



# SURVEY AND FOCUS GROUP REPORT

## The Impact of Long COVID within Madison's Marginalized and Low Income Communities

# ADVOCATING FOR LONG COVID NEEDS IN OUR MARGINALIZED AND LOW INCOME COMMUNITIES

After three years of the Pandemic, the world is still dealing with COVID-19. Long COVID, also known as post-acute sequelae of SARS-CoV-2 infection (PASC), is one consequence that we are currently grappling with. The Center for Disease Control and Prevention (CDC) defines long COVID as *“a wide range of new, returning, or ongoing health problems people can experience four or more weeks after first being infected with the virus that causes COVID-19”* (2023). Post-COVID conditions also go by several other names, including long COVID (which is the terminology we've chosen to use), long-haul COVID, chronic COVID, and post-acute COVID-19 (CDC, 2022).

While anyone can develop long COVID, current research has shown that several characteristics were associated with a greater likelihood of developing long COVID (Kim, 2023). Those characteristics included being aged 30-49, having lower education, having lower household income, living in a larger household, being Hispanic, being female, being gay/lesbian or bisexual, and being divorced/separated (ibid). Moreover, there is evidence that long COVID was associated with an increased risk of recent unemployment, financial hardship, anxiety, and depressive symptoms (ibid).

In spite of the evidence suggesting a strong impact of long COVID on several facets of human quality of life, the relationship between its long-lasting effects and social inequities remains relatively unexplored.

Based on this need, Be Well Madison, with support of a grant from the Wisconsin Department of Health Services, developed a community-based survey and focus group project that advocated for understanding the long COVID health needs of marginalized and low-income communities in Madison, WI.

This project was conducted from September 2022 through April 2023. It utilized quantitative and qualitative methods, including a community survey and focus groups. The survey was offered in English, Spanish, and Hmong and received responses from 191 community members. The survey addressed long COVID-related topics such as symptoms, impacts, needs, and access to services barriers. The focus groups reflected on the survey results and discussed potential future recommendations.

Our project revealed two important takeaways. First, the survey results included a large percentage (close to 50%) of participants self-reporting COVID symptoms lasting more than four weeks. This percentage is significantly higher than would be expected based on the CDC's current data on long COVID (CDC, 2022). Second, those participants indicated there were numerous factors, cost being the the most identified, that might impact their ability to access wellness services to address their symptoms. This is especially concerning given the survey's focus on individuals and families from marginalized and low-income communities,

# PROJECT GOALS & METHODS

## Goals

This project aimed at promoting engagement, collaboration, and reflection within the community to develop future interventions that can be more relevant to their unique needs and experiences. As such, **our general goal was to learn what vulnerable populations with long COVID in Madison want and need to help them manage symptoms and access necessary services and resources.**

Our specific goals were divided into two themes:



### 01. Services & Resources

Understand the primary needs and services relevant to people with long COVID in vulnerable communities in Madison, WI.



### 02. Barriers & Challenges

Identify barriers that people with long COVID in vulnerable Madison, WI communities regularly face in accessing resources.

## Method

Mixed methods were used to collect data. For quantitative methods, a community survey was done among 191 community members. Below are sample questions asked:

- Did you get long COVID and how long did the symptoms last?
- Did you have long-term impacts and what health needs and resources do you need?
- What were the barriers you faced accessing resources and services?

Personal questions related to self-identification and zip code (none of these questions were mandatory to answer). Convenience sampling was used to select participants, this method involves selecting participants who are readily available or easy to access.

For qualitative methods, four focus groups were done with the following community partners:

- Bridge Lake Point Waunona Neighborhood Center
- Madison Public Library
- Lussier Education Community Center
- Kennedy Heights Neighborhood Center

These centers were selected because they are familiar with the community's needs and have direct contact with community members, which makes them valuable stakeholders in developing recommendations for the community's benefit. The Be Well team asked them to reflect on the community survey results and discuss potential future recommendations.

# PROJECT LIMITATIONS

While the project aimed at addressing the health issues related to long COVID by promoting engagement, collaboration, and reflection within the community, it had some limitations that need to be acknowledged.

## Identified Limitations

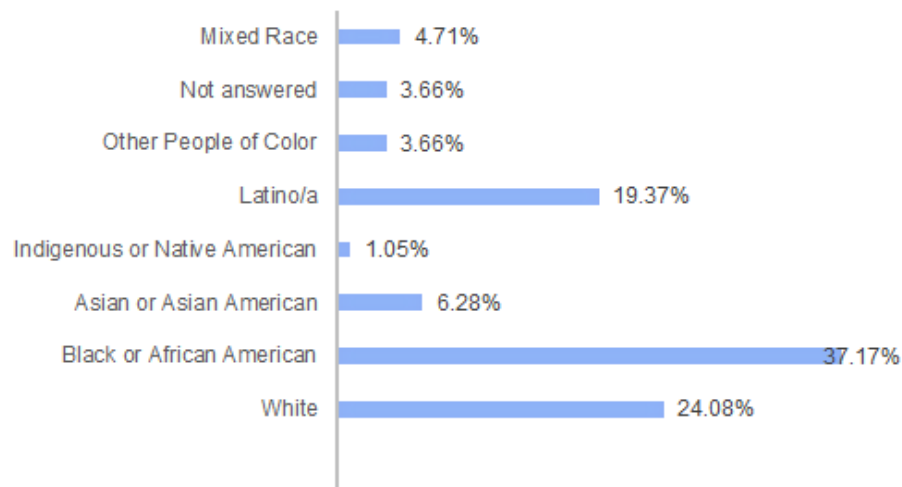
- Unwillingness to participate was a major factor in conducting surveys among community members in Madison, WI. affected by long COVID. The participants were approached based on diverse communities which means those who were unable or unwilling to participate were excluded from the project. There are multiple possible reasons, but one that was shared was lack of trust--they were skeptical of the information we were collecting. This could introduce inclusion bias, as the participants may not represent the target population's full range of experiences and perspectives. For example, those with more severe symptoms of long COVID may have been less likely to participate in the survey, due to distrusting the health care information system which could skew the results.
- Lack of information or data availability about certain groups of people who are considered marginalized, such as Native Americans and Asian Americans, led to their underrepresentation in this project. The data collected and analyzed makes it challenging to propose information that addresses the unique needs of these communities. Without this data, the health needs of these communities may continue to be overlooked and remain unaddressed.
- Information disclosure played a pivotal role in obtaining precise data. However, the omission of gender identity hindered the comprehensive coverage of significant sections in the report. Although it is crucial to respect individuals' privacy and refrain from imposing disclosure of their gender identity, it should be noted that gender identity constitutes a vital component of individual identity, which can impact health outcomes, experiences, and needs. For instance, research indicates that transgender individuals in the United States face a greater risk of developing long Covid compare to men and women (Kim, 2023).

Despite these limitations, the project provides valuable insights into the needs, challenges, and barriers faced by marginalized and low income populations with long COVID in Madison and can serve as a starting point for future interventions, responsive to the unique needs, and experiences of the affected communities.

# DEMOGRAPHICS

The survey participants were asked to self-identify by choosing all applicable categories. In this instance, more than 13 categories were available for selection. The categories were regrouped during the data analysis, resulting in the identification of 8 predominant ones. It was observed that the survey was predominantly answered by the Black or African American group. Fig.N1 Shows the categories and percentages.

**Figure N1: Self-Identification**



Source: Be Well Madison, 2023

Our study incorporated participants from low-income and marginalized communities, and we endeavored to ensure that the survey sample represented Madison's racially and ethnically diverse population. As per the most recent American Community Survey, Madison's racial composition comprises 76.1% White individuals, 6.8% Black or African American individuals, 8.9% Asian individuals, 7.8% Hispanic or Latino individuals, and 0.3% American Indian and Alaska Native individuals (U.S. Census Bureau, 2021).

# LONG COVID FINDINGS

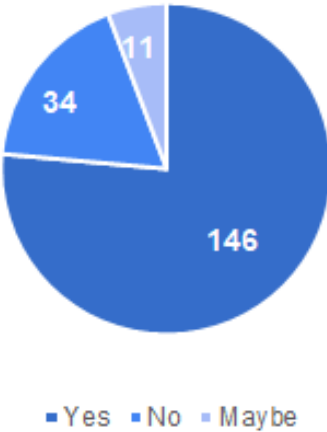
## Community Survey Findings

Since long COVID is a recently identified medical condition with varying levels of awareness among the general population (Cooper et al., 2023), participants were first asked to report whether they had contracted COVID-19 and, subsequently, whether they had experienced symptoms persisting for four or more weeks following its onset. These are the findings generated from the survey questions asked.

### 01. Amount of Community Members Who Contracted COVID

COVID infections were reported by 146 individuals (76.44%) out of 191 surveys. We observed that 34 responses (17.80%) indicated the absence of a previous infection, and 11 responses (5.76%) reported uncertainty regarding their COVID status due to the lack of testing. For reference, see Figure N2.

Figure N2: Number of Community Members who contracted COVID

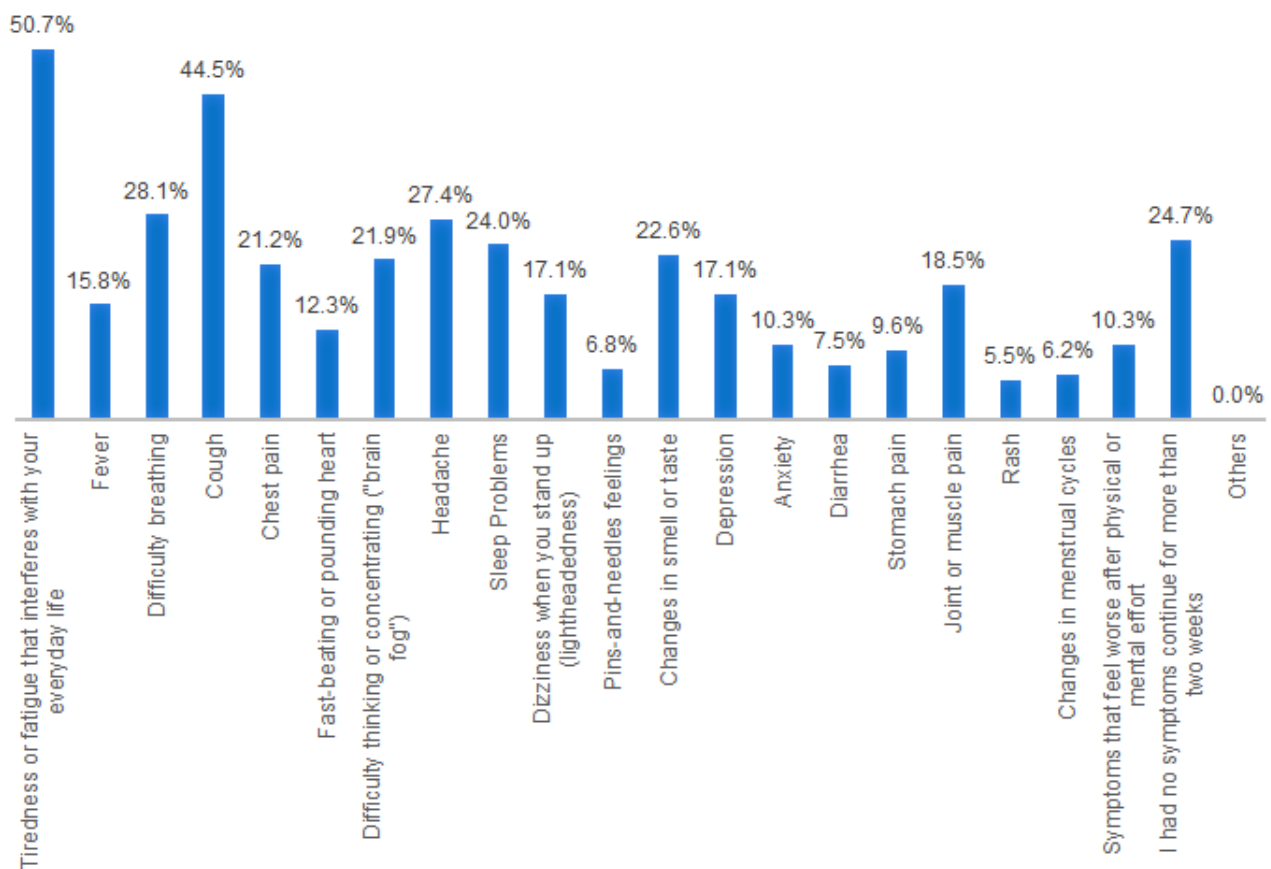


Source: Be Well Madison, 2023

## 02. Symptoms

Based on the symptoms reported by the surveyed population who answered “yes” or “possibly” to having had COVID, we found that a large percentage of respondents reported at least one symptom lasting longer than four weeks. The most prevalent symptom reported was tiredness or fatigue that interfered with their everyday life, with an occurrence rate of 50.7% among the surveyed population who answered "yes" or "possibly" to having contracted COVID. The second most frequently reported symptom was cough, with an occurrence rate of 44.5%, while headache was third with an occurrence rate of 24.7%. For reference, see Figure N3.

Figure N3: Long COVID Symptoms

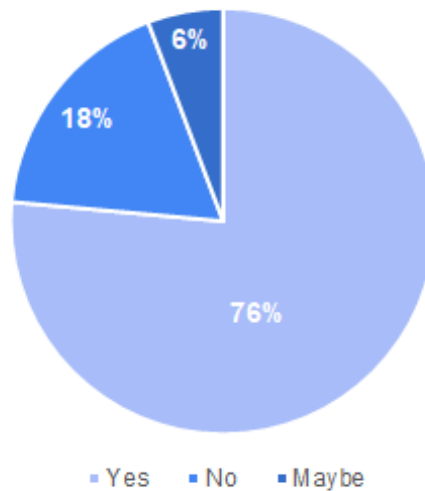


Source: Be Well Madison, 2023

### 03. Amount of Close Family Members Who Contracted Long COVID

When we asked community members whether a close family member had contracted COVID-19, 76% of survey respondents answered “yes.” Of that group 59.4% responded that a family member had experienced symptoms of long COVID. For reference, see figure N4.

**Figure N4: Number of Family Members who Contracted Long COVID**



Source: Be Well Madison, 2023

### 04. Long-Term Impacts of COVID 19

The following findings disclosed information regarding the long-term impacts of COVID-19 on community members and their close family members who contracted long COVID.

- **Long-Term Impacts among Community Members who contracted COVID**

In addition to symptoms alone, we examined other areas of life to identify potential long-term impacts of COVID-19. From the surveyed population who answered “yes” or “possibly” to having contracted long COVID, we found that 30.5% reported increased stress levels as a long-term impact of having COVID. Another significant impact identified was a loss of income, accounting for 22.7% of responses. Additionally, loss of motivation was reported by 20.6% of the respondents.

- **Impacts on Close Family Members who contracted long COVID**

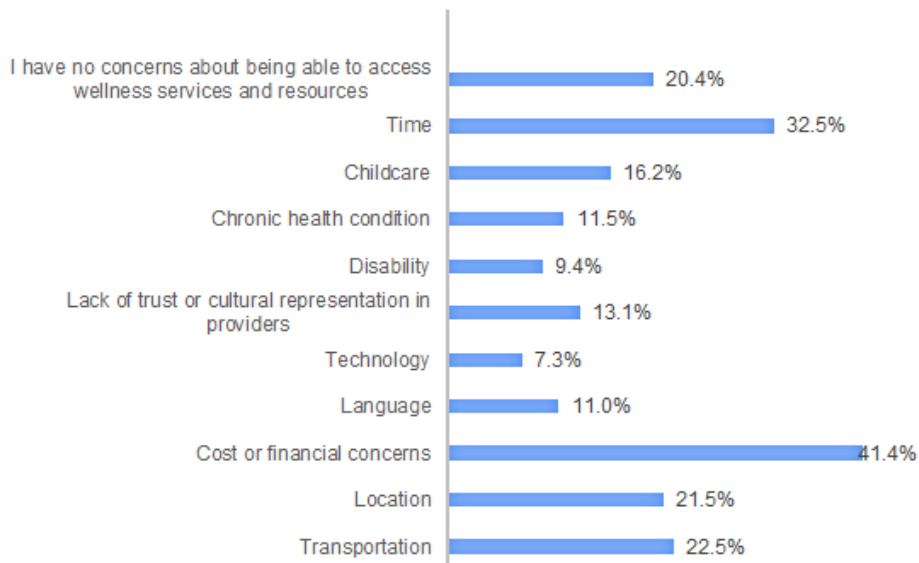
When survey participants were asked about how they were impacted by a family member having COVID, 43.5% of survey participants reported an increase in stress levels. Furthermore, 31.5% of the surveyed individuals reported that they had experienced a loss of income due to a family member having COVID.



## 05. Barriers & Challenges Accessing to Services

Regarding barriers faced by Madison's marginalized and low income communities in accessing services and resources, we found that the main barrier reported was cost or financing concerns, with a reported rate of 41.4%. The second most significant barrier was time, with a reported rate of 32.5%. Lastly, transportation was the third notable barrier, reported at a rate of 21.5%. For reference, see Figure N5.

**Figure N5: Barriers and Challenges accessing services**



Source: Be Well Madison, 2023

## 06. Services & Resources Requested

Based on the services requested by the surveyed population concerning long COVID symptoms, it was reported that the main needs are mental health counseling (e.g. psychotherapy, meditation), with 49.7% of responses; physical movement (e.g. yoga, dance, walking group), with 40.8% of responses; body practices (e.g. massage therapy, acupuncture, reiki, physical therapy), with 36.1% of responses; followed by stress reduction techniques, with 35.6% of responses. For reference, see Figure N6.

**Figure N6: Services & Resources Need it.**



Source: Be Well Madison, 2023

# Focus Group Findings

It should be noted that the survey data responses reflect what has been observed by community partners among community members (survey participants).

## 01. COVID-19

As health restrictions are being lifted in Madison, COVID-19 and its associated condition, long COVID, continue to be a health concern, as was unanimously agreed upon by all focus groups during discussions on the prevalence of individuals who had contracted COVID-19 among those surveyed.

## 02. Long -Term Consequences around COVID-19

Focus-group participants noted that an increase in stress has been observed. They reflected that the deaths of family members, loss of employment, food insecurity, and trauma responses are experienced among participants. Concerns about lack of trust in the healthcare system were also expressed.

***"I can see the increase in stress. If you know a caregiver, you will realize the stress level is higher. I'm unsurprised about that number because there are so many things related and contributing to stress levels related to COVID" (Madison Public Library Staff Member, March 23rd, 2023)***

These responses underscore the importance of acknowledging the diverse ways in which COVID-19 and long COVID have affected individuals and communities. They expressed the need for more comprehensive and inclusive surveys that account for the impact on areas such as sexual health and existing chronic conditions. A deeper exploration into what this survey has uncovered was requested and identified as a necessary step in better understanding specific long COVID needs within our marginalized and low income communities.

***"There are a whole group of people, down to the children, that are affected by this, they have thoughts and what do we do about helping them" (Bridge Lake Point Waunona Volunteer Member, April 7th, 2023).***

### 03. Requested Services

When asked about wellness services like those provided by Be Well Madison, focus group participants reported:

- **Mental Health Services**

The pandemic has exacerbated mental health disparities in marginalized and low income communities, rendering mental health assessments more critical within these populations. Providing access to mental health services and resources tailored to the unique needs of those with long COVID can help individuals manage their symptoms and improve their overall well-being.

When asked about barriers to accessing services like those that Be Well Madison can help provide to community partners, focus group participants reported:

- **Trusting relationships with healthcare and wellness service providers**

Focus group participants highlighted the importance of building trust and positive relationships between healthcare providers and patients, particularly in marginalized and low income communities such as those affected by long COVID.

Addressing these barriers is crucial to ensure that individuals can access essential resources to support their well-being. The responses from our focus group participants demonstrate the importance of understanding community-specific challenges and needs when providing wellness services. Furthermore, facilitating open communication and sharing experiences and ideas can also be effective in finding new ways to address the community's needs.

#### 04. How Do We Move Forward?

When asked to reflect on how to address long Covid health issues, the focus group participants shared the following suggestions:

- **Building trust between residents and health providers**

Focus group participants mentioned that providers can try to understand their patients' cultural backgrounds and beliefs and incorporate them into their care plans. In addition, healthcare providers can work to create a welcoming and inclusive environment that acknowledges and respects the diverse identities and experiences of their patients.

- **Building trust between residents and community centers**

Community centers can work to foster a sense of belonging and connectedness among their members by offering culturally competent services.

- **Developing a collaborative plan with partners**

Community Partners expressed that a collaborative plan with different stakeholders is needed to identify appropriate partners, build trusting relationships, and establish shared goals and objectives.

If these actions are taken, they believe we can achieve positive outcomes and improve the services and support provided to our Madison, WI, marginalized and low income communities.

***"Keep doing outreach for services needed", Kennedy Heights  
Resident, March 23rd, 2023***

# KEY FINDINGS & RECOMMENDATIONS

Conducted by Be Well Madison, this project has provided valuable insights into the needs and challenges of the Madison community, particularly those disproportionately impacted by the COVID-19 pandemic. Through our survey and focus groups, Be Well Madison has been able to identify critical areas where services and resources are lacking, as well as opportunities for collaboration and improvement.

## **Key Findings:**

1. Long COVID has had a more significant impact than expected on a higher proportion of individuals, particularly among the participants of our survey.
2. In addition to health related symptoms, our findings revealed that long COVID affects individuals surveyed in various aspects of their lives, with the most significant impacts observed in the areas of income loss and persistent stress.
3. Moreover, survey participants noted that these same consequences, loss of income and persistent stress, were experienced when a family member contracted COVID, suggesting a broader impact that has not received adequate attention.

## **Recommendations:**

1. The projects' findings suggest a significant need to prioritize and increase access for wellness services and resources in general, but specifically for mental health, stress reduction and financial support.
2. It is important to note, research has shown that individuals are more likely to utilize health services when they trust their providers and feel a sense of connection and respect toward them. Conversely, a lack of trust and negative experiences with healthcare providers can lead to hesitancy or avoidance when seeking services, even if they are desperately needed (Thom, 2017). Therefore, it is essential to prioritize building trust and fostering positive relationships with individuals in marginalized and low income communities.
3. It is imperative to find effective ways to address the barrier of cost. Structures, such as Be Well Madison's, could be one such model to consider. We strongly support the continual exploration and creation of accessible cost methods.
4. It would be beneficial for community organizations who directly work with Madison's marginalized and low income communities to create strong, positive partnerships to better address the needs this project has highlighted.
5. Additional research on the long-term impacts of COVID should be conducted, specifically to learn more about impacts beyond health-related symptoms, the effects of family members who had COVID on individuals and within community, and a broader demographic representation.

# ACKNOWLEDGEMENTS

Thank you to our community partners who were able to engage with this project.



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