



HO-CHUNK NATION
DEPARTMENT OF HEALTH

COVID-19 IMPACT STUDY

EXECUTIVE SUMMARY

Submitted January 2023



WAŽA HIGIRAWI
(We Care)



EXECUTIVE SUMMARY

COVID-19 Impact Study

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And to all of our tribal members who shared their stories. Pinagigiwi.

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PURPOSE

In 2021, the Ho-Chunk Nation Legislature asked the Department of Health (DOH) about the prevalence, or the total number, of Ho-Chunk Tribal members with post-COVID or 'long hauler' symptoms (a long hauler is someone who continues to experience COVID-19 symptoms weeks or months after their infection). This information was unknown and required a study. The COVID-19 study officially began in early 2022.

Besides understanding symptom experiences, the study was expanded to ask about the impact of a COVID-19 infection on an individual and their family's life. Because the pandemic continues to change our lives in many ways, Tribal members' stories were used to support more timely DOH public health and medical services program decisions, which are shared in more detail on page 29.

About definitions | *What is a long hauler?*

Although who is considered a 'long hauler' varies by organization, most agree it's someone who continues to experience COVID-19 symptoms at least two to four weeks after their initial infectious period (two weeks). In general, it's someone who experiences COVID-19 symptoms for a minimum of four to six weeks. **The DOH adopted the CDC's definition of a long hauler which is defined as experiencing symptoms for six weeks or more (1).** Long hauler symptoms can be experienced regularly or can go away and come back for weeks or months. A variety of symptoms may be experienced including fatigue, shortness of breath, cough, headache, "brain fog," changes in or loss of taste/smell, and fever among others.

For all definitions used in our study, please see pages 30-32

The Ho-Chunk Nation DOH shares our appreciation to our Tribal members who participated in the COVID-19 Impact Study. Thank you for sharing your stories. Pinagigiwi.



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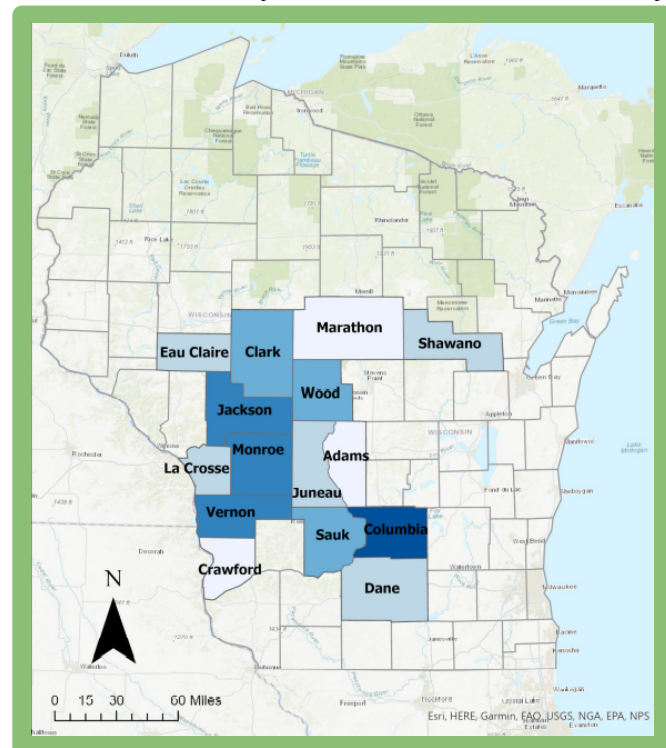


METHODS

From January to April 2022, we asked Ho-Chunk Tribal members to share their stories on how a COVID-19 infection impacted their life and their family's life. The majority of surveys were completed by telephone, but digital and paper copies were available when requested. The survey was in five parts, including sections of 1) eligibility, 2) initial symptoms, 3) long hauler symptoms, 4) impact on daily living, and 5) social/material resources and demographics.

To participate in the study, the tribal member had to meet eligibility criteria including 1) identifying as a Ho-Chunk Tribal member (enrolled OR descendant), 2) living in Wisconsin, 3) living in one of the DOH's Indian Health Services (IHS) designated Purchased Referred Care Delivery Area (PRCDA) counties, 4) having a positive lab-confirmed test result, and 5) having at least six weeks pass since their symptom onset date or testing date (for those with no symptoms). The participant was screened for eligibility before conducting the survey and lab-confirmed results were verified through the Wisconsin Electronic Disease Surveillance System (WEDSS). Youth participated through parental consent- parents needed to complete the interview on behalf of the youth member or they needed to be present while the youth member was being interviewed.

Participation was limited to our PRCDA counties (see map left) because over 78% of the Ho-Chunk Tribal population in Wisconsin lives within these counties. Most likely, these counties would have a greater number of tribal members who use our clinic and/or public health services due to distance in comparison to those who live in other counties in the state. If the DOH was going to make program and/or service changes from the study, we wanted to make sure the information reflected the perspective and lives of members who use our services.



HCN DOH IHS PRCDA Counties











METHODS CONT.

Members were recruited to participate in two different ways...

1. A stratified sample from the cases DOH has received was selected- these cases included members who had tested with the DOH, members who tested somewhere else, but whose information was forwarded to us, and members who tested somewhere else and contacted us directly about their case. In a stratified sample, the larger group is broken into subgroups. We did this by separating people by county of residence. To ensure members in all counties were represented, we wanted the number of sampled members per county to reflect the proportion of the actual population. So, a county that makes up 30% of the population should make up 30% of the sample.

2. A convenience sample from anyone who called in and wanted to participate in the study. These participants included cases the DOH had a record of or cases the DOH did not have a record of. In a convenience sample, anyone who meets the eligibility criteria can participate.

Monthly, study flyers were shared in various places including:

					
Social media	Email	Hocak Worak	HCN clinics	Prescription mail-outs	Community partners

Financial Incentive

To thank members for their participation, they were provided with \$100. Due to HCN Treasury requirements, a W-9 and verification form needed to be completed; these forms were accepted up until June 2022.

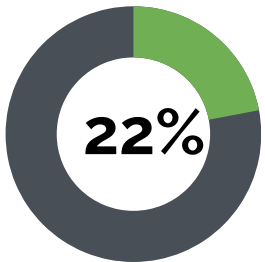


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KEY FINDINGS

The correlation between mental health impact and physical health impact was positive and moderately low (value of 0.3546). Meaning as the impact of COVID-19 on someone's physical health increased, sometimes so did its impact on their mental health (or vice versa) but this was not always the case.



- **22%** of participants **rated the impact** of COVID-19 on their **mental health as 'high'**
- Similarly, **22%** of participants **rated the impact** of COVID-19 on their **physical health as 'high'**

A variety of impacts were reported. The top three impacts across all participants included:

- 1** Seeing family/friends less often than you would like (50%)
- 2** Financial stress of any cause (42%)
- 3** Feeling isolated or lonely(39%)

Other influential impacts...

Included dealing with the loss of loved ones, the effects of children/school, and becoming more spiritual/religious to manage the stressors of the pandemic.



Of those working, 29% reported lost wages, 28% reported working reduced number of hours, & 17% reported being laid off or job loss

EXPERIENCING HIGH 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
- Living with a disability
- Having at least one underlying health condition
- Being a COVID-19 long hauler
- Adults aged 35 years or older
- Households with three-four persons

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22%

of participants were considered '**ever long haulers**' meaning they met the definition of a long hauler AND they currently had symptoms OR their symptoms had stopped

18%

of participants were considered **current long haulers** meaning they met the definition of a long hauler AND they currently had symptoms when the interview was conducted.

Of participants reporting long hauler symptoms, the number of weeks symptoms were experienced ranged from 6 to 103 weeks, with an average of 32.5 weeks.

The symptom onset date of current long haulers ranged from March 2020 to January 2022.



26%

of long haulers reported being hospitalized for COVID-19

75%

of long haulers reported receiving additional medical care for their COVID-19 symptoms and/or complications, this includes the ER, clinic, or urgent care, rehabilitation visits, and behavioral health visits

A variety of symptoms were experienced and numerous organ systems were impacted. Of organ systems significantly associated with long haulers, this included:

- Systemic (e.g., fever, fatigue, chills, weakness, sweating)
- Neurological (e.g., headache, brain fog, lost memory, hallucinations, tremors)
- Psychiatric (e.g., anxiety, depression, changes in sleep patterns)
- Pulmonary/respiratory (e.g., cough, shortness of breath, lung cramps)
- Musculoskeletal (e.g., muscle aches, muscle pain, joint pain)
- Ears, nose, throat (e.g., runny nose, sore throat, loss of smell/taste, ear infection, sneezing)
- Gastrointestinal (e.g., nausea, diarrhea, vomiting, abdominal pain)

Factors associated with being a long hauler included:

#1 Older age **#2** Not having an additional/booster COVID-19 dose **#3** Being hospitalized for COVID-19

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DEMOGRAPHICS

The different types of people who participate in your study will impact how your results can be applied. For example, in a study where most of the participants are older, it would not be appropriate to apply results to younger populations because younger persons and older persons are different- most likely, they have different thoughts, values, needs, and experiences.

Here are some of the characteristics of the tribal members who participated in our study:



Age

0-17: 30%	35-44: 17%
18-24: 7%	45-59: 18%
25-34: 14%	60+: 15%



Sex

Female: 62%
Male: 39%



Have at least one underlying health condition

Yes: 46%
No: 54%



Living with at least one disability

Yes: 18%
No: 83%



Living with children

Yes: 66%
No: 34%



Household size

1: 13%	3-4: 30%
2: 18%	5+: 39%

For definitions on all demographic categories, please see pages 30-31.
Note, categories may not add to 100% due to rounding.



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DEMOGRAPHICS CONT.



Household financial perception

Low: 35%
 Medium: 44%
 High: 21%



Have health insurance

Yes: 94%
 No: 7%



COVID-19 vaccine

No vaccine/no series: 27%
 Series complete: 42%
 Booster/additional dose: 31%



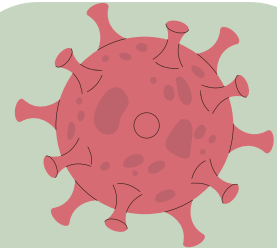
Ever hospitalized for COVID-19

Yes: 6%
 No: 94%



Ever received additional medical care for COVID-19

Yes: 16%
 No: 84%



Ever long hauler

Yes: 22%
 No: 78%



Experienced any symptoms

Yes: 96%
 No: 5%



Length of symptoms

0-2 weeks: 59%
 3-5 weeks: 19%
 6+ weeks: 22%



HCN DOH as medical home

Always: 55%
 Sometimes: 12%
 Never: 32%

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Response

In addition to who participated in your study, you need to consider how many people participated. Based on our service population, a calculation was taken at a 95% confidence interval (CI) to decide on a sample number- achieving this number meant we were 95% confident that the sample results could be applied to the larger population. A 95% CI is a very common research standard.

358
Target sample #

337
of actual participants

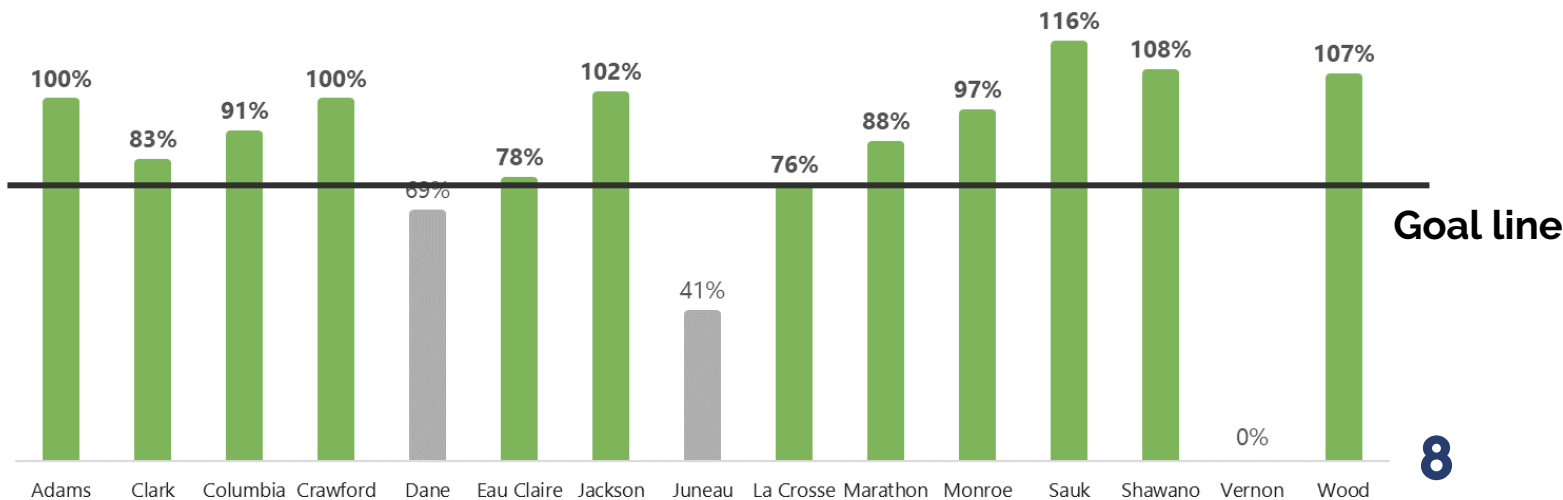
94%
Response rate



A response rate of 94% is considered very good. In telephone-based surveys, a response rate of 50-60% is typical. Our goal was to achieve at least 75-80%.

To ensure each county was fairly represented, our goal was to achieve at least a 75% response rate per county. Meaning, that at least 75% of each sample number per county be reached. So, in a county of a sample with 20 participants, we should have at least 15 interviews.

The **response rate goal** was **met in 12 out of the 15 counties**: Dane, Juneau, and Vernon did not meet the goal.



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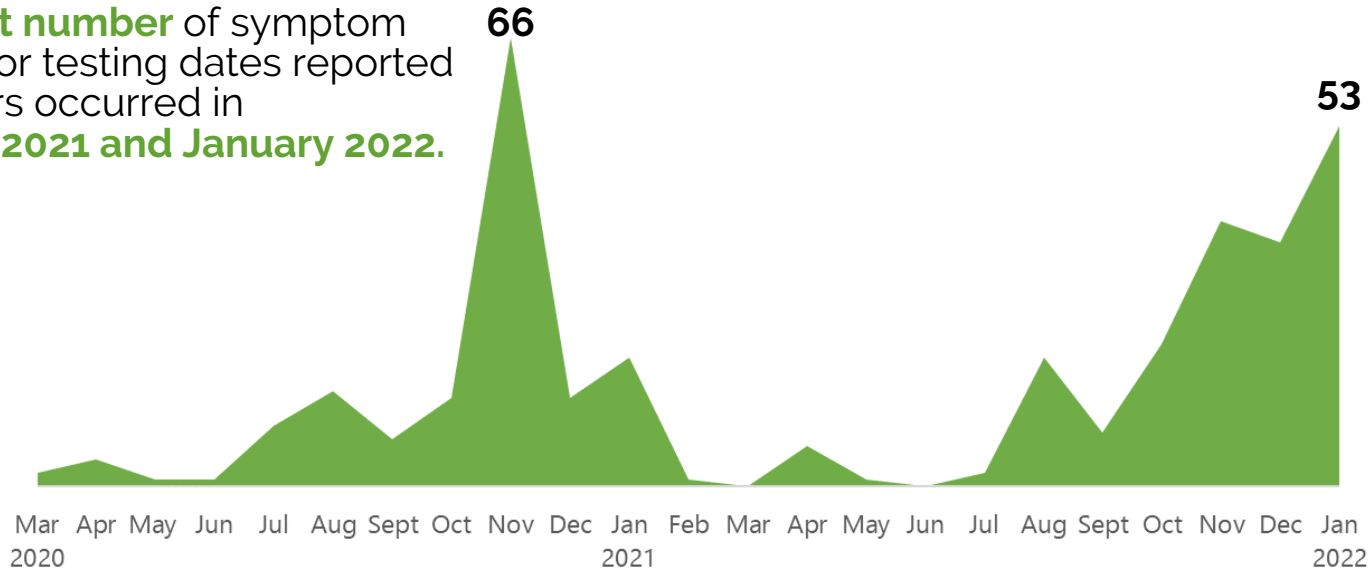


Symptom Date or Testing Date

The timing of someone's infection has a large influence on their experience. For example, timing may impact the amount or type of available resources (including testing, vaccines, and clinical care), the type of COVID-19 variants present and the kinds of symptoms experienced, the current policies/mandates in place, and the types of behaviors, activities, or beliefs of others.

For those who experienced symptoms, we use their symptom start date to describe the start of their infection. For those who do not experience symptoms, we use their testing date to describe the start of their infection. Members who experienced an infection before February 1, 2022, could participate in the study.

The **highest number** of symptom start dates or testing dates reported by members occurred in **November 2021 and January 2022.**



The months with the highest cases also match spikes reported statewide and in the Ho-Chunk Nation due to the Delta variant and Omicron variant. In addition, the shape of the graph reflects how cases have grown and decreased over time.

However, there should be a higher amount of participants with a symptom onset date or testing date in January 2022 compared to November 2021. Within the Ho-Chunk Nation (including tribal and non-tribal), there were 304 lab-confirmed cases reported in November 2021 and 504 in January 2022.



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RESULTS

Impact on daily living



IMPACT ON DAILY LIVING

We measured the impact of a COVID-19 infection on our members and their family's life by asking a few questions.

- Did you experience any of these impacts during your COVID-19 infection? (pages 11-12)
- How else has COVID-19 impacted your or your family's social, financial, mental, physical, or spiritual well-being? (page 12)
- How would you rate the experience of your COVID-19 infection on your physical health? (begins page 13)
- How would you rate the experience of your COVID-19 infection on your mental health? (begins page 18)

Impact type

We asked our participants what specific types of impacts they experienced:

<p>On finances</p>	<ul style="list-style-type: none"> • 42% reported experiencing financial stress • 28% reported working less hours • 29% reported loss wages • 17% reported being laid off or job loss
<p>On health</p>	<ul style="list-style-type: none"> • 39% reported feeling lonely or isolated • 29% reported feeling like a burden to others • 19% reported stigma or discrimination for having COVID-19 • 35% reported having to ask help from others to complete tasks • 6% reported being hospitalized for COVID-19 • 16% reported receiving additional medical care for COVID-19
<p>On school</p>	<ul style="list-style-type: none"> • 13% reported a decrease in grades • 17% reported a decrease in motivation • 10% reported decreased participation or no participation in extracurricular activities



- On daily living**
- 13% reported not having enough basic supplies like food, water, medication, or a place to stay
 - 30% reported being unable to shower/bath, eat, cook, clean, go to the toilet, or drive a vehicle like they used to
 - 32% reported being unable to take part in hobbies like they used to
 - 50% reported seeing family/friends less often than they would like
 - 32% reported participating in spiritual/religious or cultural activities less often than they would like

Open text questions

When asking participants how else has COVID-19 impacted you and your family's social, financial, mental, physical, or spiritual well-being, **over 36% of participants discussed aspects of mental health:**

- 1 Family dynamics:** interactions, responsibilities, and other demands

 - *It's hard when someone in the household gets sick and doesn't go to the doctor to get tested...more added stress.*
 - *Mental toll on family, we are divided with opinions on how much of a concern this [COVID-19] actually is.*
 - *My significant other suffered more, and I felt more strain through picking up their slack than I did when I had COVID....*
 - *I now take care of my father. I also pay for some of his food, do his appointments, and medications.*
- 2 Stress/anxiety:** changes in daily living, fear, and the unknown

 - *Trying to avoid people because they are positive and socializing made it more difficult on our mental health.*
 - *Having COVID was very stressful and caused me a lot of anxiety. I think it was mostly fear of the unknown and knowing the seriousness and severity of some of the symptoms. Being out of our normal routine gave me a lot of time to think, maybe overthink.*
 - *I would say my family and I are all very anxious of social gatherings now, very much homebodies now.*
- 3 Loss/grief:** loss of loved ones, the inability to grieve

 - *It's [COVID-19] taken a toll mentally and spiritually. Losing so many loved ones and not being able to pay my respects.*
 - *Lots of grief.... unresolved grief due to loss of loved ones with COVID.*
 - *Lost parents... always in the back of my mind.*

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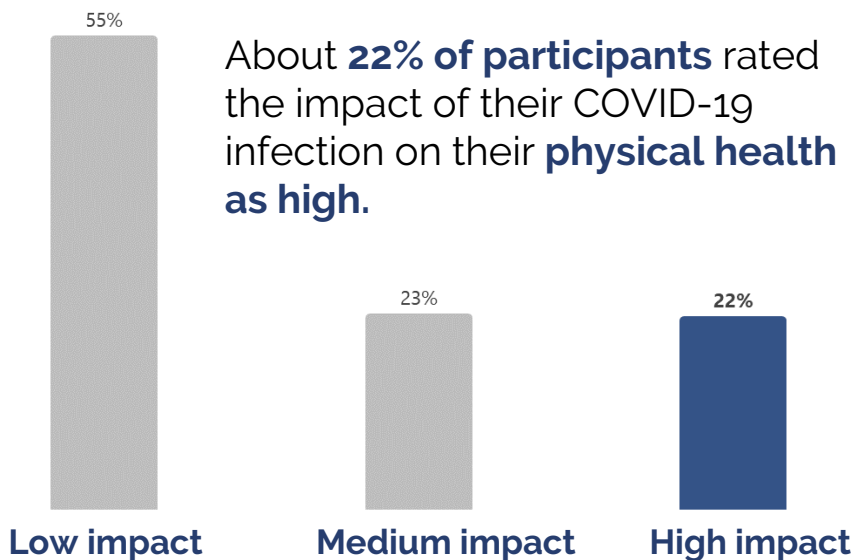


RESULTS



Impact | Physical Health

Physical health is the ability to perform daily tasks. This can include physical activity, hobbies, and basic care items like cooking, bathing, cleaning, and driving a vehicle.



About **22% of participants** rated the impact of their COVID-19 infection on their **physical health as high.**

...that's about 1 out of every 5 people

Who experienced high physical health impact?

Those with high impact were significantly associated with....

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

Experiencing symptoms for 6 or more weeks (being a COVID-19 long hauler)

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

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

Just because something is associated with something, it doesn't mean it causes it- it just means the factors are somehow connected. For example, household size may not directly influence impact, but it may influence the amount and kind of social support resources you have access to, which would impact your ability to recover.

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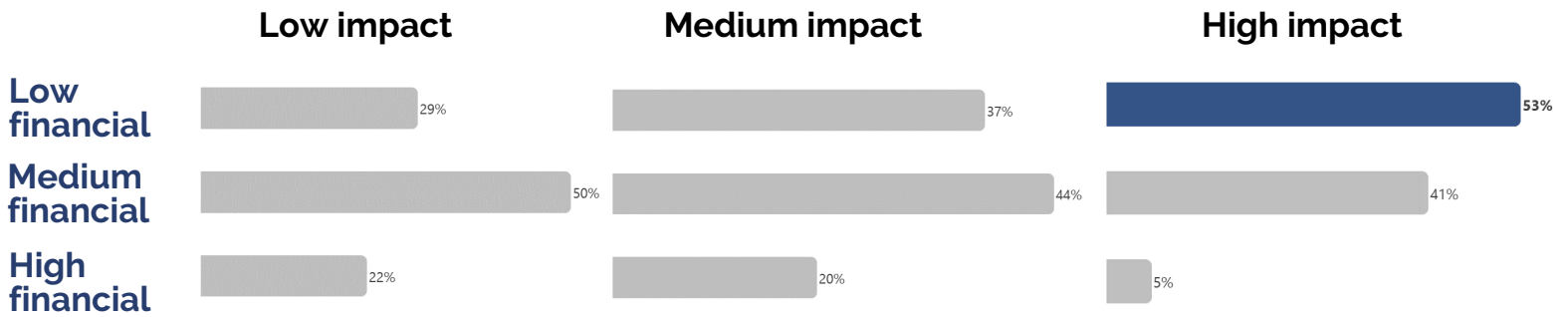
Household financial perception

This is related to someone's ideas about their household's ability to pay bills, save, and have left over money to engage in recreation. It does not directly measure someone's income.



Participants with **high physical health impact** had the **highest percentage** reporting a **low household financial perception**.

About 53% of high physical health impact participants reported a low household financial perception compared to about 37% of medium physical health impact and 29% of low physical health impact participants.



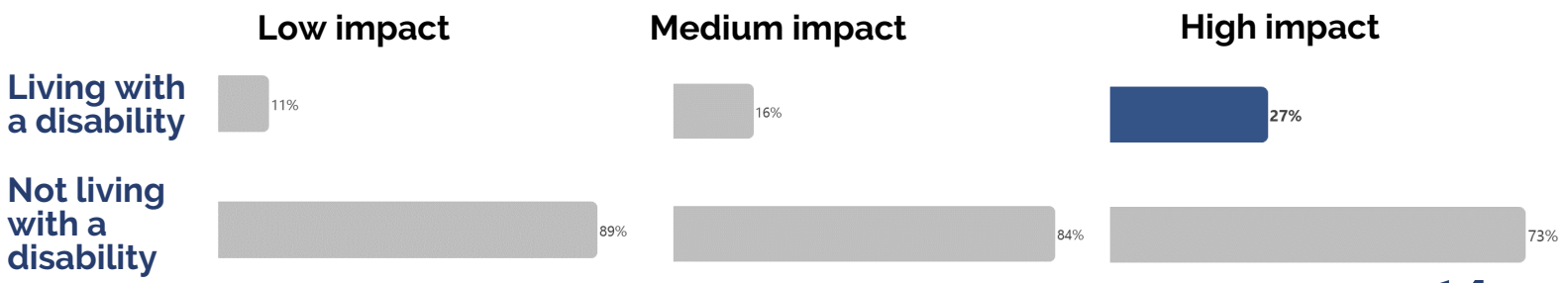
Living with a disability

This includes disabilities related to mobility, vision, hearing, speech, neurodiversity/autism, cognitive, intellectual, developmental, chemical sensitivity/environmental, or mental health.



Participants with **high physical health impact** had the **highest percentage** reporting **living with a disability**.

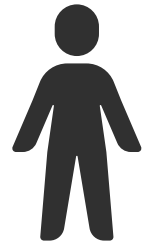
About 27% of high physical health impact participants reported living with a disability in comparison to 16% of medium physical health impact and 11% of low physical health impact participants.





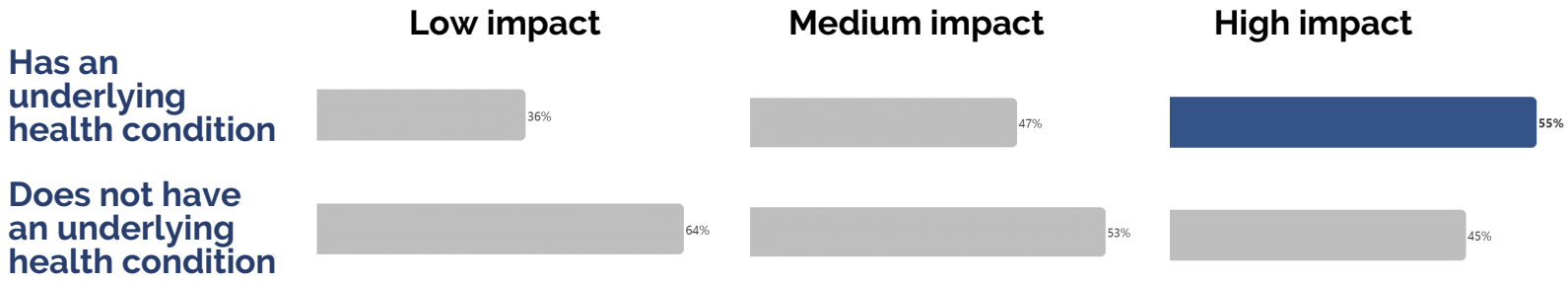
Having an underlying health condition

This includes things like diabetes, asthma, high blood pressure, obesity, neurological/developmental (cerebral palsy, epilepsy), and immunocompromised (celiac disease, lupus, cancer patients) conditions among others.



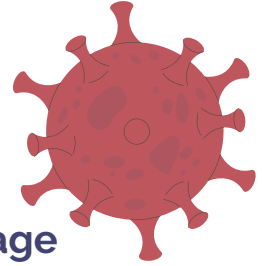
Participants with **high physical health impact** had the **highest percentage** reporting **having at least one underlying health condition**.

About 55% of high physical health impact participants reported living with a disability in comparison to 47% of medium physical health impact and 36% of low physical health impact participants.



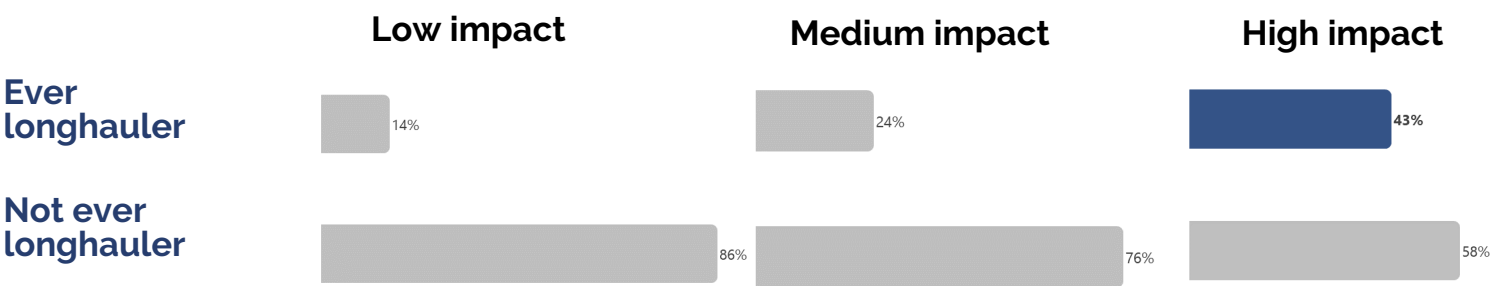
Ever long hauler

This includes someone who experienced or continues to experience COVID-19 symptoms for 6 or more weeks.



Participants with **high physical health impact** had the **highest percentage** reporting **being an ever long hauler**.

About 43% of high physical health impact participants reported being an ever long hauler in comparison to 24% of medium physical health impact and 14% of low physical health impact participants.





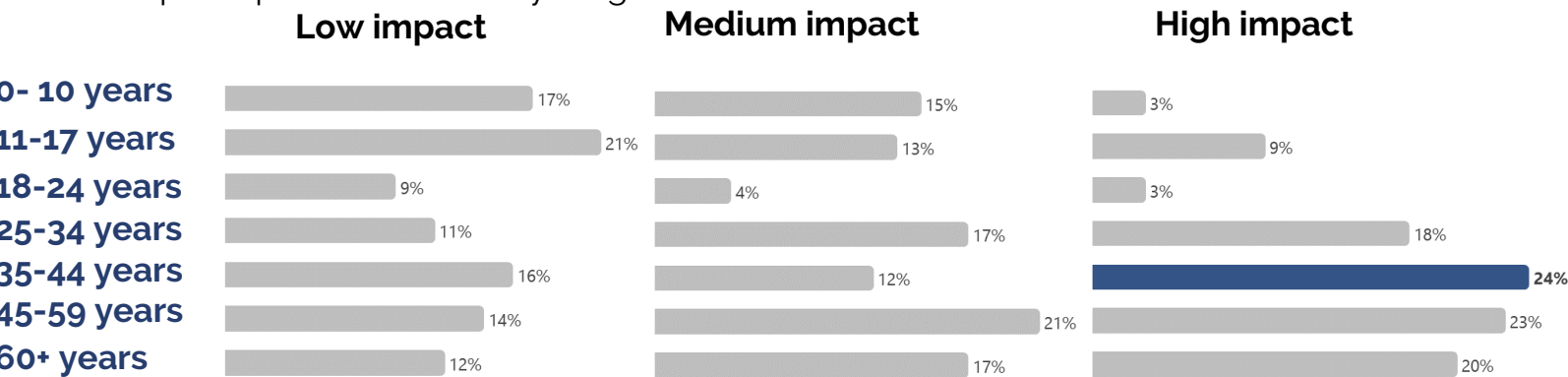
Age

This includes looking at specific age categories but also considering how the lives of these age categories differ by responsibilities, barriers, benefits, and health status.



Participants with **high physical health impact** had the **highest percentage** reporting being **aged 35-44 years**.

About 24% of high physical health impact participants reported being 35-44 years in comparison to 12% of medium physical health impact and 16% of low physical health impact participants. In addition, high impact participants were often older and low impact participants were often younger.



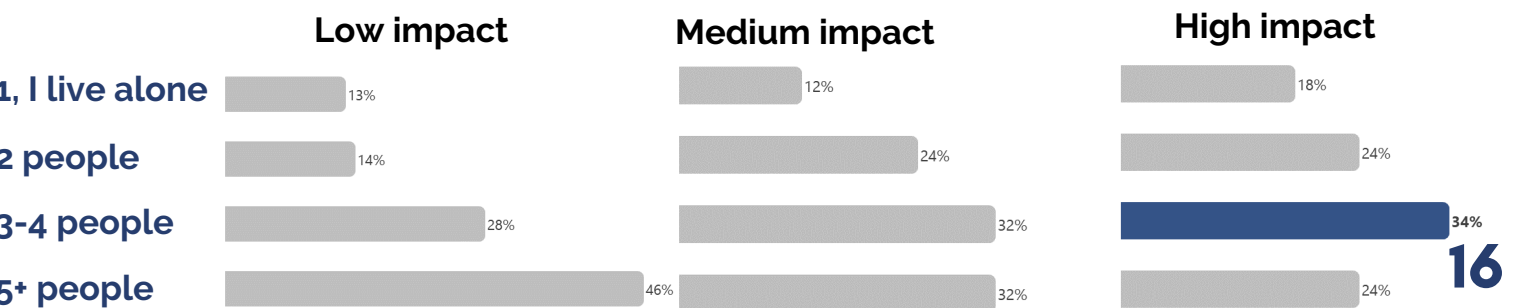
Household size

This includes looking at different household sizes but also considers how the number of people in a household may influence stress, responsibilities, available resources, and social support.



Participants with **high physical health impact** had the **highest percentage** reporting **living in households with 3-4 people**.

About 34% of high physical health impact participants reported living in a household with 3-4 people in comparison to 32% of medium physical health impact and 28% of low physical health impact participants. In addition, the largest percent of participants with low impact had larger households of 5 or more people.



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Impact Type


These are the reported impact types participants experienced, separated by low physical health impact participants and high physical health impact participants. **The percentage reflects the percentage of either low-impact or high-impact participants who experienced the impact type compared to all participants who reported the impact.**

Low physical health impact

- #1 Reduced or no participation in extracurriculars at school (62%)
- #2 Decreased motivation in 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 physical health impact

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

 Physical health impact was most strongly predicted by age and being an ever long hauler.

There were a few impact types that **low physical impact and high physical impact participants closely reported:**

- On finances**
 - 37-38% financial stress
 - 32-34% lost wages
 - 39% working a reduced number of hours
 - 36-38% laid off or job loss
- On daily living**
 - 35-38% participating in religious, spiritual, or cultural activities less often than I would like

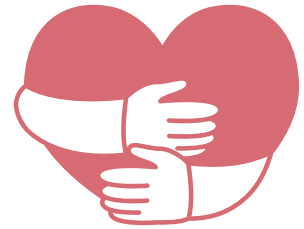
What about medium physical health impact participants?

Among these participants, there were no impact types with the highest percentage of participants reporting an experience when compared to the percentage in high-impact or low-impact groups.



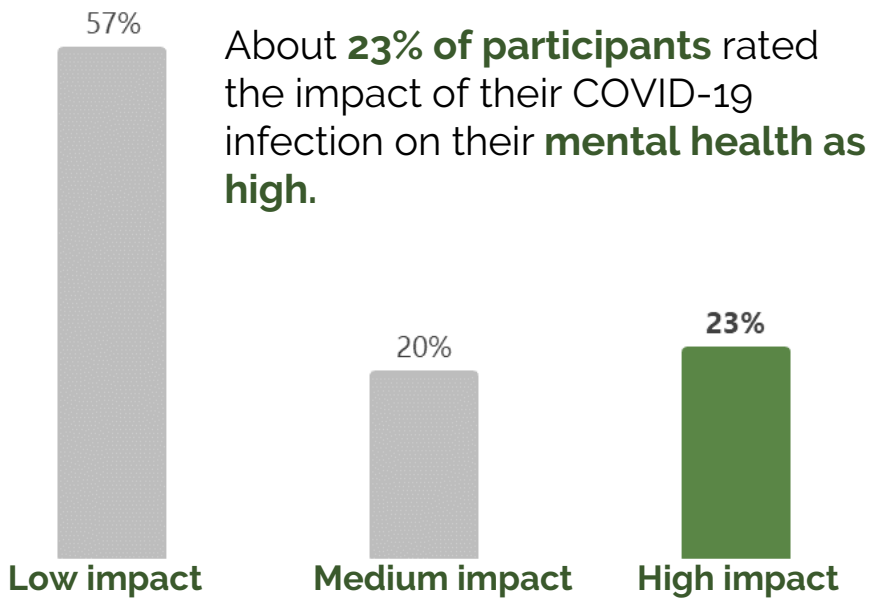


RESULTS



Impact | Mental Health

Mental health includes our emotional, psychological, and social wellbeing. It is related to our emotions, feelings, and how we interact we each other (2).



About **23% of participants** rated the impact of their COVID-19 infection on their **mental health as high.**

...that's about every 1 out of every 4 people

Who experienced high mental health impact?

Those with high impact were significantly associated with....

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

Experiencing symptoms for 6 or more weeks (being a COVID-19 long hauler)

Living with a disability

Unlike the impact of age, household size, or having an underlying health condition on physical health, these factors were not predictive for mental health.





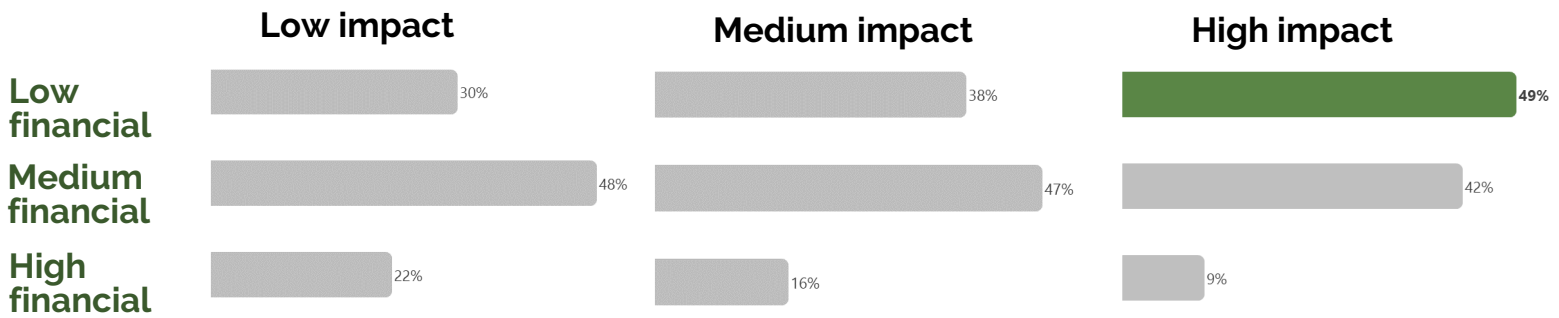
Household financial perception

This is related to someone's ideas about their household's ability to pay bills, save, and have left over money to engage in recreation. It does not directly measure someone's income.



Participants with **high mental impact** had the **highest percentage** reporting a **low household financial perception**.

About 49% of high mental health impact participants reported a low household financial perception compared to about 38% of medium mental health impact and 30% of low mental health impact participants.



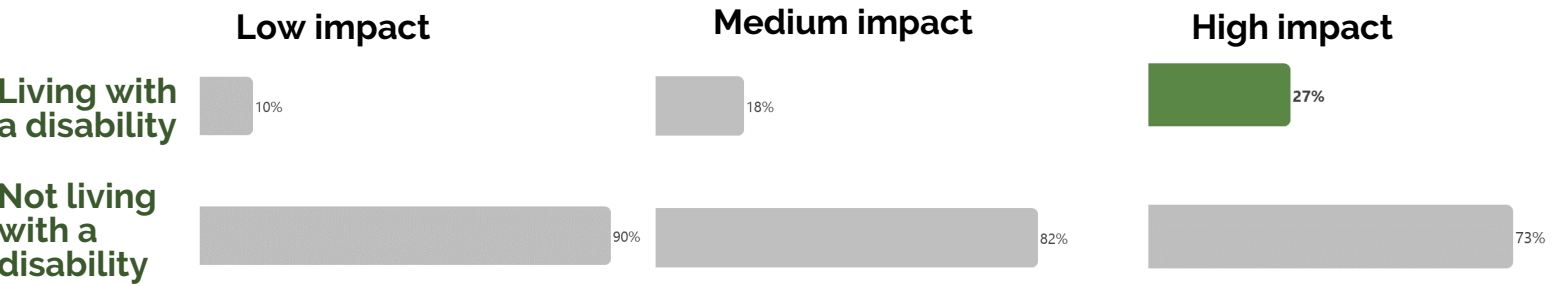
Living with a disability

This includes disabilities related to mobility, vision, hearing, speech, neurodiversity/autism, cognitive, intellectual, developmental, chemical sensitivity/environmental, or mental health.



Participants with **high mental impact** had the **highest percentage** reporting **living with a disability**.

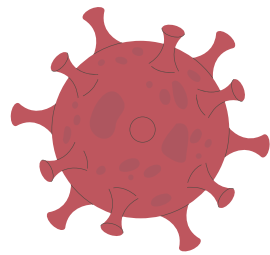
About 27% of high mental health impact participants reported living with a disability in comparison to 18% of medium mental health impact and 10% of low mental health impact participants.





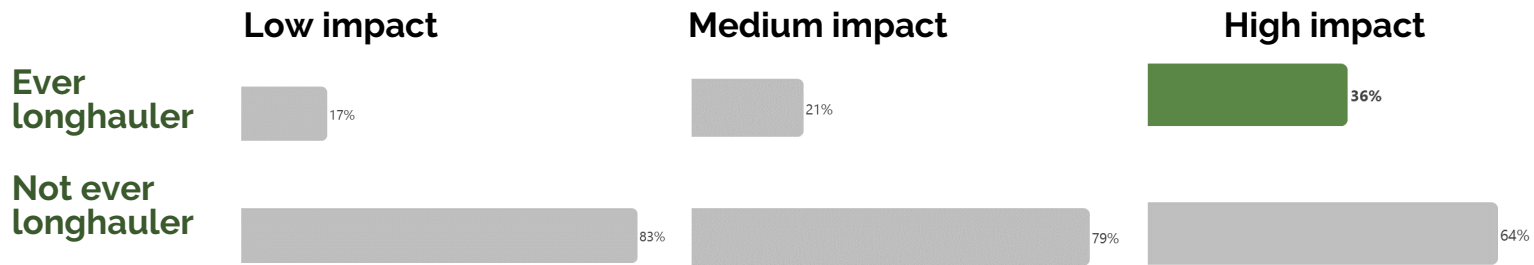
Ever long hauler

This includes someone who experienced or continues to experience COVID-19 symptoms for 6 or more weeks.



Participants with **high mental impact** had the **highest percentage** of those reporting **being an ever long hauler**.

About 36% of high mental health impact participants reported being an ever long hauler in comparison to 21% of medium mental health impact and 17% of low mental health impact participants.



Impact Type

These are the reported impact types participants experienced, separated by low mental health impact participants and high mental health impact participants. **The percentage reflects the percentage of either low impact participants or high impact participants who experienced the impact type compared to all participants who reported the impact.**

Low mental health impact

- #1 Decreased motivation in school (45%)
- #2 Experiencing financial stress (44%)
- #2 Working a reduced number of hours (44%)
- #3 Seeing family/friends less often than you would like (42%)

High mental health impact

- #1 Being hospitalized for COVID-19 (53%)
- #2 Feeling like a burden to others (49%)
- #3 Laid off or job loss (44%)
- #4 Not having enough basic supplies like food, medications, water, or a place to stay (42%)
- #5 Being unable to participate in hobbies like I used to (40%)
- #6 Receiving additional medical care for COVID-19 (38%)
- #7 Lost wages (34%)





There were a few impact types that **low mental health impact and high mental health impact participants** closely reported:

- On health**
 - 38-39% reported feeling lonely or isolated
 - 36-38% reported having to ask help from others to complete tasks
 - 32-34% reported stigma or discrimination for having COVID-19
- On daily living**
 - 36-39% reported participating in spiritual/religious or cultural activities less often than they would like
 - 33-36% reported being unable to shower/bath, eat, cook, clean, go to the toilet, or drive a vehicle like they used to
- On school**
 - 35-38% reported decreased participation or no participation in extracurricular activities

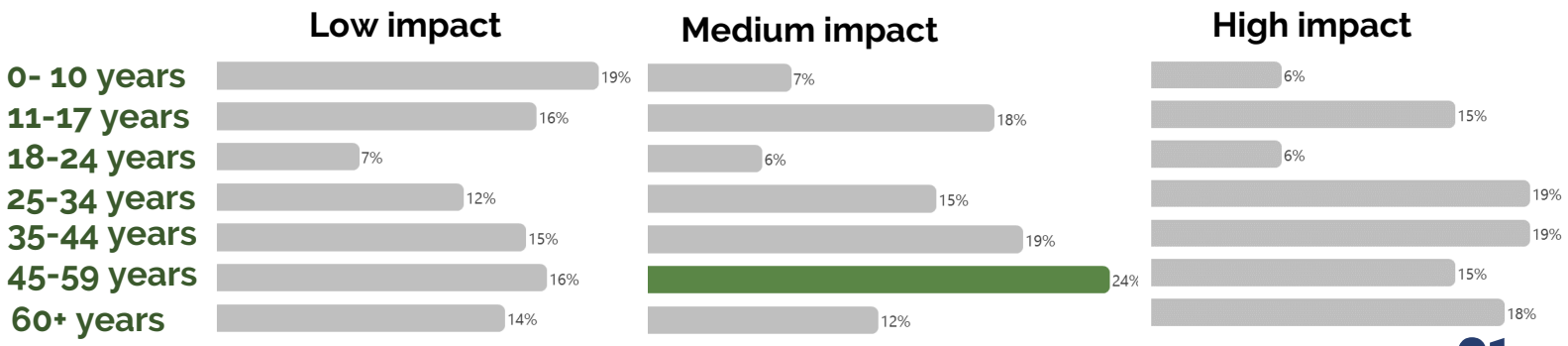
What about medium mental health impact participants?


In comparison to medium physical health impact participants, those reporting medium mental health impact had only one impact type with the highest percentage when compared to the other impact groups: **About 41% of these participants reported a decrease in grades.**

What about age?

Unlike physical health impact, mental health impact was harder to predict among participants by age. Although youth and adults were impacted, this impact was not linear and this difference was not considered statistically significant. This means there were other factors, besides age, which had a larger impact on someone's mental health.

About 24% of medium mental health impact participants were aged 45-59 years. For high impact participants, a variety of age categories were reported.



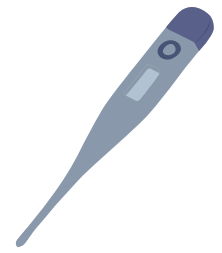
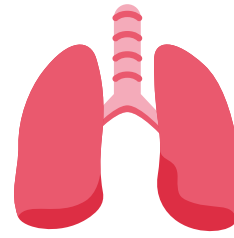
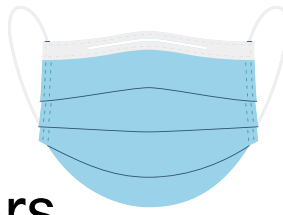


RESULTS

COVID-19 Long hauler



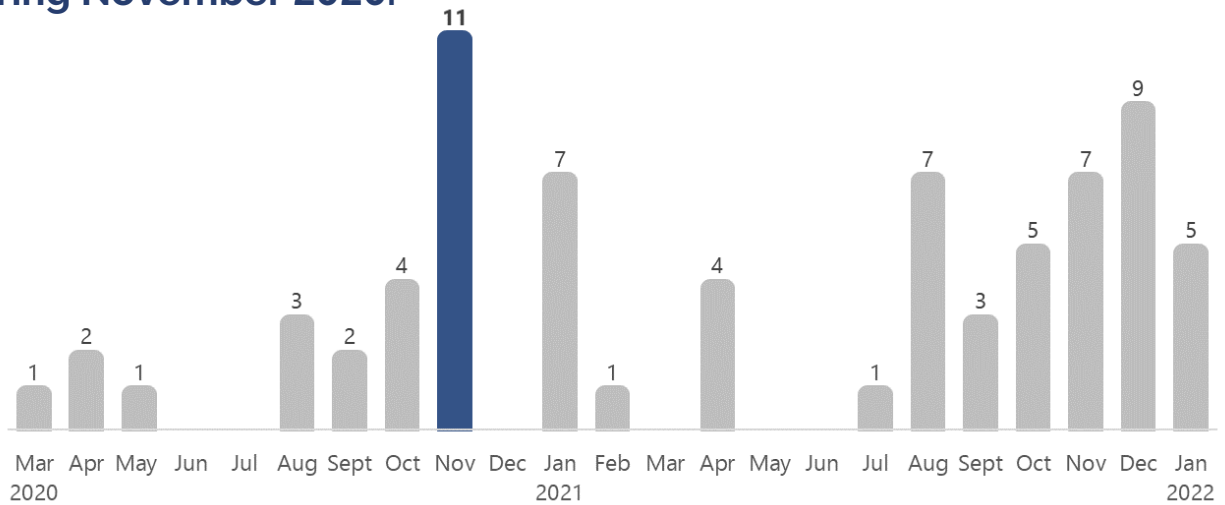
RESULTS



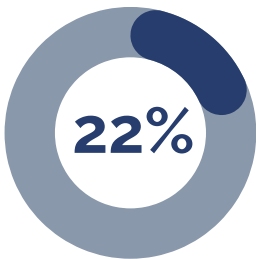
COVID-19 Long haulers

To determine if someone was a COVID-19 long hauler, we asked how long their symptoms lasted. Additionally, we asked if they currently had symptoms or if they had stopped.

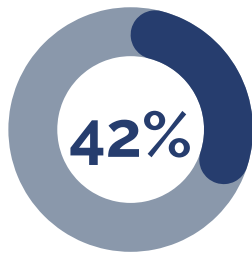
The **greatest number of ever long haulers** reported that their **symptoms began during November 2020**.



A few facts....



% of participants who were ever long haulers



% of ever long hauler participants who had symptoms for 6+ months

DYK?



The World Health Organization estimates that globally, 10-20% of persons recovering from COVID will become a long hauler. As of July 2021, being a COVID long hauler was included as a disability under the Americans with Disability Act (ADA).

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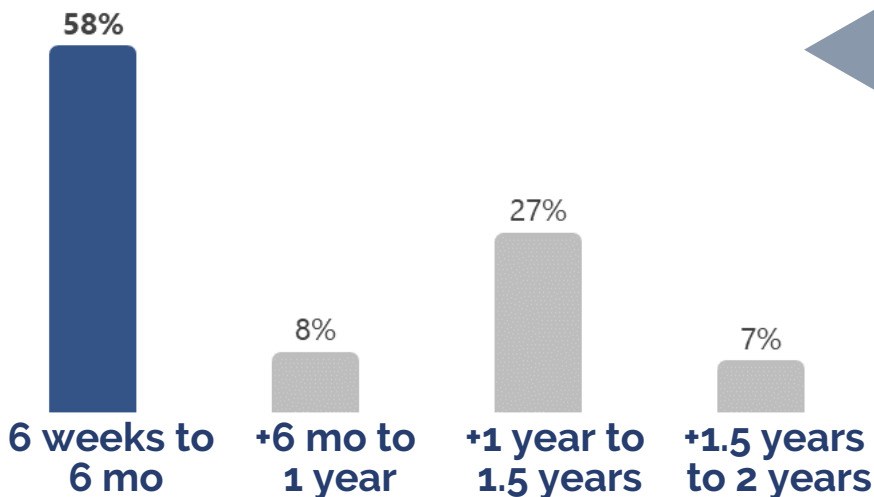


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The majority of ever long hauler participants experienced symptoms from 6 weeks to 6 months.



KEEP IN MIND...
 Our study recorded information like a snapshot in time.
 The percentages reflect the number of weeks symptoms were experienced at the time the study was conducted. Someone may continue to experience symptoms after they were interviewed and this would not be recorded.

Who are ever long haulers?

Those identified as ever long haulers were significantly associated with...

- Elders, aged 60 years or older
- Not having an additional or booster dose of the COVID-19 vaccine
- Being hospitalized for COVID-19 and receiving additional medical care
- Reporting high impact on one's physical and mental health

Unlike the impact of age, household size, having an underlying health condition, living with a disability, or household financial perception on physical health and mental health, these factors were not predictive for being an ever long hauler.

Are there other factors?

It may be challenging to predict the risk factors for long haulers due to differences among study designs like the included populations, length of follow-up time, reported symptoms, the definition of a long hauler, and differences in variant characteristics (3).

Some studies have reported factors like (4-5):

- Age
- Gender
- Underlying health conditions
- Socioeconomic status
- Smoking status

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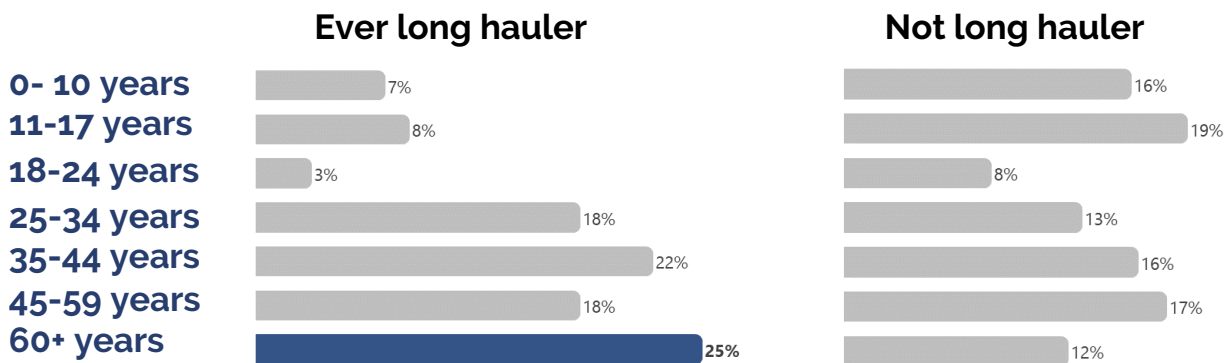
Age

This includes looking at specific age categories. Often, as age increases, so does the risk for health outcomes because of its impact on someone's ability to recover, immune system, overall health status, and more.



Participants who were **ever long haulers** had the **highest percentage** reporting being **aged 60+ years**.

About 25% of ever long hauler participants reported being aged 60+ years in comparison to 12% of not long hauler participants.



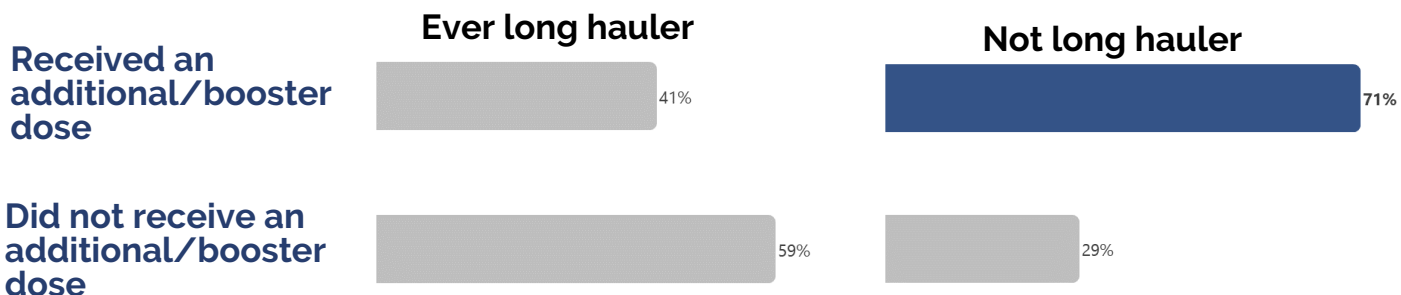
Vaccine status

This includes someone who received an additional/booster COVID-19 dose at any time (before or after infection). Because of when the study was conducted, this additional/booster dose relates to the original booster doses- these vaccines were first administered during Fall 2021.



Participants who were **not long haulers** had the **highest percentage** reporting having an **additional/booster COVID-19 dose**.

About 41% of ever long hauler participants reported having an additional/booster dose in comparison to 71% of not ever long hauler participants.



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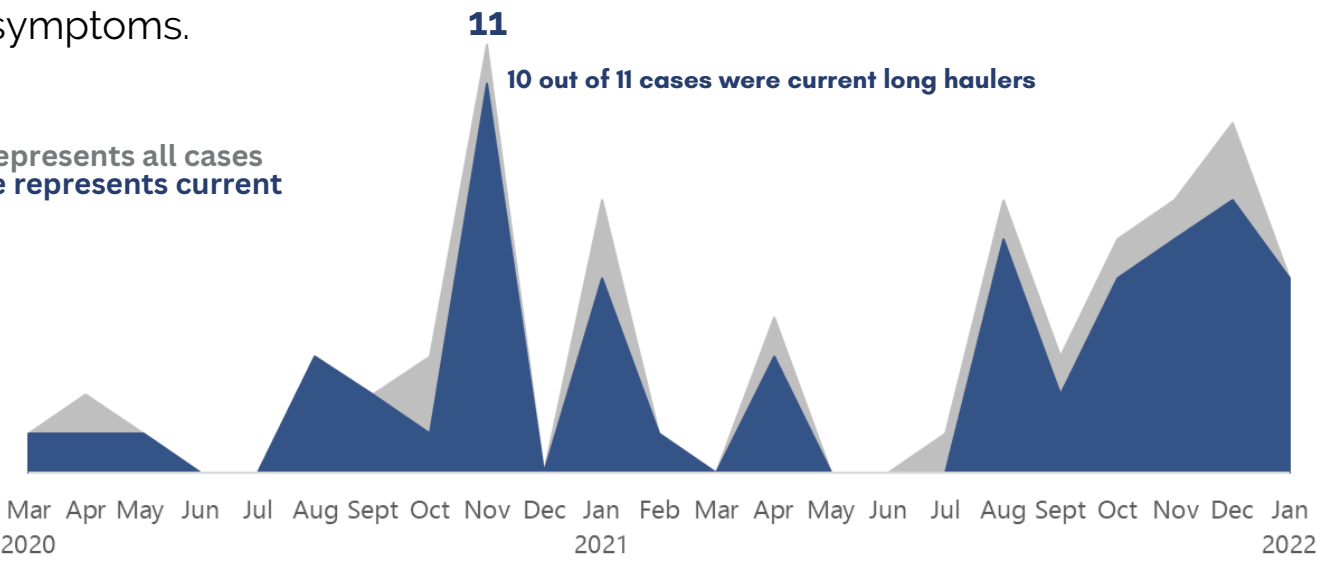
Historical and current long haulers

We asked long hauler participants if their symptoms stopped or if they currently had symptoms. This helps the Department understand what kind of resources, programs, and services are currently needed. **Among ever long haulers, about 81% currently had symptoms.**

The **earliest symptom start date** reported by a **current long hauler was March 2020**. In addition, the majority of ever long haulers currently had symptoms.

By month

Where the gray represents all cases and the dark blue represents current long haulers.

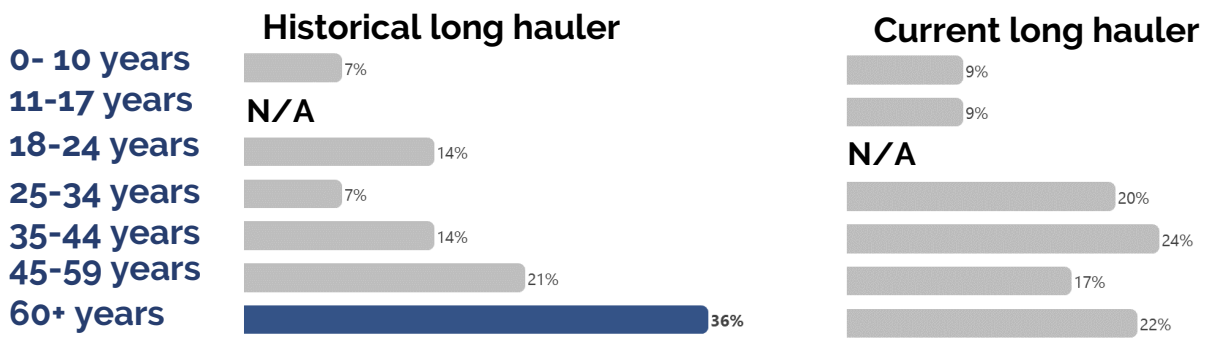


Age

As the pandemic progressed, and new variants emerged, changes to policies/procedures occurred, and the vaccine was introduced, age groups were impacted differently by COVID-19 throughout time.

Participants who were **historical long haulers** had the **highest percentage** reporting being aged **60+ years**.

About 36% of historical long hauler participants reported being aged 60+ years in comparison to 22% for current long hauler participants. In addition, only 7% of historical long haulers were youth, aged 0-17 years, compared to 18% of current long haulers.





Other current long hauler characteristics



Here are some of the characteristics of current long haulers. These characteristics were selected because they inform the resources, barriers, or advantages a tribal member might experience during their recovery.

- On finances**
 - Almost half reported low household financial perception (about 46%)
- On social support**
 - Experiencing moderate social isolation. Most participants felt they had someone they could trust but they did not have someone that could help them if they were sick or disabled.
 - Experiencing moderate social loneliness. Most participants felt they didn't lack companionship but they often felt isolated.
- On health care access**
 - About half considered the Ho-Chunk Nation Department of Health their medical home (48%)
 - The majority had health insurance (97%)
 - The majority felt they had access to regular care (95%)
 - The majority felt they had affordable care (90%)
 - The majority felt they had a medical place where they feel like they belong, are respected, and receive culturally appropriate care (90%)
- On household responsibilities**
 - About 2/3 reported living with children (66%)
- On health status**
 - About half were living with at least one disability (53%)
 - About 1/3 were living with at least one underlying health condition (27%)





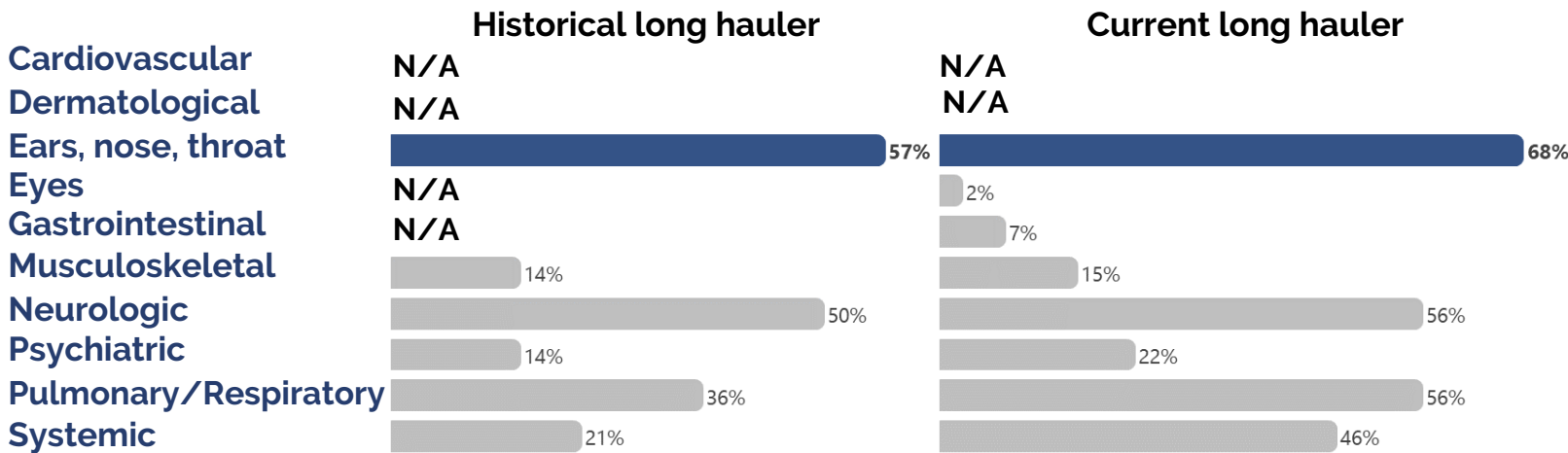
Organ system (symptom) experiences

A variety of symptoms and organ systems were impacted. Changes in symptom type, frequency, or severity may be influenced by many personal characteristics, such as age, underlying health conditions, vaccine status, or access to health care in addition to COVID-19 variant characteristics. In addition, the symptom experience can change throughout the infection and during recovery.

After the initial infection (15 days and more)

For both **historical and current long haulers**, the **most commonly reported organ symptom** experienced after the initial infection was **ears, nose, and throat**.

About 57% of historical long hauler participants reported experiencing ear, nose, and throat symptoms compared to 68% of current long haulers.



For organ system definitions, please see page 32.

Symptom frequency

After the infectious period, long hauler participants experienced an average of four symptoms, but the number of symptoms ranged from 1-15. Symptom frequency also varied but a few patterns were present:

- **Daily:** impaired/loss of smell or taste, cough, fatigue, shortness of breath, brain fog, headaches
- **Daily (morning and night only):** cough, shortness of breath
- **During physical activity:** cough, shortness of breath, fatigue, congestion

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NOTE...



After the two-week period, no long hauler participants reported experiencing symptoms related to the cardiovascular or dermatological organ systems. In addition, historical long haulers did not report experiencing any symptoms related to the eyes or the gastrointestinal systems.



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WHAT NOW?

The Ho-Chunk Nation Department of Health thanks our members who shared their stories. These stories have been used in Medical Services and Public Health to inform service and programming decisions to better meet our tribal members' COVID-19 needs.

Tribal members stories showed that.....

- ➔ COVID experiences were different for every person. Many types of symptoms were reported and the impact of those symptoms on someone and their family's life was unique.
- ➔ Many people who experienced long hauler symptoms did not have COVID boosters to help protect their bodies.

Tribal members' COVID stories have been used in preventing disease, death, and disability. The program changes that came from this study include:

-  The Public Health division changed the way they encouraged and promoted COVID-19 vaccines to focus on preventing long haul symptoms. This includes continued messaging and health promotion efforts surrounding COVID-19 vaccines in the clinic and at community sites.
-  Creating an integrated COVID long hauler treatment plan, taking place in our clinic and community settings. This includes services from Medical, Behavioral Health, Community Health, and outside referrals. We focus on understanding the impact of COVID on the patient and their family's lives to provide meaningful recovery resources.
-  A greater understanding of our tribal community's needs and priorities. Our previous community health assessment (CHA) was completed in 2017-2019. Since then, the pandemic has greatly changed the way we live our lives. We found some of the information we collected back then was now outdated. During the next CHA, we aim to focus on some of these new areas including communication, health perceptions, and vulnerable populations.





APPENDIX

Category definitions



Additional medical care

This includes receiving additional medical care for COVID-19 symptoms or complications. This includes clinic, ER, urgent care, rehabilitative visits (e.g., physical therapy, occupational therapy, speech pathology), or behavioral health visits.

COVID-19 Vaccine Dose Stage

- No vaccine/no series: Someone who has no doses of the COVID-19 vaccine or has not completed the vaccine series- this is two doses of Moderna or Pfizer and one dose of Johnson & Johnson
- Series complete: Someone who has completed the vaccine series and has no additional doses or booster doses- this is two doses of Moderna or Pfizer and one dose of Johnson & Johnson
- Booster/additional dose: Someone who has completed the vaccine series and has one additional dose or one booster dose

Household financial perception

- Low perception: Someone who reports not having enough money to pay the bills to meet basic household needs or is living paycheck to paycheck, using most or all monthly income to cover expenses with no money left over and none for savings
- Medium perception: Someone who reports paying the bills to meet household needs and has a little bit of money left over for other items such as savings, recreation, etc. or paying the bills to meet household needs and having some money to pay for other items such as savings, recreation, etc.
- High perception: Someone who has enough money to live quite comfortably without much financial stress; they can pay the bills and have quite a bit of money for other items such as savings, recreation, etc.

Long hauler

- Ever long hauler: Someone who had a COVID-19 infection for 6 weeks or more but no longer experiences symptoms (1).
- Current long hauler: Someone who had a COVID-19 infection for 6 weeks or more and currently experiences symptoms (1).





Medical home

A medical home is an organization or facility where you receive most of your primary health services including medical, dental, optical, and behavioral health.

Mental Impact

- Low : Someone who rated the impact of their COVID-19 infection on their mental health as having 'no impact' or 'a little impact.'
- Medium Someone who rated the impact of their COVID-19 infection on their mental health as having 'some impact.'
- High: Someone who rated the impact of their COVID-19 infection on their mental health as having 'much impact' or 'very much impact.'

Physical Impact

- Low : Someone who rated the impact of their COVID-19 infection on their physical health as having 'no impact' or 'a little impact.'
- Medium: Someone who rated the impact of their COVID-19 infection on their physical health as having 'some impact.'
- High: Someone who rated the impact of their COVID-19 infection on their physical health as having 'much impact' or 'very much impact.'

Significantly associated

This means a variable was statistically connected to another. When this occurs, it is unlikely differences among groups are due to chance. Association tests include things like T-Tests, ANOVA, and chi-square.

Social loneliness

This includes feeling included and feeling like you have meaningful social connections. Someone who does not have meaningful social connections is often thought to be socially lonely (6).

Social isolation

Social isolation measures usually include asking about resources you have from social connections including receiving help if you were sick or injured and having someone you trust. Someone who has low social resources, or a low number of interactions is often thought to be socially isolated (6).

Socioeconomic status

Socioeconomic status often includes someone's educational level, income, and occupation type.



Organ system definitions

Organizing COVID-19 symptoms into organ systems can be challenging because a symptom may be related to multiple systems. Given this, one symptom may be listed in multiple organ systems. The organ system definitions below were adapted from Davis et al. (2021) and Tran et al. (2022). The included symptoms are those participants described they experienced during their COVID-19 infection and recovery (7-8).

Cardiovascular

- Lightheaded
- Heart issues

Eyes

- Worsening vision
- Eye pressure
- Red eye
- Red spot in eye

Musculoskeletal

- Muscle aches
- Joint pain
- Body pain
- Felt weaker

Pulmonary/Respiratory

- Shortness of breath
- Cough
- Asthma
- Lung cramps
- Agitated lungs

Dermatological

- Hair loss
- Rash

Gastrointestinal

- Constipated
- Nausea
- Diarrhea
- Vomiting
- Abdominal pain
- Loss of appetite

Neurologic

- Lost memory
- Hallucinations
- Tremors
- Shaking
- Dizziness
- Weakness
- Headache
- Brain fog
- Restless
- Involuntary finger movement
- Loss of appetite
- Loss taste
- Loss of smell
- Worsened taste
- Worsened smell
- Changes in sleep patterns
- Food tasted & smelled bad
- Felt weaker

Ears, nose, throat:

- Sneezing
- Scratchy throat
- Dry throat
- Catch in back of throat
- Runny nose
- Sore throat
- Dizziness
- Loss of smell
- Loss of taste
- Ear infection
- Food tasted & smelled bad
- Worsened taste
- Worsened smell

Psychiatric

- Anxiety
- Depression
- Hallucinations
- Loss of appetite
- Mood changes
- Changes in morale
- Changes in sleep patterns
- Felt weaker



Ho-Chunk Nation Department of Health

COVID-19 Impact Study Questionnaire*

*Interviewer edition

Adapted from Harkness et al. (2020), Hughes et al. (2004), Fillenbaum (1975), Sauk County Public Health Department Community Health Survey (2021), Suryanarayanan (2019), Tran et al. (2021), and Wisconsin Department of Health Services (2021). These include citations 8-14.

Interviewer Edition

Interviewer: If the participant has experienced multiple COVID-19 infections, please have them think back on their first infection.

Section 1: Eligibility

NOTE: If participant answers "no" to any of the questions below, the participant is not eligible to complete the survey. The participant must have a test date or symptom date six weeks prior to interview date to be eligible.

1. Do you identify as a Ho-Chunk Tribal member (enrolled or descendant)?
 - o Yes
 - o No.
2. Are you an enrolled member or descendant?
 - o Enrolled member
 - o Descendant
3. Do you live in Wisconsin?
 - o Yes
 - o No
4. Do you live in one of the HCN DOH service area counties in Wisconsin? These counties include Adams, Clark, Columbia, Crawford, Dane, Eau Claire, Jackson, Juneau, La Crosse, Marathon, Monroe, Sauk, Shawano, Vernon, and Wood.
 - o Yes
 - o No
5. Which county do you live in? Please write-in.

6. Did you ever receive a positive, lab-confirmed test result? Rapid tests and antibody tests do not count. If Yes, interviewer, confirm through WEDSS.
 - o Yes
 - o No





In order to confirm your test result through the state surveillance system, I need a little more information.

7. What is your first and last name?

8. What is your birthdate? (MM/DD/YYYY)

9. What is the address associated with the test?

10. What is the participant's date of symptom onset or testing date (for asymptomatic cases). Interviewer, verify through the interview tab and/or lab result (MM/DD/YYYY).

11. Are you completing the interview for yourself or someone else?
o Myself. **End of section. Skip to section 2, consent.**
o Someone else.

12. Who are you completing the interview for?
o My spouse or partner
o My sibling
o My child
o My parent or step-parent
o My grandchild
o My grandparent
o Other family (this includes aunts, uncles, and cousins)
o A friend
o Not listed (please write-in): -----

13. What is your relationship to the individual we are talking about today?
o Family member
o Legal guardian
o Caretaker
o Not listed (please write-in):-----

Section 2: Consent

Read the consent statement. Participant must agree to consent to continue the interview.



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Section 3: Part A

Describe burden & assess for long hauler eligibility

This first section is related to your experiences during the first two weeks after you got your positive test and/or started having symptoms. We will ask you some questions about your symptoms and how you felt about them.

14. What kind of symptoms did you experience? **Check all that apply.**

- Cough
- Headache
- Runny nose
- Muscle aches
- Fatigue
- Sore throat
- Loss of/impaired smell
- Loss of/impaired taste
- Chills
- Fever
- Shortness of breath
- Diarrhea
- Nausea
- Abdominal pain
- Vomiting
- Congestion
- Brain fog
- Changing mood/impact on morale
- Changes in typical sleeping patterns (sleeping more, sleeping less, trouble falling asleep, or staying asleep)
- Not listed (please write-in):_____
- No symptoms. I did not experience any symptoms during this time. **Skip to question 16.**

15. Of all the symptoms you experienced, which symptom was the most severe? **Check one answer.**

- Cough
- Headache
- Runny nose
- Muscle aches
- Fatigue
- Sore throat
- Loss of/impaired smell
- Loss of/impaired taste
- Chills
- Fever
- Shortness of breath
- Diarrhea
- Nausea
- Abdominal pain
- Vomiting
- Congestion
- Brain fog
- Changing mood/impact on morale
- Changes in typical sleeping patterns (sleeping more, sleeping less, trouble falling asleep, or staying asleep)
- Not listed (please write-in):_____



16. From the day your symptoms started, how many weeks did they last?
----- weeks

Interviewer

- If participant experiences symptoms (consistently or intermittently) for **six weeks or more**, participant is considered a long hauler. **Continue to question 17, Section 3, Part B.**
- If participant experiences symptoms (consistently or intermittently) **less than six weeks**, participant is not considered a long hauler. **Skip to question 22, Section 3, Part C.**

**Section 3: Part B
Long hauler experiences**

Based on the length of time you experienced/continue to experience your COVID-19 symptoms, you are considered a COVID long hauler and we would like to ask you a few more questions about these experiences.

17. Two weeks after your positive test or initial symptoms, what kind of symptoms did you experience? **Check all that apply.**

- Cough
- Headache
- Runny nose
- Muscle aches
- Fatigue
- Sore throat
- Loss of/impaired smell
- Loss of/impaired taste
- Chills
- Fever
- Shortness of breath
- Diarrhea
- Nausea
- Abdominal pain
- Vomiting
- Congestion
- Brain fog
- Changing mood/impact on morale
- Changes in typical sleeping patterns (sleeping more, sleeping less, trouble falling asleep, or staying asleep)
- Not listed (please write-in):-----
- No symptoms. I did not experience any symptoms after the initial two-week period. **Skip to question 22.**





18. Of the symptoms you reported, which was/is the most severe? **Check one answer.**

- Cough
- Headache
- Runny nose
- Muscle aches
- Fatigue
- Sore throat
- Loss of/impaired smell
- Loss of/impaired taste
- Chills
- Fever
- Shortness of breath
- Diarrhea
- Nausea
- Abdominal pain
- Vomiting
- Congestion
- Brain fog
- Changing mood/impact on morale
- Changes in typical sleeping patterns (sleeping more, sleeping less, trouble falling asleep, or staying asleep)
- Not listed (please write-in):_____

19. Do you currently have COVID-19 symptoms or have they stopped?

- I currently have symptoms. I may have symptoms consistently or intermittently after the initial two-week period.
- Not sure if I currently have symptoms. I have COVID-19 type symptoms but I'm not sure if they're related to my COVID-19 infection or something else.
- I do not have symptoms, they stopped. **Skip to question 21.**

20. How often do you experience these symptoms?





21. Is there anything else you would like to share with us about your symptom experience?

Section 3: Part C Vaccine status

One of the questions we are wanting to know is if the COVID-19 vaccine is helpful in reducing the severity of COVID-19 symptoms or the likelihood of experiencing long hauler symptoms (COVID symptoms for 6 weeks or more) in our Tribal population. I will now ask you some questions about your vaccine history.

22. Have you received at least one dose of any COVID-19 vaccine type? This includes Moderna, Pfizer, or Janssen.

- o Yes
- o No. **Skip to question 26, Part D.**

23. Which type of vaccine have you received for your first and/or second dose?

- o Janssen
- o Moderna
- o Pfizer

24. Which type of vaccine have you received for your third dose or booster?

- o Janssen
- o Moderna
- o Pfizer

25. What are the vaccination dates (DD/MM/YYYY) for your COVID-19 vaccine doses?

If unsure, please write "don't know." For doses you have not gotten yet, leave the space blank.

- | | |
|----------------|---------------|
| o First dose: | Third dose: |
| o Second dose: | Booster dose: |



Section 3: Part D Impact on daily living

We would now like to ask you some questions about how your COVID-19 infection/symptoms impacted your daily living.

26. Thinking back on your COVID-19 infection, do you/did you experience any of these situations due to your symptoms? **Check all that apply.**

- Financial stress
- Feeling isolated or lonely
- Feeling like a burden to others
- Having to ask for help to complete tasks
- Stigma or discrimination from other people (people treating you differently because you had symptoms or were positive for COVID-19)
- Being hospitalized for COVID-19
- Receiving additional medical care for your COVID-19 symptoms. This includes clinic, ER, urgent care, rehabilitation visits (like physical therapy or occupational therapy), and behavioral health visits.
- Not having enough basic supplies like food, water, medications, or a place to stay.
- Unable to complete OR unable to complete at the same frequency/intensity daily tasks I used to do. **Check all that apply:**
 - Basic care items. This includes showering, bathing, going to the toilet, eating/cooking, and driving a vehicle.
 - Hobbies
 - Spending time with family or friends
 - Spiritual, religious, or cultural activities
- Related to school. This includes virtual, hybrid, in-person, and homeschool.
 - I was/am not a student. I was/am not enrolled in school during this time.
 - I was/am a student. I was/am enrolled in school during this time. **Check all that apply:**
 - Decrease in grades
 - Decrease in motivation
 - Reduced participation in sports, music, or other after-school activities.
 - Not listed (please write-in):_____
 - None of these. I did not experience any school-related impacts.

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- Related to employment. This includes full-time or part-time work.
 - I do not/did not work. This includes retired persons, caregivers, stay-at-home, volunteers, and those currently unemployed but looking for work.
 - I do/did work. This includes full-time or part-time work. **Check all that apply.**
 - Lost wages
 - Working a reduced number of hours
 - Laid off or job loss
 - Not listed (please write-in):_____
 - None of these. I did not experience any work-related impacts.
- Anything else not listed? (please write-in): _____

27. Thinking back on your entire COVID-19 infection/symptom experience, how would you rate its level of impact on your physical health?

- Not at all
- A little
- Some
- Much
- Very much

28. Thinking back on your entire COVID-19 infection/symptom experience, how would you rate its level of impact on your mental health? This includes things like changes in sleep patterns, stress, anxiety, depression, and feeling lonely or isolated.

- Not at all
- A little
- Some
- Much
- Very much



Section 3: Part E Assess for resources

We now would like to ask you a few more questions to learn about you and to understand what kinds of resources you have access to.

29. Do you currently have health insurance?

- o Yes
- o No. **Skip to question 31.**
- o Unsure.

30. What is your primary health insurance plan? This is the plan which pays the medical bills first or pays most of the medical bills. **NOTE: Contract health is not health insurance.**

- o Auxiant
- o Other private health insurance plan purchased from employer or workplace
- o Other private health insurance plan purchased directly from an insurance company or through the Marketplace
- o Medicare
- o Medicaid/BadgerCare
- o The military, Tricare, the VA
- o Not listed (please write-in): _____
- o Don't know

31. Did the COVID-19 pandemic impact your insurance status?

- o Yes
- o No
- o Unsure

32. Do you consider the Ho-Chunk Nation Clinic(s) your medical home? That is, you receive most of your primary services here. This includes medical, dental, optical, and behavioral health services.

- o Yes, always.
- o Sometimes. **Interviewer, please ask why:** _____
- o No, never or rarely. **Skip to question 34. Interviewer, please ask why:** _____

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- 33. Which location do you most frequently go to to use our services?
 - o Baraboo (House of Wellness)
 - o Black River Falls (Ho-Chunk Health Center)
 - o Other satellite sites (Madison, Nekoosa, Tomah, Wittenberg, La Crosse)
- 34. Do you have a medical place where you can receive regular care?
 - o Yes, always
 - o Sometimes. **Interviewer, please ask why:** _____
 - o No, never or rarely. **Interviewer, please ask why:** _____
- 35. Do you have a medical place where you can receive care that is affordable?
 - o Yes, always
 - o Sometimes. **Interviewer, please ask why:**_____
 - o No, never or rarely. **Interviewer, please ask why:**_____
- 36. Do you have a medical place where you feel like you belong? That is, you feel respected and listened to and that this organization is considerate to your cultural, religious, and spiritual beliefs/needs.
 - o Yes, always
 - o Sometimes. **Interviewer, please ask why:**_____
 - o No, never or rarely. **Interviewer, please ask why:**_____

37. Do you consider yourself to have an underlying health condition? **Check all that apply.**

- o Diabetes
- o High blood pressure
- o Asthma
- o Obesity
- o Emphysema
- o Chronic Kidney Disease
- o Chronic Liver Disease
- o Chronic Lung (Pulmonary Disease)
- o Neurological or Neurodevelopmental. This includes things like Multiple Sclerosis (MS), Parkinson's Disease, Epilepsy, and Cerebral Palsy.
- o Neurological or Neurodevelopmental. This includes things like Multiple Sclerosis (MS), Parkinson's Disease, Epilepsy, and Cerebral Palsy.
- o Neurological or Neurodevelopmental. This includes things like Multiple Sclerosis (MS), Parkinson's Disease, Epilepsy, and Cerebral Palsy.
- o Not listed (please write-in):_____
- o I'm not sure if I have any underlying health conditions.
- o I do not have any underlying health conditions.





38. Do you consider yourself to be living with a disability? This includes disabilities related to mobility, vision, hearing, speech, neurodiversity/autism, cognitive, intellectual, developmental, chemical, sensitivity/environmental, or mental health.

- o Yes
- o No
- o Not sure

39. What is your age?
----- years

40. What gender do you identify with?

- o Man
- o Woman
- o Non-binary/Two-spirit
- o Not listed (please write-in):_____

We would now like to ask you some questions about your social support and how you feel about it.

41. Is there someone who would give you any help if you became sick or disabled?

- o Yes
- o Maybe
- o No. **Skip to question 44.**

42. Is there someone who would take care of you as long as you needed? Or someone who would help you now and then?

- o Someone would take care of me as long as I needed.
- o Someone would take care of me for a short time, like a few weeks up to six months.
- o Someone would take care of me now and then. This includes things like taking me to appointments or making lunch.





43. Of the person who would give you help if you became sick or disabled, who is the person that first comes to your mind?

- o My spouse or partner
- o My sibling
- o My child(ren)
- o My parent or step-parent
- o My grandparent
- o Other family (this includes aunts, uncles, and cousins)
- o A friend
- o Not listed (please write-in):_____

44. Do you have someone you can trust and confide in?

- o Yes, always
- o Sometimes
- o No, never or rarely

Please respond to the following questions as "never/rarely, sometimes, or often."

	Never/rarely	Sometimes	Often
45. How often do you feel you lack companionship?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. How often do you feel left out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. How often do you feel isolated from others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

And finally, we have some questions related to your financial situation and any barriers you might experience.

Questions continue on to the next page





48. In thinking about your current household's financial situation, would you say you...? **Check one response.**

- Don't have enough money to pay the bills to meet basic household needs.
- Live paycheck to paycheck, using most or all of your income to cover monthly expenses, with no money left over and none for savings.
- Pay the bills to meet household needs and have a little bit of money left over for other items including savings, recreation, etc.
- Pay the bills to meet household needs and have some money left over for other items including savings, recreation, etc.
- Have enough money to live comfortably without much financial stress. I/we can pay the bills and have quite a bit of money for other items including savings, recreation, etc.

49. What is your household's income last year before taxes? Only include income you can reasonably use including but not limited to child support, per capita payments, unemployment, social security, supplemental security income, etc.

- | | |
|------------------------|------------------------|
| ◦ Less than \$10,000 | ◦ \$35,000 to \$49,999 |
| ◦ \$10,000 to \$14,999 | ◦ \$50,000 to \$74,999 |
| ◦ \$15,000 to \$24,999 | ◦ \$75,000 to \$99,999 |
| ◦ \$25,000 to \$34,999 | ◦ \$100,000 or more |

50. Including yourself, how many people are in your household?

----- people

51. Of the people in your household, how many are children (17 years and younger)?

----- people

52. Is there anything else you would like to tell me about how COVID-19 has impacted you or your family's social, financial, mental, physical, or religious/spiritual well-being? Are there any resources which would have been helpful?

End of survey



**WAŽA HIGIRAWI
(We Care)**



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