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# Fostering Equity: A Strategic Framework for Addressing Long COVID Disparities through Community Engagement

A Summary of Community Insights to Address Long COVID

# Acknowledgements

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# Executive Summary

Transforming, Atlanta, GA

The COVID-19 pandemic has starkly illuminated pre-existing health disparities, particularly among minoritized racial and ethnic communities, accentuating the profound negative impact of systemic and structural racism.

Evidence shows that minoritized racial and ethnic communities are disproportionately affected by severe outcomes of COVID-19, facing higher rates of hospitalization and mortality compared to their white counterparts. Moreover, these disparities extend beyond race and ethnicity, encompassing socioeconomic factors such as employment and living conditions. Essential workers, often from marginalized backgrounds, bear a disproportionate burden of COVID-19 infections due to non-remote job requirements, inadequate resources, crowded housing, and language barriers, among other factors. These inequalities underscore the pivotal role social determinants of health play in exacerbating disparities and driving inequities.

The emergence of Long COVID presents a new layer of health challenges, with preliminary data indicating that minoritized racial and ethnic communities are once again bearing a disproportionate burden. Long COVID's adverse effects are exacerbating existing disparities in employment, financial security, and access to healthcare. The response to Long COVID demands a

comprehensive, multi-faceted approach, necessitating robust data collection, equitable distribution of resources, and proactive community engagement.

The Long COVID response also requires that we tackle ongoing systemic issues such as underrepresentation in clinical trials and insufficient awareness and support services. Engaging communities directly in understanding and mitigating the impacts of Long COVID is crucial for developing tailored public health interventions and fostering health equity in the post-pandemic landscape.

Embracing community voices not only enhances the relevance and efficacy of interventions but also empowers individuals to become active stakeholders in their own well-being, ultimately driving positive health outcomes and fosters a resilient, inclusive nation.

## Our Approach

In 2023, Community Catalyst initiated the "Impact of Long COVID in Black and Hispanic/Latinx Communities" project, aiming to assess the mental, physical,

and economic effects of Long COVID in these communities and develop community-driven solutions. This initiative sought to inform future policies and programs addressing Long COVID within Black and Hispanic or Latinx communities by leveraging community expertise and experiences.

Using a community engagement and strengths-based approach, Community Catalyst supported six community-based organizations (CBOs) in hosting community-led listening sessions to gather insights and recommendations to address Long COVID and health disparities. Tools and resources including training materials, surveys, and facilitation guides were developed to support CBOs in collecting data and hosting discussions on Long COVID's impact.

In addition, Community Catalyst surveyed 25 communities to assess vaccination behavior, COVID-19 diagnosis, Long COVID experiences, and the impact of Long COVID on their communities.

## Our Findings

Our Long COVID impact survey, from 587 respondents, found that over half (51.8%) had experienced COVID-19 illness and 53.5% had at least one household family member experiencing COVID-19 illness. A vast majority (89.3%) of respondents reported having at least one COVID-19

vaccination, and 74.4% of those participants had received at least one additional COVID-19 or “booster” vaccination.

Nearly half (49.7%) of respondents reporting prior COVID-19 illness also reported having Long COVID symptoms. Change in smell or taste was the most often reported Long COVID symptom among respondents (47.0%). Most respondents (58.9%) with Long COVID symptoms sought support or treatment, with more than half (58.4%) seeking support from their primary care provider.

The respondents also indicated that they saw the greatest impact to social determinants of health was seen in their ability to interact with family, friends, coworkers, and/or community members (social context) and their ability to obtain or maintain employment or afford basic needs (economic stability).

Over a third of respondents with Long COVID symptoms were most satisfied with the ease of accessing Long COVID support (38.4%) and availability of medical support for Long COVID (34.5%), however there were challenges with the availability social and community-based support (e.g., housing and food support) in their communities.

Listening sessions revealed that access to education and information, access to healthcare, community-level attributes, level of community and faith-based leader engagement, and intrapersonal

attributes were all strengths that their respective communities brought to the table to address Long COVID and persistent health disparities.

Communities also saw opportunities to leverage these strengths to reach their access to health care, community attributes, and health outcomes or health equity goals.

## Our Solutions

Community Catalyst believes a community-first public health approach is necessary to have a strategic impact on both Long COVID challenges and to reduce overall health disparities seen in communities and across the nation.

The work by Community Catalyst reveals that communities, when adequately equipped with tools and resources, are essential thought and implementation partners for all public health efforts. Cornerstones to this community engaged approach are:

- Proven community engagement strategies.
- Engagement of whole communities – leaders, policymakers, and community members.
- Acknowledgement of community strengths and mutual respect between the community and public health entities.
- Engagement of communities in collaborative design and implementation of public health strategies.
- Addressing community-based organization capacity to support efforts.
- Funding, resources, and partnerships allocated for communities.
- Evaluation and monitoring of efforts.

Community Catalyst will continue to seek and provide support to move forward community-level strategies to address Long COVID and health disparities. The following are recommendations on how we can and will engage locally and nationally to address identified public health challenges:

- Use lessons learned to inform organizational Long COVID policy and advocacy efforts.
- Share learnings with applicable local, state, and federal partners to inform their Long COVID efforts.
- Develop and make easily available quality and relevant education and information about Long COVID.
- Develop tools and resources to help communities facilitate community-wide discussion about important issues impacting their communities.
- Support CBOs, public health, and healthcare provider partnerships.
- Identify and provide flexible funding for communities to address social determinants of health factors exacerbated by COVID-19.





My hope for the future is to have

**MORE:**

make getting the vaccine affordable for  
all.

My 34 yr old Nephew battled long COVID For over  
4 weeks in the hospital before passing. (was on IV, ventilator)  
HE had underlying medical: ASTHMA growing up?

to help support my community with  
**LONG COVID**

# Introduction



The COVID-19 pandemic has exacerbated historical and persistent disparities in health and highlighted the impact of systemic and structural racism among minoritized racial and ethnic communities, widening the gap in equitable access to quality healthcare and health inequity.

In the United States, minoritized racial and ethnic communities with COVID-19 infection are more likely to be hospitalized and/or experience death (Mirajkar, Oswald, & Rivera et al., 2023). In 2020, people of Hispanic or Latin descent were five times more likely to experience death from COVID-19 than their white counterparts, followed by Black or African American, who were 3.5 times more likely (Hill & Artega, 2022). With the emergence of the Delta variant in 2021, American Indian and Alaska Native communities experienced higher rates of death than any other racial and/or ethnic group, followed by Black or African American and Hispanic or Latino/a/x/e (Latinx) communities. This trend continued in 2022 with the appearance of the Omicron variant (Hill & Artega, 2022).

In addition to racial and ethnic disparities, the COVID-19 pandemic highlighted inequities by class. Essential workers, such as workers in grocery, transportation, warehouse, delivery, and residential facility industries, experienced the worst of the COVID-19 pandemic (Economic Policy Institute, 2020). The high incidence of COVID-19 infection in these communities can be attributed to having non-remote jobs, lack of resources and/or preparedness for a pandemic, living in overcrowded housing, the use of public transportation, language barriers, and other preventable causes (Pasquini & Keeter, 2022; Ramprasad, Qureshi, & Lee et al., 2022). This demonstrates the importance of addressing social determinants of health and to reduce the resulting negative impacts that can be key drivers of health disparities and inequities.

The global COVID-19 pandemic also had an impact on mental health in communities, in addition to its physiological effects. Research shows that 58% of U.S. adults also experienced psychological distress during the pandemic (Pasquini & Keeter, 2022). In a recent study, the highest prevalence of severe and moderate psychological distress due to the COVID-19 pandemic was among Hispanic or Latinx respondents, 22% and 65% respectively; followed by Asian (18%; 60%) and Black (16%; 57%) respondents (Wen, et al., 2023). Individuals expressed that loneliness and stress due to low income and/or disability prevented them from working or fully engaging with family. Also, many of these individuals experienced physical reactions, such as sweating or a pounding heart, when thinking back on their lives during the pandemic (Pasquini & Keeter, 2022).

## Black and Latinx communities disproportionately affected by the COVID-19 pandemic are now feeling the weight of another public health burden – Long COVID.

After having COVID-19, some people experienced lingering or new symptoms and illness, or Long COVID. Long COVID or Post-COVID Conditions are persistent symptomatic symptoms or new chronic health conditions that arise after having COVID-19 infection. Long COVID is not easily diagnosed, treated, or understood; it is considered an invisible illness (Ireson et al., 2022) and inconsistency in terminology and definitions of Long COVID impacts healthcare providers' ability to effectively diagnose, treat and educate patients on Long COVID (Rando et al, 2021).

While it is too soon to know the full extent of Long COVID impacts on minoritized racial and ethnic populations, it is suggested that the Long COVID disparities closely resemble those of the COVID-19 pandemic. For example, Latinos and residents in the Bronx, a borough in New York City with the highest rates of poverty, largest Black and Hispanic and Latinx population, and the highest rate of COVID-19-related deaths during the pandemic, also reported disproportionately high rates of Long COVID symptoms (Luft, 2022). According to the U.S. Census Household Pulse Survey, Black and Hispanic individuals showed a higher prevalence of Long COVID symptoms between June and December 2022, compared to other groups (Glassman, 2023). Additionally, respondents of this survey who identified as “transgender” or “none of these” (male, female, or transgender) were more likely to experience Long COVID symptoms than those identifying as male or female. Research has also shown that people who experience Long COVID are more likely to struggle with financial insecurity (Glassman, 2023) and unemployment (Sanchez, et. al., 2022). According to Sanchez et al. (2022), unemployment due to Long COVID disproportionately impacts minoritized racial and ethnic and low-income communities because members of these communities are more likely to work in essential roles with hourly wages and little to no sick leave.

The U.S. Department of Health and Human Services (HHS) released a report, “Service and Support for Longer-Term Impacts of COVID,” identified through listening sessions with researchers, advocacy groups, and national organizations that challenges to engaging individuals in using available Long COVID resources was due to a lack of awareness of resources and difficulties reaching families (HHS, 2022). Unfortunately, the report did not include demographic information about participants, therefore, it is unknown if the results were representative of communities most impacted by COVID-19. The National Institutes of Health (NIH), through the RECOVER Initiative, has initiated Long

COVID support to provide a continuity of care through multi-disciplinary approaches in over 200 clinical research sites. However, accessibility to many of these clinics and the clinical trial remains a barrier (Verduzco-Gutierrez et al, 2021); further contributing to the underrepresentation of people of color in COVID-19 clinical trials due the lack of information and unaddressed historical and ongoing racism (Hill & Artega, 2022).

In 2022, Community Catalyst initiated a project to understand the impact of Long COVID on communities and to assess the availability of information resources and support by national and state governmental agencies. An environmental scan showed that there is an overall lack of visibility of Long COVID as an emerging public health crisis. Only one-third of the 24 national organizations reviewed discussed Long COVID in any capacity. Among the eight national organizations that discussed Long COVID, only five provided resources and activities for communities or individuals. Similarly, only one-third of state health departments discussed Long COVID on their public websites, with only 11 states providing resources and 5 states reporting on their activities. This project also surveyed 32 community-based organizations (CBOs), supported by Community Catalyst through funding provided the CDC to promote COVID-19 and influenza vaccination confidence, revealing that 78.9% of the CBOs had heard of or discussed Long COVID and that 62.5% understood the symptoms of Long COVID and its impact on their community. Half of the CBO reported that Long COVID had a low to moderate impact on their COVID-19 vaccination activities; yet 71.9% reported moderate to significant impact of Long COVID in the communities they served. Among the CBOs, only 43.8% provided education or support to the community for Long COVID.

Reducing the impact of Long COVID, particularly among systemically excluded communities requires a multi-pronged approach. Effectively addressing Long COVID must include the collaborative and systematic collection of high-quality data to be used in real-time to improve system learning and bolster the public health response (Berger, 2021). In addition, resources are needed to ensure equitable access to and distribution of health care in global, national, community, and individual settings (Berger, 2021).

The lack of availability of Long COVID outcome and impact data, the recommendations from Berger et al. (2021), and lessons learned from the VEAP community partners, demonstrated the critical need for community conversations to understand the impact of Long COVID on communities.



# The Long COVID Project

Black Health, New York City, NY

## Project Overview

In 2023, Community Catalyst, in partnership with Trifecta Advising, developed and implemented the “*The Impact of Long COVID in Black and Hispanic or Latino/a/x Communities*” (the “Long COVID Project”) with the goal of understanding the mental, physical, and economic impact of Long COVID on Black and Hispanic or Latinx communities. In addition, Community Catalyst sought to develop strengths-based and community-driven recommendations on addressing the impact of Long COVID in minoritized racial and ethnic communities. This project was designed to gather valuable insights from communities to influence future Community Catalyst initiatives, policies, and programs to address Long COVID. To achieve these goals, Community Catalyst:

- **Convened an advisory group of community-based organizations.** Community Catalyst leveraged access to Vaccine Equity and Access Program (VEAP) CBO partners to support the establishment of a 25-member organization Long COVID advisory group. The Long COVID Advisory Group helped to identify and actively contribute to the development of a Long COVID impact survey, community resources, and support needed to respond to and address Long COVID concerns.
- **Partnered with communities to host virtual and/or in-person listening sessions.** Among the advisory group, Community Catalyst partnered with six CBOs, working in Black and Hispanic or Latinx communities, to host listening sessions in their communities about the impact of Long COVID and to identify community-driven strengths-based recommendations.
- **Developed tools and resources to facilitate community level discussions and collect impact data.** Community Catalyst developed a CBO partner training, a listening session facilitation guide, a Long COVID impact survey for communities, and a listening session evaluation.

Community Catalyst’s Vaccine Equity and Access Program (VEAP) has been funded by the CDC since 2021 to support over 125 CBOs to develop and implement effective health communication and community engagement strategies designed to increase vaccine confidence and acceptance in minoritized racial and ethnic communities at increased risk of COVID-19 infection and death. VEAP CBO partners were at the forefront of COVID-19 pandemic, recognized as trusted sources for vaccine education and have played an essential role in reducing COVID-19 infection and increasing vaccination rates in their communities.



Table 1. Participating Community Organization Profiles

Organization	Description
<p><b>Black Health</b> New York City, NY   Social Services Organization   Black and African American Serving   Urban Community</p>	<p>Aims to reduce disparities and achieve health equity for Black communities through advocacy, policy, and action. Black Health committed to policy changes and legislative decisions that increase funding for preventative testing, address existing health care crises, and maintain affordable treatment and care for improved quality of life.</p>
<p><b>Doulas Latinas</b> Portland, OR   Health &amp; Healthcare Organization   Black and African American and Hispanic or Latino/a/x serving   Urban and Rural Communities</p>	<p>Aims to provide emotional and linguistic support during pregnancy and childbirth, all while championing health equity for Latino families. Doulas Latinas International also actively engages in other community outreach initiatives, including vaccine campaigns, tobacco awareness, and programs to tackle climate change.</p>
<p><b>Patients R Waiting</b> Lancaster, PA   Health &amp; Healthcare Organization   Black and African American serving   Rural Community</p>	<p>Focuses on increasing the pipeline of minority clinicians, making the pipeline of minority clinicians less leaky, and supporting minority clinicians in practice.</p>
<p><b>Randolph County Caring Community</b> Moberly, MO   Social Services Organization   Black and African American serving   Rural Community</p>	<p>A Black-male led organization that works with and mobilizes faith-based organizations and focuses on their local, senior African American population. Their mission is to engage the community in action towards enhancing the quality of life of all residents.</p>
<p><b>Tennessee Justice Center</b> Nashville, TN   Advocacy Organization   Black and African American serving   Urban Community</p>	<p>Advocates for and with vulnerable Tennessee families and helping them to access the basic necessities of life. They work to elevate the needs of marginalized groups—including, low-income families, seniors, and people with disabilities as well as make Tennessee’s policies more just and compassionate.</p>
<p><b>Transforming</b> Atlanta, GA   Advocacy Organization   Black and African American and Hispanic or Latino/a/x serving   Urban Community</p>	<p>Focuses on trans, intersex, non-binary, and gender non-conforming persons. Through advocacy, education, leadership development, coalition-building, peer support, and direct service they work to ensure their communities live with dignity and wellness. They also address basic needs and build a sense of community while mobilizing to transform oppressive institutions and systems.</p>



## Community Engagement Approach

Community engagement stands as the cornerstone of effective public health decision-making, serving as a vital conduit for understanding local needs, fostering trust, and co-creating sustainable solutions.

Community engagement is an approach that has been shown to effectively address health inequities by centering the voices of communities, championing inclusiveness, leveraging partnerships and resources, influencing systems, and empowering communities (Ahmed & Palermo, 2010; Wallerstein et al, 2020; Garcia et al, 2021). Effective engagement of communities in planning and decision-making processes also has positive impacts on health outcomes, moves theory to implementation faster, and increases potential uptake of interventions within the community, due to buy-in from the community at the onset of the engagement (Ahmed & Palermo, 2010; Wallerstein et al, 2020; Garcia et al, 2021).

Engagement of the community organizations in the Long COVID project required a strategic approach that facilitated the inclusion of community members in the collection of data and insights to inform project outcomes. Community Catalyst used nine principles of community engagement (Figure 1) to successfully engage communities in the project.

Figure 1. Principles of Community Engagement



Adapted from CTSAC, 2011

Using appreciative inquiry, Community Catalyst adapted the strengths-based process, strength, opportunities, aspirations, results (SOAR) analysis, to engage communities in strategic discussions that builds on community strengths to improve health outcomes for the entire community. Appreciative inquiry is a process of capturing positive features of an organization or system and mobilizing their members to strive for greater performance (Acosta & Douthwaite, 2005).

SOAR leverages appreciative inquiry to focus on community strengths and to understand whole systems by including the voices of relevant stakeholders (Sprangel, et. al., 2011; CLHO, n.d.). The SOAR process is also a future forward facilitation method which allows participants to focus on their current strengths and opportunities, and to create a vision of future aspirations and the results they will bring. The application of the SOAR process in community listening sessions was meant to facilitate broader discussion about those factors in communities that can be leveraged to implement broader public health strategies. The process was also ideal in helping to identify what was most important to communities and defining how they expected to see the results of collaborative engagement.

The adapted SOAR process used facilitation methods based on the Technology of Participation (ToP) best practices that are designed to “transform the way groups think, talk and work together” (Institute of Cultural Affairs (ICA), 2024). Implementation among community organizations was very interactive and intended to move the group to consensus and decision-making (Figure 2).

Figure 2. SOAR Process Overview



Adapted from Sprangel, et al., 2011

## Supporting Communities

The core activities for the community organizations included distribution of a community survey to assess the impact of Long COVID and hosting in person and/or virtual listening

sessions. Community Catalyst provided tools, training, and technical assistance to CBO partners to effectively host community listening sessions that would contribute to overall learnings about the impact of Long COVID.

To ensure uniformity of each of the listening sessions, Community Catalyst developed a listening session facilitation guide and hosted facilitation training for participating CBO partner staff members. The facilitation guide included information on the facilitation process and methodology, listening session logistics (e.g., event location, set-up, necessary materials and supplies, event registration), and tools for listening session surveys and evaluation.

In addition, Community Catalyst conducted pre-event one-to-one sessions with CBO partners to review the facilitation guide, discuss any questions, and provide technical support to implement the SOAR process and survey distribution. Training was critical to ensure community organizations were equipped with best practices for facilitation of both in-person and virtual community listening sessions as well as information on the strengths, opportunities, aspirations, results (SOAR) facilitation process which was to be utilized during each event. The tools developed were informed by the Long COVID Project Advisory Group, which helped to provide insight in community-level capacity, knowledge, and anticipated level of engagement.



Community Catalyst and Randolph County Caring Community Listening Session Facilitation Teams



OPPORTUNITIES

How can we make  
the most of our strengths?  
What support do you want  
available?

# Findings

Patients R Waiting, Lancaster, PA

## Community Experiences

The Long COVID Project CBO partners surveyed their respective communities to assess vaccination behavior, COVID-19 diagnosis, Long COVID experiences, and the impact of Long COVID on their communities. A total of 587 responses were received from the Long COVID Project communities. Surveys were disseminated in two phases. Phase one focused on implementation sites in Missouri, New York, Pennsylvania, Oregon, Georgia, and Tennessee. These communities hosted listening sessions using the SOAR facilitation process and collected Long COVID impact data before, during, and after the hosted event in both English and Spanish. Implementation sites accounted for 64.4% of surveys collected through the Long COVID Project.

Phase two surveys included all CBO partners participating in the Long COVID Project Advisory Group. The additional data contributed to broader understanding of vaccination practices and impact of Long COVID over a more racially, ethnically, and geographically diverse population. A total of 209 surveys were completed during phase two of the Long COVID survey implementation. In addition to the states participating in phase one, surveys were received from respondents in Florida, Illinois, Maryland, Mississippi, New Jersey, Ohio, Virginia, Washington, and the District of Columbia. Phase two surveys were provided electronically in English, Korean, and Spanish.

Among survey participants, over half (51.8%) had experienced a COVID-19 diagnosis, and 53.5% of participants reported that one or more of their household family members had been diagnosed with COVID-19. Among persons having a prior COVID-19 diagnosis, 49.7% reported having lingering symptoms of COVID-19, new post-COVID conditions, or Long COVID. Table 2 shows the demographic characteristics of survey respondents.

Table 2. Demographic Characteristics of Survey Respondents by COVID-19 diagnosis and Long COVID symptoms.

Demographic Characteristic	Total <sup>1</sup> (n=587)	No COVID-19 Diagnosis (n=270)	COVID-19 Diagnosis Only (n=153)	Long COVID Symptoms (n=151)
All Survey Respondents	--	46.0%	26.1%	25.7%
<b>Age Group</b>				
Under 16 years	0.7%	0.4%	2.0%	0.0%
16 - 20 years	1.7%	2.6%	0.7%	1.3%
21 - 30 years	6.6%	6.7%	8.5%	4.6%
31 - 40 years	8.9%	7.4%	13.1%	7.3%

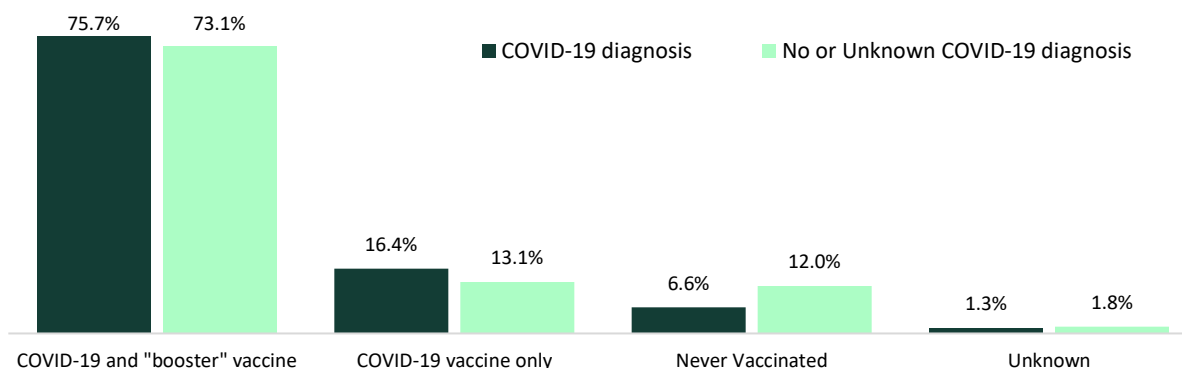
Demographic Characteristic	Total <sup>1</sup> (n=587)	No COVID-19 Diagnosis (n=270)	COVID-19 Diagnosis Only (n=153)	Long COVID Symptoms (n=151)
41 - 50 years	12.3%	8.5%	11.1%	21.2%
51 - 64 years	23.5%	23.0%	24.2%	23.2%
65+ years	23.9%	31.5%	20.3%	13.9%
Unknown	22.5%	20.0%	20.3%	28.5%
<b>Ethnicity</b>				
Hispanic or Latinx	21.3%	15.6%	21.6%	31.1%
Non-Hispanic or Latinx	66.1%	73.0%	63.4%	58.3%
Unknown	12.6%	11.5%	15.0%	10.6%
<b>Racial Identity</b>				
Asian or Asian American	9.7%	10.7%	13.1%	5.3%
Black or African American	60.1%	64.4%	60.1%	53.6%
Native American or Alaska Native	0.9%	1.5%	0.0%	0.0%
White or Caucasian	9.4%	5.2%	10.5%	14.6%
Other	3.7%	3.0%	3.3%	6.0%
More than one race	2.4%	2.6%	2.6%	2.0%
Unknown or prefer not to specify	13.8%	12.6%	10.5%	18.5%
<b>Gender Identity</b>				
Man	19.4%	18.1%	21.6%	18.5%
Woman	72.2%	74.8%	73.2%	68.2%
Non-binary	1.4%	1.1%	0.0%	3.3%
Transgender	3.1%	1.9%	2.0%	6.6%
Other	0.3%	0.4%	0.7%	0.0%
Unknown or prefer not to specify	3.6%	3.7%	2.6%	3.3%

<sup>1</sup> Note: 2.2% of survey respondents did not provide COVID-19 or Long COVID status information.

A vast majority (89.3%) of survey respondents reported they had received at least one COVID-19 vaccination, and 74.4% had received the vaccination and at least one additional COVID-19 or “booster” vaccine. As seen in Figure 3, there were no significant differences in vaccination status among respondents with or without a COVID-19 diagnosis.



Figure 3. Vaccination Status by COVID-19 diagnosis.



COVID-19 diagnosis n=304; No or unknown COVID-19 diagnosis n=283

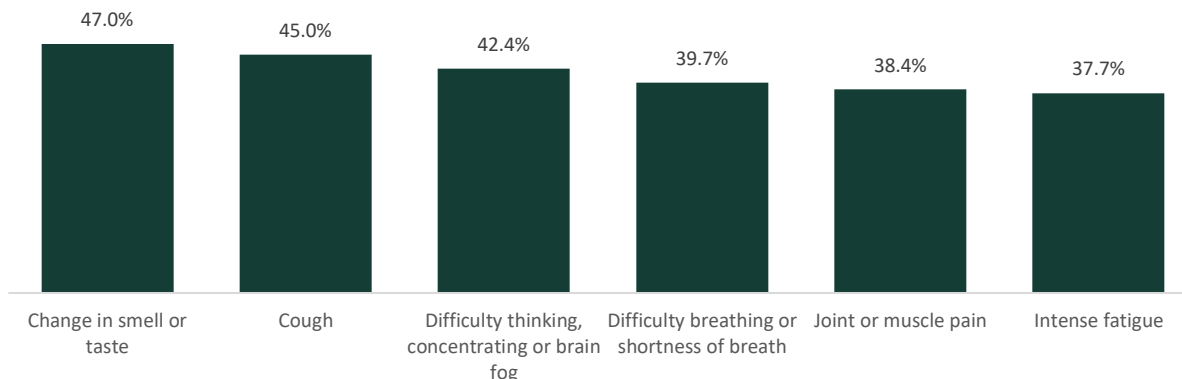
Nearly half (49.7%) of survey participants, with a prior COVID-19 diagnosis, reported experiencing symptoms of Long COVID. When asked about which symptoms people experienced, the responses varied among 20 known symptoms, with the most frequently reported Long COVID symptoms being change in smell or taste (47.0%).

“ Other community members also experienced long-COVID but because their symptoms were different than mine, it was odd. We weren't all seeing the same signs.

**Survey Respondent**  
Nashville, TN

Figure 4 shows the most frequently reported Long COVID symptoms among survey respondents.

Figure 4. Most Frequently Reported Long COVID Symptoms

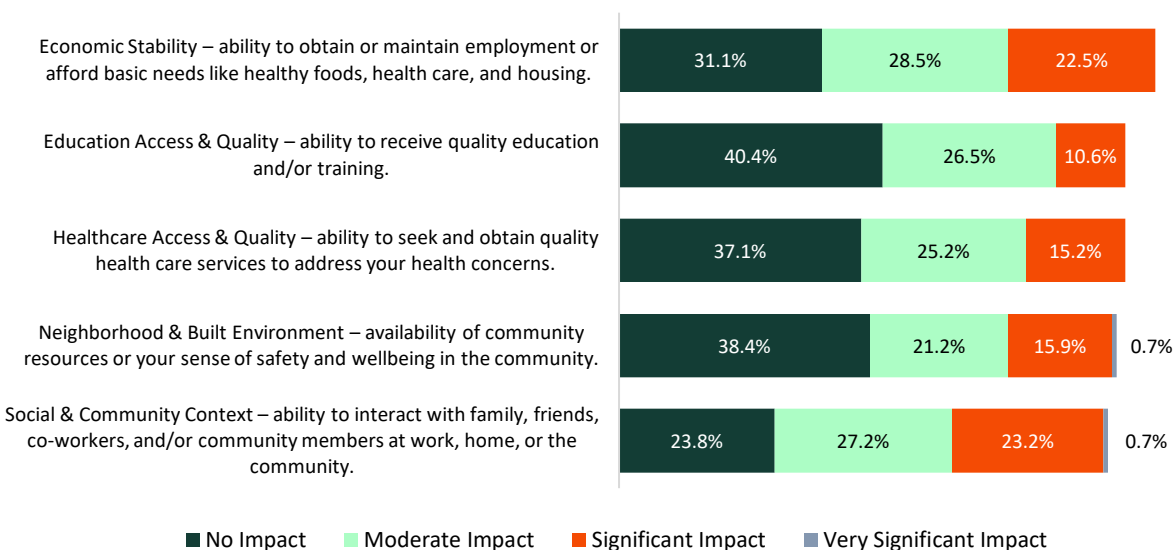


n=151

In addition to the known symptoms, some survey respondents reported symptoms as severe as ringing in the ear and kidney infection and failure. Sixty-three percent of respondents reported they experienced Long COVID symptoms or conditions for less than 3 months (31.6%) or more than one year (31.6%).

When asked about the impact of Long COVID on social determinants of health, more than one-third of respondents reported Long COVID had no impact on education access and quality (40.4%), neighborhood and built environment (38.4%), and healthcare access and quality (37.1%). Over half (51.0%) of respondents reported Long COVID had moderate to very significant impact on both social and community context (e.g., ability to interact with family, friends, co-workers, and/or community members) and economic stability (e.g., ability to obtain or maintain employment or afford basic needs). Figure 5 shows the level of impact based on each of the five social determinants of health.

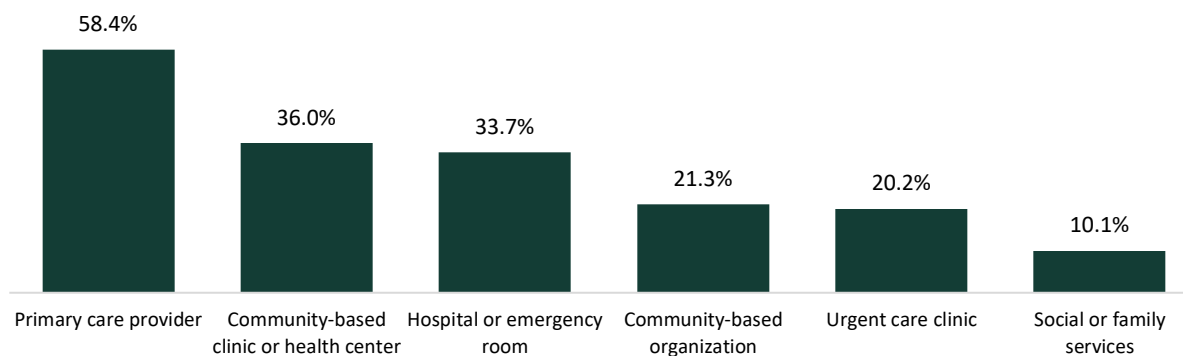
Figure 5. Impact of Long COVID on Social Determinants of Health



Note: Data not shown for unknown or missing responses. n=151

Most (58.9%) survey respondents with Long COVID symptoms indicated they sought support or treatment. Among those seeking support for Long COVID, 58.4% indicated they sought support or treatment from their primary care provider. Most survey respondents (55.1%) only sought care from one source. Figure 6 provides a breakdown of where respondents reported seeking care.

Figure 6. Locations Where Respondents Sought Care for Long COVID



n=89.

“ I was lucky enough to have my primary care physician, who was proactive in helping me figure out the symptoms related to my long-term COVID diagnosis. And we were able to figure out a plan to deal with the symptoms. Communication and follow-up was key.

**Survey Respondent**

Cleveland, OH

When asked about their satisfaction with access to and availability of support and care in their communities, respondents reported being very satisfied (14.6%) or somewhat satisfied (23.8%) with the ease of accessing Long COVID support. More people were somewhat or very dissatisfied with the availability of social and community-based support (e.g., funding for treatment, housing, and other aid) and availability of medical support for Long COVID; 15.9% and 15.2%, respectively.

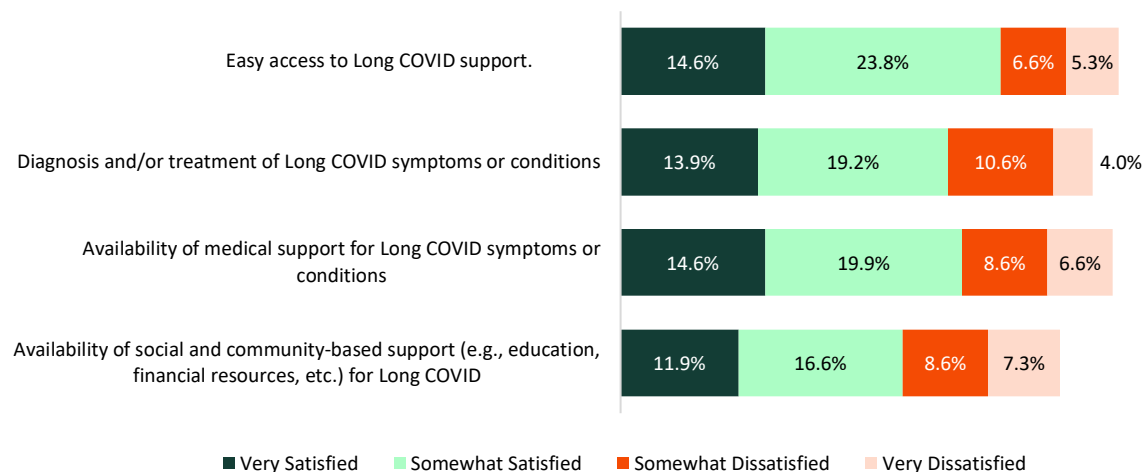
“ I had to [borrow] money for my treatments and buy oxygen, antibiotics. Pay for therapies and more.

**Survey Respondent**

Gainesville, FL

Figure 7 shows the respondent's level of satisfaction with the support and care available in their communities.

Figure 7. Respondents with Long COVID Satisfaction with Support and Care



Note: data is not shown for missing or not applicable responses. n=151.

Although the survey did not specifically ask about the quality of the healthcare they received, many included comments that indicated that they did not get the treatments they felt were effective.

“ The doctors would treat the symptoms which kept coming back, they would never address the possibility of long term covid complications caused the symptoms.

**Survey Respondent**

Jackson, MS

## Community Voices

CBO partners hosted six in-person and one virtual listening session in six communities in Atlanta, GA; Moberly, MO; New York City, NY; Portland, OR; Lancaster, PA; and Nashville, TN – reaching nearly 340 community members. Listening session participation ranged from 8 to 171 community participants. Two-thirds of CBO partners served urban, mostly Black or African American communities. One CBO partner served an urban Hispanic or Latinx community and provided their listening session in Spanish.

This section of the report provides an overview of key themes, organized by components of the SOAR process, consistent among all communities participating in the listening sessions.

## Strengths

Communities were asked to identify what was working well in their communities to address Long COVID and/or health disparities. There were six key themes that consistently emerged among the listening sessions.

Key Themes	Description
<p><b>Access to Education and Information</b> Availability of quality and relevant education and information about COVID and/or Long COVID.</p>	<p>Community members thought they were well equipped with education and information about COVID in their communities. They did not specifically call out the availability of information for Long COVID, but broadly discussed availability through media, community events, etc.</p>
<p><b>Access to Healthcare</b> Availability of healthcare resources, such as healthcare providers, vaccinations, and testing within the community.</p>	<p>Community members felt the availability of vaccines and tests, in various locations by a diverse group of providers, to address COVID-19 more broadly was a strength of their community.</p>
<p><b>Community Attributes</b> Characteristics the community embodies that facilitate support and resources.</p>	<p>Many of the discussion groups pointed out community attributes that impacted their ability to address their health. Resiliency, unity, care for one another, loyalty, compassion, and creativity were a few community attributes noted during listening sessions.</p>
<p><b>Community Engagement</b> Opportunities for community members to engage with local organizations and community members to discuss or learn about the impact of COVID and/or Long COVID.</p>	<p>Many community members identified that the availability of community forums and meetings to discuss issues and have interactive engagement were strengths of the community. Community members also reflected that events like listening sessions demonstrate respect for their voice in making change.</p>
<p><b>Faith-Based Community Engagement</b> Engagement of community members through their faith, religious, or cultural affiliations.</p>	<p>Faith leaders played an important part in facilitating community access to resources and information. Many of the communities discussed the inclusion of these leaders in the COVID-19 vaccination and education efforts and how they were trusted in the community to deliver positive messages. As seen in the quote below, faith-based organizations, played an important role in providing access to vaccinations.</p>

Key Themes	Description
<p><b>Individual Attributes</b></p> <p>Characteristics community members identified in themselves that helped them to manage and/or overcome challenges during the pandemic.</p>	<p>When reflecting on their own attributes that helped them navigate the COVID-19 pandemic and resulting impacts, community members mentioned their own sense of personal resilience, perseverance, and accountability. They indicated they were proud of what they were able to accomplish during the pandemic.</p>

“ My church always want[ed] to help get out the word and be a place to give the shots.

**Community Member**

Listening Session hosted by Tennessee Justice Center, Nashville, TN

In addition to the key themes identified, review of community responses indicated that community members noticed and appreciated preventative measures (e.g., masking, handwashing) that were being implemented throughout the community. They also spoke about the availability of resources in the community that helped them to meet their basic needs (e.g., food, housing, and financial support). In addition, community members reflected on how the COVID-19 pandemic impacted their relationships with family, friends, and neighbors. Most of those comments indicated that community members grew closer to their loved ones and were able to establish meaningful relationships and a sense of social responsibility towards one another.

## Opportunities

Communities were asked to identify how they could leverage their strengths to create new opportunities that addressed Long COVID and/or health disparities. Five key themes emerged from community discussions.

Key Themes	Description
<p><b>Access to Education and Information</b></p> <p>Availability of quality and relevant education and information about COVID-19 and/or Long COVID.</p>	<p>Communities discussed staying informed about COVID-19, vaccinations, and Long COVID. They also addressed opportunities to expand information to combat stigma and fear. Communities highlighted opportunities to provide more non-political, age- or population-specific content within the community so that the individual impact was clear.</p>



Key Themes	Description
<p><b>Access to Healthcare</b></p> <p>Availability of healthcare resources, such as healthcare providers, vaccinations, and testing within the community.</p>	<p>Communities talked about opportunities that could be created by inclusion of more holistic health focus in COVID-19 and Long COVID care, allowing for community members to make decisions about the specific care they receive. It was also important that communities leveraged opportunities to expand insurance coverage and expand access to free health care – specifically for Long COVID and broadly.</p>
<p><b>Community Attributes</b></p> <p>Characteristics the community embodies that facilitate support and resources.</p>	<p>Communities discussed leveraging community connections, unity, and loyalty to create systems of support for one another. They also discussed the opportunities to enhance the environments in which they live so that they are safer and supported with relevant resources to address their diverse needs.</p>
<p><b>Community Engagement</b></p> <p>Opportunities for community members to engage with local organizations and community members to discuss or learn about the impact of COVID-19 and/or Long COVID.</p>	<p>Communities noted that there were many opportunities to create spaces where they could come together and discuss issues impacting their lives, using facts rather than politics. The listening sessions or “town hall” format was effective in engaging the broader community and they felt seen and heard. Community engagement events could also help community members share their stories and experiences.</p>
<p><b>Social &amp; Community Support</b></p> <p>Availability of social and community support to address community basic social, emotional, and physiological needs.</p>	<p>Communities discussed the opportunity to expand availability of funding and resources to support food, housing, and other shortages (e.g., lost wages) that have been exacerbated by COVID-19. In more rural communities the need for reliable transportation showed up as an opportunity to support communities in addressing Long COVID by helping them to gain access to healthcare and other resources.</p>

“ ...in case jobs shut down [having] clinics, food support, and more resources for the community.

**Community Member**

Listening Session hosted by Doulas Latinas, Portland, OR

In addition to the key themes identified, participants also suggested communities become more engaged in policymaking and that policymakers become more engaged in community initiatives. They also felt it was important that policymakers and other government officials advocate for sustainable resources to address COVID-19 and reiterate the importance of engaging in health-promoting behaviors such as masking and social distancing to communities.

“ More government representatives advocating for sustainable resources around COVID and other health needs.

**Community Member**

Listening Session hosted by Black Health, New York City, NY

## Aspirations

Discussions on community aspirations were designed to help identify what inspired community members to act and how they wanted their community to be seen by others. Five key themes surfaced when discussing aspirations for the community.

Key Themes	Description
<p><b>Access to Education and Information</b> Availability of quality and relevant education and information about COVID-19 and/or Long COVID.</p>	Community members spoke of well-informed communities, where people could attend workshops, gather health information, and educate themselves on how to protect and preserve their health.
<p><b>Access to Healthcare</b> Availability of healthcare resources, such as healthcare providers, vaccinations, and testing within the community.</p>	Communities expressed desire to ensure access to healthcare resources for all. They also discussed a desire to bring medical resources into communities that lacked those necessary supports.
<p><b>Community Attributes</b> Characteristics the community embodies that facilitate support and resources.</p>	In most of the sessions, community members expressed their hopes and aspirations for their communities to not be left behind in public health efforts to prevent or reduce the burden of COVID-19 and Long COVID. They envisioned communities where people were interconnected and supported each other with compassion, fostered healthy lifestyles, and centered the needs of their families.

Key Themes	Description
<p><b>Community Engagement</b></p> <p>Opportunities for community members to engage with local organizations and community members to discuss or learn about the impact of COVID-19 and/or Long COVID.</p>	<p>Increasing community member participation in community events and activities was a top priority for many participants. Having activities for the entire family that promoted more discussions focused on critical issues addressed in their daily lives (e.g., access to food, housing, and jobs) and to develop solutions were desired within communities.</p>
<p><b>Improved Health Outcomes &amp; Health Equity</b></p> <p>Community and individual outcomes in health and well-being.</p>	<p>Communities aspired to improve health outcomes for all while addressing health disparities and increasing representation among healthcare providers. They also discussed equity in general – focusing on ensuring equitable access to support and services in the community.</p>

In addition to these common themes, some communities, particularly in the listening session hosted by Doulas Latinas in Portland, OR emphasized the importance of individuals being empowered to take charge of their own health. This community also felt particularly vulnerable to COVID-19 and Long COVID because they felt they were “marginalized, and sometimes rejected” by mainstream systems (e.g., healthcare).

“ I wish my community was known and taken into consideration because we are a very vulnerable, marginalized, and sometimes rejected community due to being immigrants.

**Community Member**

Listening Session hosted by Doulas Latinas, Portland, OR

## Results

Community members were asked to identify the results they would see if they leveraged their strengths and achieved their aspirations. Three key themes were reflected in discussions that would be indicators that there were community-level health improvements.

Key Themes	Description
<p><b>Access to Healthcare</b> Availability of healthcare resources, such as healthcare providers, vaccinations, and testing within the community.</p>	<p>Community members indicated that integration of healthcare, where providers talk with each other, would demonstrate commitment to improved health outcomes. They also indicated that positive community results in healthcare would mean affordability and increased access to rehabilitation centers and treatment within the community.</p>
<p><b>Community Attributes</b> Characteristics the community embodies that facilitate support and resources.</p>	<p>Communities felt they would achieve goals if there was a foundation of empathy, compassion, trust, unity, and humility. They also mentioned living in communities where they feel safe.</p>
<p><b>Improved Health Outcomes &amp; Health Equity</b> Community and individual outcomes in health and well-being.</p>	<p>Positive outcomes in some communities meant a reduction in discriminatory practices at all levels. They also indicated that reduction in COVID-19 infection, improved health outcomes for all, and less hospitalizations would be positive indicators of community-wide success in addressing the pandemic.</p>

In the listening session hosted by Randolph County Community Cares in Moberly, MO, one community member captured the sentiment of improved health outcomes and health equity by saying a positive result looks like “*everyone hav[ing] health equity*”. At another listening session hosted by Transforming in Atlanta, GA, one community member expressed that because of this focused work there would be a “*healthy whole [community] and equitable resources.*”



# Conclusion

Doulas Latinas International, Portland, OR

Centering community voices and experiences as we address public health threats can have far reaching implications that lead to equitable health outcomes and address systemic inequities.

## Discussion

Over half (51.8%) of the survey participants had experienced COVID-19, and 25.7% of all respondents reported having Long COVID symptoms and conditions; higher than the national average of 40% and 16% respectively (NCHS, 2023). The Long COVID Project population also had a higher representation of minoritized racial and ethnic groups than the national population, developing a clearer picture of the impact of Long COVID and , suggesting that more information is needed to fully describe the populations most vulnerable to Long COVID. Although many of the respondents were satisfied or very satisfied with the Long COVID support they received, this work suggests there is still much more to do to inform healthcare providers about Long COVID and to address the community's healthcare needs.

“ My primary care [doctor] did not believe me and the emergency room sent me home 4 times before my daughter advocated for me and [they kept] me.

**Survey Respondent**  
South Euclid, OH

Community engagement starts with honoring and centering communities as experts. Community Catalyst believes that a community-first public health approach is essential and community-based organizations are foundational to the success of any public health system. Implementation of community-centered forums, led by community members and CBO partners, demonstrated the commitment of Community Catalyst to learn from communities about their strengths and support needed to address Long COVID in their community. Although not explicitly stated during the listening sessions, communities were able to communicate their strengths, opportunities, and aspirations, and the results often aligned with one or more social determinants of health – economic stability, education access, quality healthcare access, neighborhood and build environment, and social and community context.



Participants in the listening session were very satisfied with their overall listening session experience (88.1%; n=261) and gave the sessions an average rating of 4.74 on a scale of 1 to 5, with 5 being the highest rating.

“ I loved the open floor opportunity to add input and to hear from other community members about COVID/Long COVID.

**Community Member**

Listening Session hosted by Transforming, Atlanta, GA

Community members also saw the benefit and value of bringing them together to discuss the issue of Long COVID, many of the participants indicated that they learned new information, felt good about being able to be a part of the process, and wanted more engagement within their community to address Long COVID and other issues impacting the community.

“ Coming together as small groups help[ed] to shine a light on some thoughts and information that are needed to fight COVID-19.

**Community Member**

Listening Session hosted by Tennessee Justice Center, Nashville, TN

Although the findings provided very helpful insights into the impact of Long COVID and ways in which communities can be supported, it is even more clear that additional information and resources are needed to identify and design effective, community-based approaches to address Long COVID in racial and ethnic minoritized communities.

## Reflections

When specifically addressing engaging communities to mobilize them for action, there are a few cornerstones that are necessary to be successful.

- Use a community engagement approach that allows communities to lead decision-making.

- Identify and engage whole communities – organizations, leaders, policymakers, and community members – in the decision-making process to improve health outcomes.
- Ascertain community strengths and use those as levers for change.
- Listen to communities - acknowledge their expertise in community norms, needs, and strengths.
- Create a variety of opportunities for communities to engage and provide input into public health planning processes.
- Find ways to engage faith and cultural leaders, among other trusted leaders, in community engagement and strategy planning activities.
- Build public health efforts *with* the community rather than for the community.
- Consider community capacity to engage in planning processes, plan to provide training and education on core concepts so that they can feel they are equally equipped to develop solutions to pressing issues.
- Identify "backbone" organizations to provide funding, resources, and support and partnerships in the community to support community engagement and accountability.
- Use lessons learned to improve future community engagement efforts.

## Taking Action

Core recommendations for moving this work forward and effectively addressing community needs related to Long COVID include:

- **Use lessons learned to inform Community Catalyst's Long COVID policy and advocacy efforts.** Communities expressed a need for opportunities to create spaces where they could come together and discuss issues impacting their lives, using facts rather than politics. The politicization of COVID-19 and vaccines has resulted in general hostility towards COVID-19 conversations in some communities. In some instances, even elected and governmental officials perpetuate misinformation and anti-vaccine rhetoric. Continued partnership with CBOs and communities to understand the policy and systems that impact their community can facilitate recognition of the intersection of public health and policy and allow communities to engage in collaborative conversations with policy makers at the local, state, and national level.
- **Share learnings with applicable local, state, and federal partners to inform their Long COVID efforts.** While there are several federal efforts available to support Long COVID, many fail to reach the communities most impacted. Disseminating learnings from the Long COVID Project can aid in educating local, state, and

federal partners such as local/state health departments, policy makers, and other organizations and create a shared understanding of challenges and opportunities for deepened community engagement in racial and ethnic communities related to Long COVID.

- **Develop and make easily available quality and relevant education and information about Long COVID.** Community members did not specifically call out the availability of information on Long COVID, but broadly discussed availability through media, community events, etc. There is a need for continued education, resources, and expanded community opportunities that provide education and information to combat stigma and fear related to COVID-19, vaccinations, and Long COVID.
- **Develop tools and resources to help communities facilitate community-wide discussions about important issues impacting their communities.** Community-based organizations leading these discussions found the tools and resources developed for the project very useful as a guide to initiate conversations on challenging topics. Continuing to support CBOs with tools and resources would allow them to engage in meaningful, strengths-based, conversations with community members about public health and other critical issues impacting their community.
- **Support CBOs, public health, and healthcare provider partnerships.** Community members expressed the need for more public health and healthcare resources and indicated that the integration of healthcare, where providers talk with each other, would demonstrate commitment to improved health outcomes. Communities also aspired to improve health outcomes for all while addressing health disparities and increasing representation among healthcare providers.
- **Identify and provide flexible funding for communities to address social determinants of health factors exacerbated by COVID-19.** There is a critical need for investments to support the inclusion of communities in the decision-making process to address Long COVID. Communities want to be a part of developing solutions that do not leave them behind as the country implements efforts to prevent or reduce the burden of COVID-19. They also identified the need to expand the availability of flexible funding and resources that can be used to support food, housing, and other shortages (e.g., lost wages) based on their community needs. Having communities at the forefront of addressing Long COVID and other health disparities that directly affect them is effective and has the potential to replicate the success of the VEAP CBO partners as trusted messengers in communities to reduce vaccination hesitancy and the spread of COVID-19.



# Appendix

Randolph County Caring Community, Moberly, MO

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## Appendix B: Long COVID Project Partners

### Advisory and Listening Session Implementation CBO Partners

- Doulas Latinas International (Gresham, OR)
- Black Health (New York, NY)
- Patients R Waiting, Inc. (Lancaster, PA)
- Randolph County Caring Community, Inc. (Moberly, MO)
- Tennessee Justice Center (Nashville, TN)
- Trans(forming) (Atlanta, GA)

### Advisory CBO Partners

- Adams Compassionate Healthcare Network (Chantilly, VA)
- Arkansas Coalition of Marshallese (Springdale, AR)
- Asia Pacific Cultural Center (Tacoma, WA)
- Black Church and Domestic Violence Institute, Inc. (North Beach, MD)
- Black Ladies in Public Health (Arlington, TX)
- Christ Congregational Church Onward Women of Color (Silver Spring, MD)
- ICNA Relief USA Programs Inc (Tempe, AZ)
- Knock and Drop Iowa (Des Moines, IA)
- Korean Community Services of Metropolitan NY, Inc. (Bayside, NY)
- Make the Road States, d/b/a Make the Road Nevada (Las Vegas, NV)
- Melinated Moms (Trenton, NJ)
- New Horizon Ministries, Inc. (Jackson, MS)
- Northeast Ohio Black Health Coalition (Cleveland, OH)
- Palmetto Project, Inc. (North Charleston, SC)
- Rural Women's Health Project (Gainesville, FL)
- SGA Youth and Family Services (Chicago, IL)
- South Carolina Association of Community Action Partnerships (Columbia, SC)
- The Roberti Community House (Waukegan, IL)
- Total Lifestyle Change (Fayetteville, GA)