión

Elija su idioma preferido

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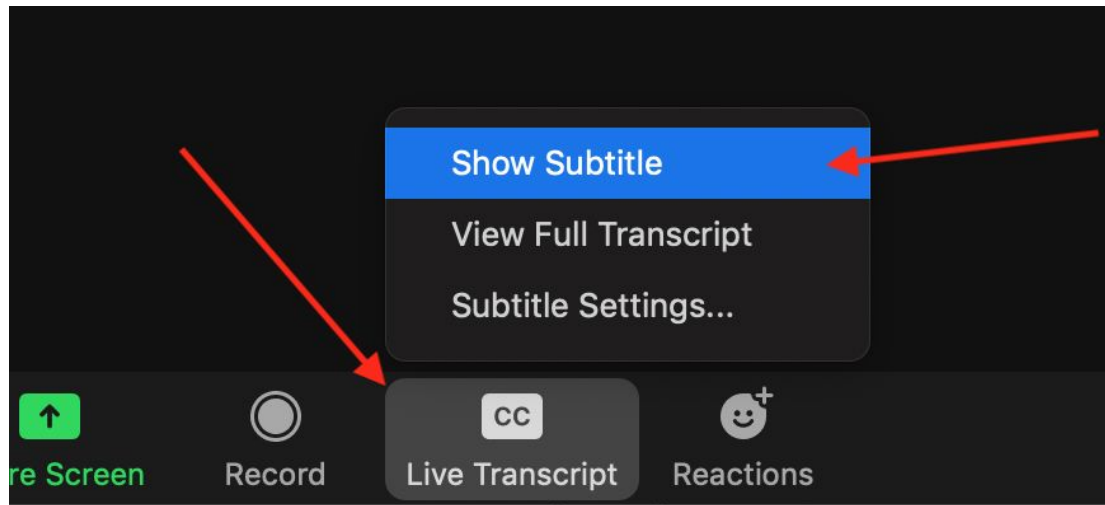
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closed captioning

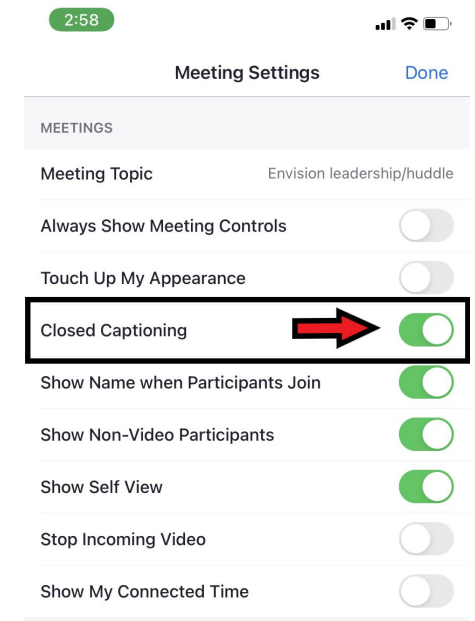
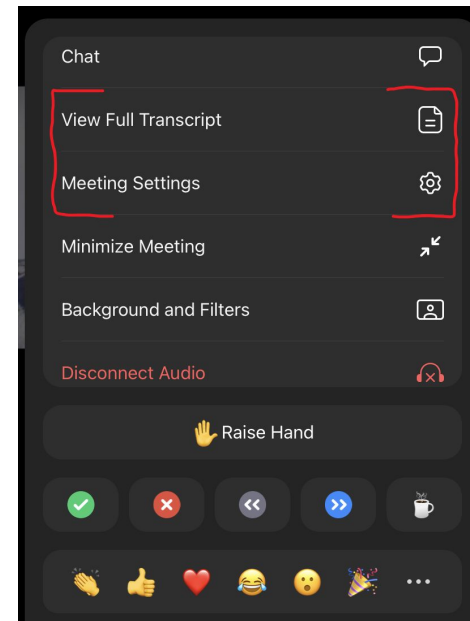
Computer Controls:

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welcome





who is envision?

- collaboration of CHWs & allies working with CDC to elevate the role of CHWs
- supports CDC recipients to address CCR
- collective experience spans decades
- commitment to equity



WISCONSIN DEPARTMENT
of HEALTH SERVICES



Mobilizing Action Toward
Community Health (MATCH)
University of Wisconsin Population Health Institute
SCHOOL OF MEDICINE AND PUBLIC HEALTH



CENTER FOR
COMMUNITY HEALTH
ALIGNMENT

LSU Health
NEW ORLEANS

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envision news

- [Envision is Hiring CHW coaches](#)
- [Envision page has the latest news, job information, and more](#)

Envision equitable healthy communities.



operating agreements

Zoom

- Stay on mute when you're not talking
- Use chat box for questions & networking
- Do what you need to take care of yourself

Envision equitable healthy communities.



learning objectives

- Long COVID definitions and prevalence nationally along with (Tribal and State examples) will be given to CCR recipients
- Participants will have a greater understanding of the impact of Long COVID on vulnerable communities
- Program management will gain greater insight on how to address Long-term COVID effects in vulnerable communities
- Recipients will have a greater understanding of CHW/CHR needs around Long COVID

Envision equitable healthy communities.



today's agenda

- Envision Introduction and News
- Long COVID Introduction
- Long COVID Panel
- Q&A
- Wrap up

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LONG COVID

- What is it?
- Who is affected?
- What are the risks?

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LONG COVID

Dear Pandemic: Community Level Resources

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LONG COVID



Envision equitable healthy communities.



LONG COVID

Dear Pandemic:

Community Level/ programmatic & Data lens resources

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Assessing the Impact of long COVID in a Tribal Community: Ho-Chunk Nation

Ho-Chunk Nation Department of Health
August 25, 2022



WAŽA HIGIRAWI
(We Care)





About me



Sarah Reed-Thryselius (she/her), MPH
Epidemiologist
Ho-Chunk Nation
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- Background in sociology and epidemiology
- Non-tribal
- Began working for the Nation in January 2021
- Focus on applied epidemiology and research into community practice



Agenda

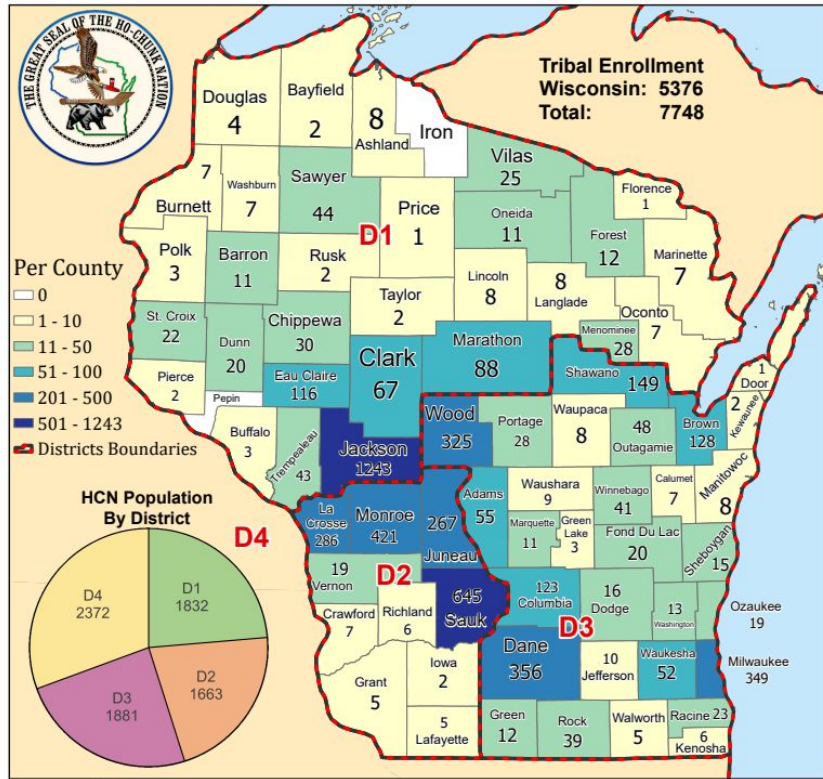


- About the Ho-Chunk Nation
- COVID-19 burden
- About long COVID
- Impact of long COVID in the Ho-Chunk Nation
- Next steps
- Lessons learned

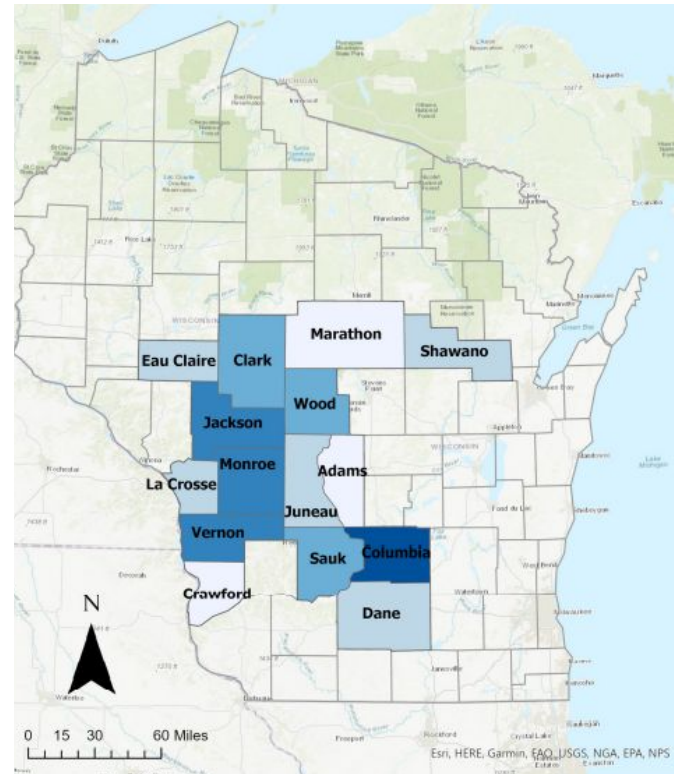


About the Ho-Chunk Nation

Ho-Chunk Nation Enrollment: February 2022



Ho-Chunk Nation DOH IHS PRCDA



Hocąk Wazijacira Hižąkiišana Hįni Karagiwiną

The Ho-Chunk Nation Greet each and everyone of you



What's the burden?



COVID-19 and the Ho-Chunk Nation

Understanding this Dashboard:
 This dashboard reflects the COVID-19 burden overtime and the characteristics of positive cases that the HCN Department of Health has received.

Other information:
 A 'Positive Case' is a positive lab-confirmed confirmed case or probable as of 1/1/2022.
 A 'Confirmed Case' is defined as a positive PCR or NAT test. A 'Probable Case' is defined as a person who has not received a confirmatory laboratory test result but

Disclaimer: This map is for reference only and includes data up until 8/13/2022. For the most up-to-date COVID-19 case information, please visit [Ho-Chunk Nation Department of Health COVID-19 Data](#). Ho-Chunk Nation data is provided by the [Ho-Chunk Nation Department of Health](#). For state data, please visit the [State of Wisconsin Department of Health Services](#).

HCN Tribal COVID-19 Burden (Case Rate per 1,000 Persons)

County	Case Rate per 1,000 Persons
Eau Claire	83
Clark	75
Marathon	90
Shawano	228
Jackson	416
Wood	287
La Crosse	155
Juneau	219
Vernon	0
Sauk	415
Crawford	429
Dane	138

Percent of Cases by Age Group (Tribal and Non-Tribal)

Age Group	Percent of Cases
0-17	23.6%
18-24	9.7%
25-34	17.4%
35-44	15.4%
45-59	20.2%
60+	12.7%

Percent of Hospitalized Cases

Positive Cases

2097

All Cases | HCN Tribal Cases

Hospitalized Cases

100

All Cases | HCN Tribal Cases

Cases Resulting in Death

23

All Cases | HCN Tribal Cases

COVID 19: Confirmed Case Summary | HCN

*Includes cumulative outcomes and hospitalization/death details

This report was updated on 8/9/22 and includes data through 8/6/2022

Data for this snapshot is collected from the following sources:
 Local, tribal case data: Wisconsin Electronic Surveillance System (WEDSS)
<https://ct.wedss.wisconsin.gov/WEDSS/pages/login/login.aspx>

Understanding This Report

Definitions

Confirmed: A person positive for COVID-19 by PCR or NAT
Probable: A person who meets clinical criteria AND epidemiologic evidence but with no confirmatory lab testing performed (Antigen, PCR)
Suspect reinfection: A person who has previously tested lab-confirmed positive and receives a new lab-confirmed positive result outside of the original infectious period with medical provider evidence/support of a "suspect reinfection." **Cases prior to 10/1/2021 cannot be counted as new persons per state guidance.**



What is long COVID?

“Some people who have been infected with the virus that causes COVID-19 can experience long-term effects from their infection, known as post-COVID conditions (PCC) or long COVID (CDC, 2022).”



COVID-19: Post-COVID Conditions

On August 11, 2022, Centers for Disease Control and Prevention (CDC) updated the [COVID-19 guidance for community, school, and early childhood education settings](#).¹⁸ The Wisconsin Department of Health Services (DHS) supports these updates and is currently working to update its website and materials to reflect these changes.

Curious about the long COVID Survey? Jump to [How We Are Learning More](#)

[Post-COVID Conditions](#)¹⁹ are physical and mental health problems that can be ongoing or develop four or more weeks after being infected with SARS-CoV-2, the virus that causes COVID-19. Post-COVID conditions can cause a wide range of new health problems with ongoing symptoms.

Post-COVID conditions are called many names, including: long COVID, PASC (post-acute sequelae of SARS-CoV-2 infection), long-term COVID-19, or chronic COVID. Some people with post-COVID conditions call themselves "long-haulers." People with post-COVID conditions experience new, returning, or ongoing symptoms and/or new health conditions long after they had COVID-19. The symptoms and severity of post-COVID conditions differ from person to person.





So what?

The World Health Organization estimates that globally, 10-20% of persons are COVID long haulers. Since July 2021, being a long hauler was included as a disability under the Americans with Disability Act (ACA).



...impacts multiple areas of wellbeing



What's the impact?

- **Symptom characteristics** (duration, type, severity)
 - Long hauler vs. non long hauler / current long hauler vs. ever long hauler
- **Impact type**
 - Yes/No situations
 - Self-rated impact on physical health and
 - Open ended questions on individual/wellbeing, helpful programs
- **Social/material resources**
 - Financial perception
 - Social isolation and loneliness
- **Other characteristics**
 - Age
 - Underlying health conditions
 - Living with a disability



COVID-19 IMPACT STUDY

Thank you for your interest in participating in the Ho-Chunk Nation Department of Health's COVID-19 Impact study.

The study is completely confidential and voluntary. The goal is to gather information to understand how COVID-19 has impacted our tribal members' lives and how COVID-19 has personally impacted you or your child's life. These surveys can be used to inform the addition or creation of new services to meet our members' needs, especially those related to COVID-19 resources. In addition, if this is the first time hearing about your infection, your aggregate (de-identified) information, including age, gender, county of residence, and month of testing date will be added to public COVID-19 reports, like daily Department of Health case updates and our dashboard, and included in COVID-19 burden reports given to Legislative.

Participating in this survey takes about 20-30 minutes and to show our appreciation of your time, you will be provided with \$100. We expect no more than minimal risk in participating in this survey. At any time, you may skip any question you do not feel comfortable answering. By participating in this survey, you consent to its participation and agree that you meet the eligibility criteria to participate.

This survey is only eligible to Ho-Chunk Nation Tribal members who have previously experienced a positive, lab-confirmed COVID-19 test result and live within one of our 15 county service area delivery counties in Wisconsin. These counties include Adams, Clark, Columbia, Crawford, Dane, Eau Claire, Jackson, Juneau, La Crosse, Marathon, Monroe, Sauk, Shawano, Vernon, or Wood.

If you do not meet the eligibility criteria you will not be able to participate.



What's the impact?

Those who reported a 'high' impact on their physical or mental health were significantly associated with....



Not having enough money to cover basic needs or living paycheck to paycheck



Experiencing symptoms for 6+ weeks (long COVID)



Living with a disability or having at least one underlying health condition



Adults aged 35 years or older and households with 3-4 people



What's the physical impact?



Low

1. **Reduced participation in extracurriculars (62%)**
2. Decrease in motivation at school (53%)
3. Decrease in grades (52%)
4. Seeing friends/family less often than you would like (46%)
5. Feeling isolated or lonely (41%)
6. Having to ask others to help you complete tasks (39%)

High

1. **Being hospitalized for COVID-19 (53%)**
2. Feeling like a burden to others (47%)
3. Needing additional medical care (46%)
4. Stigma or discrimination because I have or had COVID-19 (42%)
5. Being unable to participate in hobbies like I used to (42%)
6. Not having enough basic supplies like food, medications, water, or place to stay (41%)



What's the mental impact?



Low

1. **Decrease in motivation at school (45%)**
2. Financial stress of any cause (44%)
3. Working a reduced number of hours (44%)
4. Seeing family/friends less often than you'd like (42%)
5. Participating in spiritual/cultural doings less often than you'd like (39%)

High

1. **Being hospitalized for COVID-19 (53%)**
2. Feeling like a burden to others (49%)
3. Being laid off or job loss (44%)
4. Not having enough basic supplies like food, water, medications, or a place to stay (42%)
5. Hobbies (40%)
6. Receiving additional medical care (38%)
7. Reduced participation in extracurriculars (38%)
8. Lost wages (34%)



What about long haulers?

22.1%

'Ever' long hauler

17.8%

Current long hauler

32.5

Average # of weeks
symptoms experienced

For ever long hauler vs. never long hauler, statistically different among:

- Hospitalizations (26% vs. 3%)
- Receiving additional medical care (75% vs. 17%)
- Age (60+)
- Having at least one booster dose

Not significant against:

- Gender
- Underlying health conditions
- Living with at least one disability
- Household financial perception
- Having at least one vaccine dose, series complete, or having series complete before OR after infection



What about current long haulers?



Age:

- Age range diverse, younger persons impacted

Finances:

- Majority reported low household financial perception (46%)

Social Support:

- Slightly moderate of social isolation
- Slightly moderate for social loneliness

Health care access:

- Health insurance: 97% yes
- Access to regular care: 95% always
- Affordable care: 90% always
- Place where you feel like you belong: 90% always

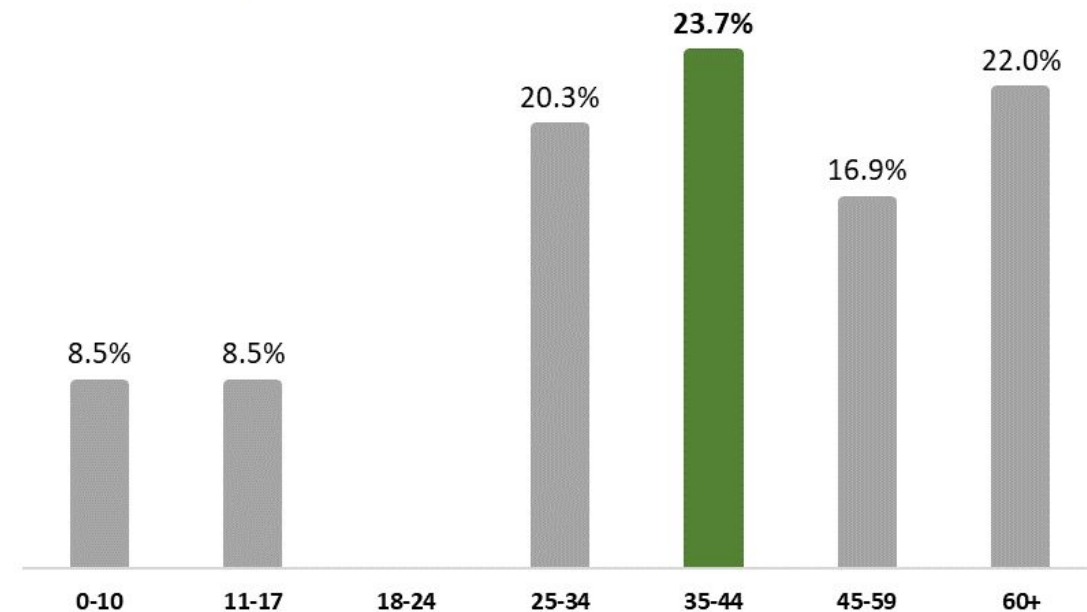
Household responsibilities:

- Living with children: 66% yes

Health status:

- Living with at least one disability: 53% yes
- Having at least one underlying health condition: 27% yes

The **highest percentage** of **current long haulers** are aged **35-44 years**.





What now?



Try to address through clinical and public health strategies

- **Clinic:**
 - Integrated treatment plan to comprise of providers, dieticians, exercise physiologists, behavioral health clinicians, in-home nursing staff
 - Traditional medicine and healers
 - Use screening evaluation tool for symptoms and impact questions to understand context- internal and external referrals
 - Utilize performance measures and program evaluations

- **Public health:**
 - Education on what long COVID is, video narrative campaign
 - Vaccine confidence (*importance of boosters*)
 - Elevate CHW/CHRs to share information and connection families to resources
 - Listening/facilitated sessions to community to explore how they want information used



Lessons learned



- Culturally relevant methods and tools
- Incorporate CHWs/CHRs even more
 - Working with community to define 'impact'
 - Collection process
 - Impacts who can participant and ultimately, what knowledge is shared
 - Work in communities directly and events
 - Interpretation of results and how to apply information
 - Sharing back information
- Community based participatory action research (CBPR)
 - Community led
 - Adapt to use indigenous evaluation framework
 - UIHI defines as 1) community is created wherever Native people are, 2) resilient and strength based, 3) decolonizes data, 4) centers of/around the community (2018)
 - <https://www.uihi.org/projects/indigenous-evaluation/>

Pinagigi,
thank you
for your stories





Final thoughts



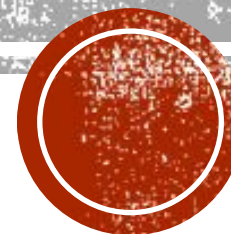
- Long COVID is complex, a variety of symptoms and impacts experienced
- Begin by asking communities how it has impacted them, let communities guide your process
- Identify existing resources, current values, vulnerable populations
 - Elders, youth
 - Those living with a disability
 - We care, love one another
- Communication plan:
 - In-plain language, culturally relevant, use pathways that communities identify and recognize with
 - Use trusted community leaders (can be formal or informal)



#Wookixete
Love one another

LIFE IN POST COVID ENVIRONMENT LET'S TALK **LONG** **COVID**

A **C**ommunity **H**ealth & **W**ellness Perspective



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ABOUT USA CENTER FOR HEALTHY COMMUNITIES (CHC)



The future of health begins with you.

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USA HEALTH

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CHC guiding principle is that: Through community based research, education, and empowerment both the Gulf Region citizens and the university may contribute to an improvement of not Gulf Coast health alone, but also to people's livelihood.



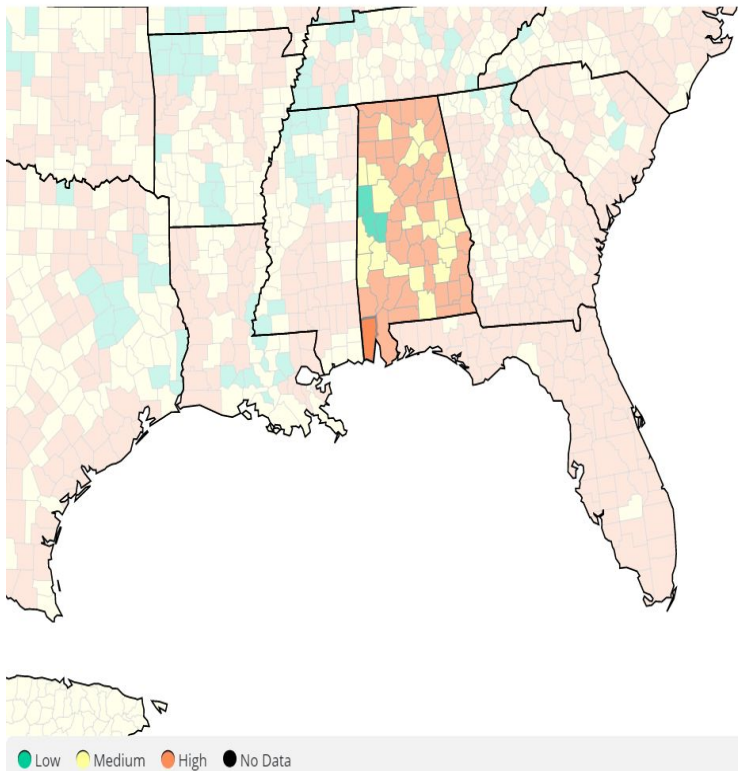
CHC AND MOBILE COUNTY HEALTH DEPARTMENT

- Collaborator with Mobile County Health Department – recipient of CDC-RFA-DP21-2109 (Community Health Workers for COVID Response and Resilient Communities).
- Grant services 13 zip codes where health disparities and high Covid19 infection rates were prevalent
- Mobile County higher than state and national average of uninsured 11.6% (10; 9.5)
- Mobile County population living in poverty also higher than state & national average 19.3 (17.5; 10.5)



COVID 19 IN MOBILE, AL 2022

COVID-19 Community Levels in Alabama



Tue Aug 16 2022 15:05:57 GMT-0500

- Considered **HIGH Community Level**
- 50.9 % Total Population fully vaccinated
- 37% Total Population Vaccinated – 1 BoosterDose

Current Precautions Recommended:

- ❖ Wear a mask indoors in public
- ❖ Wear a mask on public transportation (bus)
- ❖ Get tested if you have symptoms
- ❖ National : Text Zipcode to 438829 (getvcz)
- ❖ Mobile Co App:



SO YOU THINK YOU'VE BEEN EXPOSED TO COVID

- Individuals infected with the virus that causes COVID-19 can experience a range of symptoms and effects dependent on their vaccine status, pre-existing chronic ailments, even gender.
- Long-term effects from infection (typically lasting for more than 6 weeks), known as post-COVID conditions (PCC) or long COVID.
 - ❖ Post-Covid conditions called by many names: long COVID,
 - ❖ Long-haul COVID,
 - ❖ Post-acute COVID-19,
 - ❖ Post-acute sequelae of SARS CoV-2 infection (PASC),
 - ❖ Long-term effects of COVID,
 - ❖ Chronic COVID.

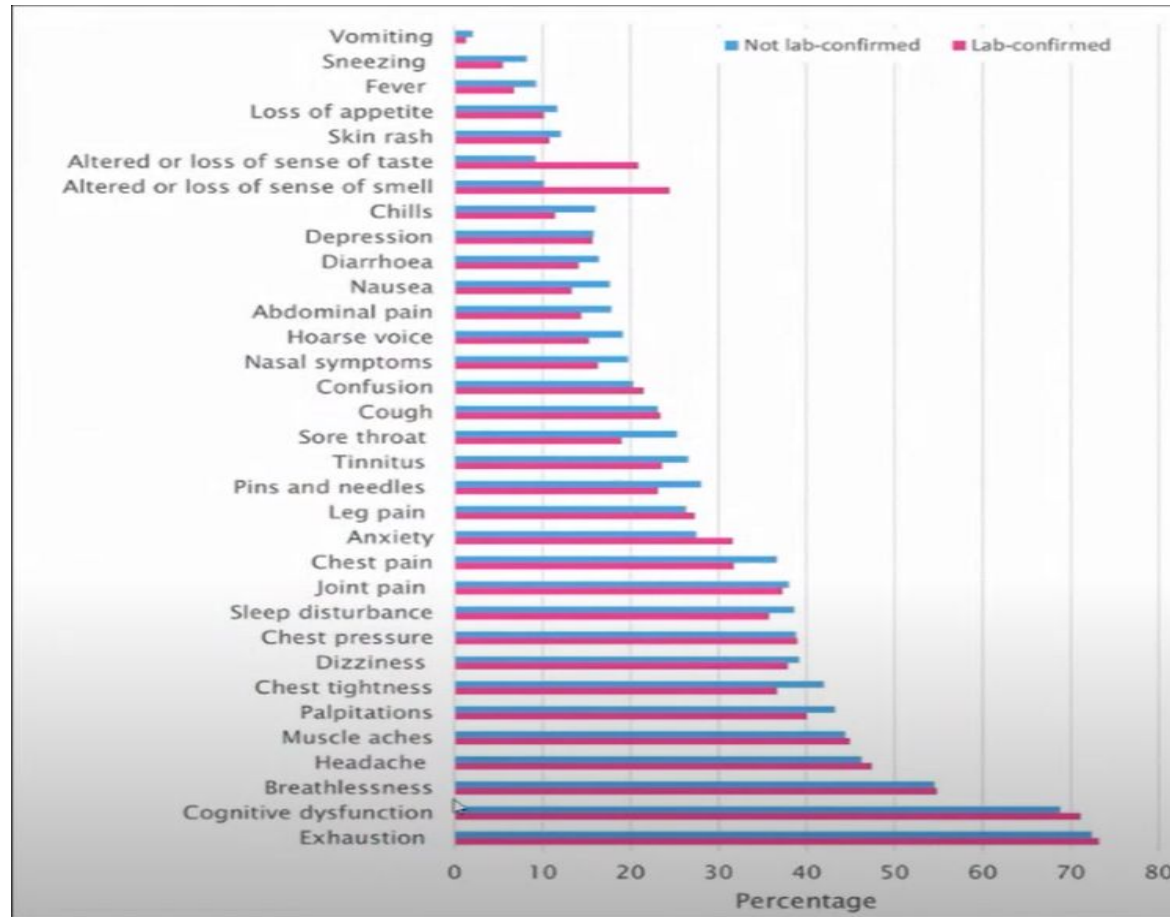


LONG COVID & THE ASYMPTOMATIC

- While most people with post-COVID conditions have evidence of infection or COVID-19 illness, in some cases, a person with post-COVID conditions **may not have tested positive for the virus** or known they were infected
- Persons who think they may have been exposed to Covid19 may speak to a pharmacist or other health professional about an antibody test
- The FDA has recommended that positive antibody test can help support a diagnosis when patients present with complications of COVID-19, such as multisystem inflammatory syndrome or other post-acute sequelae of COVID-19.
- Immunocompromised individuals should follow the COVID19 Prevention guidelines and the medical practitioner advice, that may prevent use of such tests.



SO WHAT DOES LONG COVID LOOK LIKE



YOU ARE NOT ALONE



LONG COVID AS A PIVOT POINT FOR CHW CONVERSATIONS

- Active Listening - A lot of Long Covid sufferers say they aren't heard
- Advocacy & Empowerment – Encourage your clients to start writing down their bouts of symptoms and how long .
- Vaccine Compliance – Research continues to show that though vaccination does not prevent Long Covid, fewer persons that have been vaccinated or boosted have reported suffering from bouts of Long Covid.
- Fear and rage – Mental fogginess, fatigue, and spasmodic black outs mean make Mental Health and finding pathways for expression critical to manage Long Covid uncertainty



LONG COVID” AS A DISABILITY UNDER THE ADA

- Long COVID can be a disability under Titles II (state and local government) and III (public accommodations) of the Americans with Disabilities Act (ADA)
- ▣ Section 504 of the Rehabilitation Act of 1973 (Section 504)
- ▣ Section 1557 of the Patient Protection and Affordable Care Act (Section 1557).

Each of these federal laws protects people with disabilities from discrimination.

- The Office for Civil Rights of the Department of Health and Human Services (HHS) has the following page on civil rights and COVID-19:

<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/index.html>.

- Aging & Disability Resource Centers(ADRCs) can help to locate resources for persons 60+
800-677-1116.



SO HOW CAN WE HELP

- Understand Long Covid is not homogenous...different persons, different symptoms, different patterns of impact. Write it down and find a path
- Remember to be open and to the team approach i.e. find Occupational/Physiotherapists. Mental Health First Aid Training. Video-Telehealth Appointments. Delegate wherever and wherever possible.
- Find your joy/smile moment in each day, consider doing a gratitude or smile journal
- Learn that in the nothingness, healing can whisper....learn to be content with bouts of nothingness



THANK YOU.....ANY QUESTIONS

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REFERENCES

- Centers for Disease Control and Prevention, *Post-COVID Conditions*, www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html (last visited July 21, 2021).
- Centers for Disease Control and Prevention, *Interim Guidelines for COVID-19 Antibody Testing*, https://www.cdc.gov/coronavirus/2019-ncov/lab/resources/antibody-tests-guidelines.html#anchor_1616006253870 (last visited August 17, 2022).
- US Department of Health and Human Services, Office of Civil Rights, Guidance on “Long COVID” as a Disability Under the ADA, Section 504, and Section 1557, <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html> (last visited August 17, 2022).
- Lumley SF, O’Donnell D, Stoesser NE, Matthews PC, Howarth A, Hatch SB, et al. Antibody status and incidence of SARS-CoV-2 infection in health care workers. *N Engl J Med*. 2020 Dec 23;384:533-40.





q&a

What questions do you have for our panelists, or
around LONG CVOID?

Envision equitable healthy communities.



wrap up

- Satisfaction poll
- Materials will be sent out in a follow-up email
- [Also accessible via AMP](#)
- [EnvisionEquity.org](https://www.EnvisionEquity.org).

Envision equitable healthy communities.



thank you

