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Long COVID impacts: the voices and views of diverse Black and Latinx residents in Massachusetts

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Abstract

Objective To understand how Long COVID is impacting the health and social conditions of the Black and Latinx communities.

Background Emerging research on Long COVID has identified three distinct characteristics, including multi-organ damage, persistent symptoms, and post-hospitalization complications. Given Black and Latinx communities experienced significantly higher COVID rates in the first phase of the pandemic they may be disproportionately impacted by Long COVID.

Methods Eleven focus groups were conducted in four languages with diverse Black and Latinx individuals ($n = 99$) experiencing prolonged symptoms of COVID-19 or caring for family members with prolonged COVID-19 symptoms. Data was analyzed thematically.

Results Most participants in non-English language groups reported they were unfamiliar with the diagnosis of long COVID, despite experiencing symptoms. Long COVID impacts spanned financial and housing stability to physical and mental health impacts. Participants reported challenging encounters with health care providers, a lack of support managing symptoms and difficulty performing activities of daily living including work.

Conclusions There is a need for multilingual, accessible information about Long COVID symptoms, improved outreach and healthcare delivery, and increased ease of enrollment in long-term disability and economic support programs.

Keywords Long COVID, Multilingual focus groups, Black and Latinx populations

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Background

Long COVID has been defined “as an infection-associated chronic condition that occurs after SARS-CoV-2 infection that is present for at least three months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems” [1]. Although Long COVID can have debilitating effects on physical health [2] as well as implications for mental health and socioeconomic wellbeing [3], little is known about the etiology of Long COVID, its actual prevalence in the population, and associated risk factors. Despite these limitations in current knowledge, it is estimated that at least 10–30% COVID-19 survivors may be impacted [2], making long COVID a public health priority.

The emergent literature on Long COVID indicates it impacts multiple organs including the heart, lungs, brain, pancreas kidneys, liver, and spleen as well as the gastrointestinal tract and blood vessels [4]. Symptoms described in the literature include fatigue, brain fog as well as respiratory symptoms, chronic pain, mental health symptoms [4–6]. Because Long COVID impacts physical and mental health, it can also delay or impede return to work [7]. Thus, Long COVID may have far reaching impacts on economic stability and community wellbeing. And although Long COVID inequities have been theorized, given pervasive inequities in acute COVID-19 [8], literature on the impact of Long COVID on diverse Black and Latinx communities is lacking. However, evidence to date indicates Black and Latinx patients may be disproportionately impacted but less likely to be diagnosed with Long Covid [8–11].

There have been calls for a focus on Long COVID equity [12], the voices, and views of diverse Black and Latinx patients remain absent in the current discourse. In Massachusetts, Black and Latinx communities experienced significantly higher rates of COVID-19 during the first five months of 2020, when the state had amongst the highest case and death rates in the country [13]. For example, in the first COVID-19 surge, among patients hospitalized for COVID-19 at Massachusetts General Hospital, 35% were Latinx, although Latinx patients comprised only 8% of inpatient discharges at MGH in 2017 [14]. In addition, after adjusting for age, higher COVID-19 death rates have been seen in Black and Latinx than in white populations in Massachusetts [15]. Employment has been a major driver of COVID-19 inequities among diverse Black and Latinx immigrant communities, who are overrepresented in essential frontline positions [16–20].

High rates of COVID-19 in communities of color may fuel inequities in Long COVID, yet evidence in this realm is limited. Intentional efforts to engage and partner with residents and organizations in impacted communities is

necessary to understand how Black and Latinx communities are being impacted by Long COVID. Qualitative approaches that allow participants to share the nuances of their experiences may advance our understanding of the priorities and needs of diverse residents. Moreover, such efforts may help to drive equity in the delivery of and access to Long COVID care.

The PASC “Long COVID” Health Equity group seeks to ensure that Massachusetts establishes systems and services to treat Long COVID that are responsive to the needs of and accessible to highly impacted communities across the state. As a first step in understanding the impact of Long COVID among diverse Black and Latinx individuals and their families living in highly impacted Massachusetts communities qualitative research was conducted between August and November of 2022.

Methods

Eleven focus groups were conducted in four languages with diverse Black and Latinx individuals from highly impacted communities in Massachusetts. Languages included English, Spanish, Haitian Kreyol, and Portuguese. The study was led by the PASC Long COVID Health Equity partnership, which includes researchers from four hospitals, three universities, and the social marketing partner. The study was approved by the Boston University, Charles River Campus Institutional Review Board protocol 6565X. Of note, all field staff were trained in human subject’s research in relevant languages using a presentation and case-based human subjects training approved for use by the Boston University IRB (Institutional Review Board). In addition, reliance agreements were signed with field staff from our partner organization.

Sampling and recruitment

A non-probability sampling strategy, purposive sampling [21], was used to identify individuals experiencing symptoms of COVID-19 lasting more than 30 days, as well as individuals with family members experiencing prolonged symptoms of COVID-19. Recruitment was ongoing and occurred between July and November. It involved outreach through community partner organizations across the State and through media outlets. A recruitment flier was developed in English, Spanish, Haitian Kreyol, Portuguese, and Cape Verdean Creole languages; and electronically circulated via community partner organizations in Black and Latinx communities with high COVID-19 case numbers across the state. Agencies included immigrant serving, social service, civic and religious organizations. We shared the flyer with our RECOVER partner institutions and community health centers. In addition, to emails the flier was posted and partners organizations were tagged on social media. We also promoted the study

via radio. The principal investigator spoke about Long COVID and the study on Spanish language radio shows, and study information was disseminated via non-English social media outlets that reach highly impacted communities across the state.

Procedures

Individuals interested in the study were required to complete a screening questionnaire, which assessed demographic characteristics, as well as the extent to which they or a family member were experiencing symptoms beyond 30 days from their SARS-CoV-2 infection. The screener could be completed by calling, texting, or scanning a QR code that directed the participant to an online form. Those who texted or called in were screened by a trained staff member in their preferred language. Individuals who met the inclusion criteria were given an overview of the study's purpose and procedures. They were then scheduled for a focus group in their preferred language.

The focus group script was developed by an interdisciplinary team of investigators from across five academic medical centers and reviewed by community partners for this study. A copy of the script is available as a supplementary file in English; Spanish, Portuguese, Cape Verdean Creole and Haitian Kreyol versions of the protocol are available upon request. All groups were conducted on Zoom and facilitated by trained bilingual facilitators. Informed consent was administered at the start of each focus group. The facilitator read a series of prompts exploring participant awareness of Long COVID, symptoms experienced for a prolonged period more than 30 days, and the impact of prolonged symptoms on participants and their family members as well as community resources that participants accessed to address the impact of those symptoms. Focus groups participants received \$50 remuneration and groups lasted about 90 min on average. All focus groups were recorded and transcribed. Non-English transcripts were then translated into English by a professional translator.

Data management and analysis

The data were managed using NVivo 12 [22]; and thematic analysis was conducted following the steps outlined by Braun and Clarke 2006 [23]. Three researchers immersed themselves in the reading data reading the transcripts to become familiar with the data and developed initial codes. The codes and their descriptions were entered in NVivo. The three researchers then assigned the codes to text segments, meeting throughout the coding process to reconcile discrepancies in the coding identified by merging coding files in NVivo. Reports were generated for each code and the team searched the codes for themes by identifying patterns and created definitions for each theme [23]. Summaries were written up based on the themes and text segments from the data were selected to illustrate each of the identified themes.

Individual reflexive practices including ongoing written reflection including memoing and group meetings were used to reduce bias and increase the credibility and validity of the study [24]. Memos and notes were used by coders as they discussed patterns in the data as well as their interpretations of the data. Through these meetings the team explored the ways in which their positionality, training and experience influenced interpretations of the data to identify potential bias. In addition, the findings were shared back with the larger interdisciplinary partnership to both explore potential bias and further synthesize themes. These practices facilitate research awareness of the ways in which identity and experiences can shape interpretations of the data.

A final report on the focus group finding and recommendations as well as information on how to stay involved with Long COVID efforts in Massachusetts was sent to the participants in the language of the group they participated in. As seen in Table 1, a total of eleven virtual focus groups were conducted with diverse Black and Latinx residents ($n=99$) in Massachusetts. Groups were conducted in multiple languages including Spanish, Haitian Kreyol, English and Portuguese. About two-thirds of the focus group participants identified as women ($n=78$).

Table 1 Participants by language and gender

Group	Language	N	Female	Male
1	English	8	8	0
2	English	5	5	0
3	Spanish	11	11	0
4	Spanish	9	9	1
5	Spanish	8	7	1
6	Spanish	10	7	3
7	Spanish	8	7	1
8	Spanish	12	4	8
9	Haitian Kreyol	8	6	2
10	Haitian Kreyol	9	4	5
11	Portuguese	11	10	1

Results

Overall, sixty-nine participants (70%) identified as Latinx which included Brazilians. Thirty-six participants identified as Black or African American and thirteen identified as white. Those who reported white as their racial identity also reported being Brazilian, Salvadoran, Peruvian, or Guatemalan. About half of the participants identified as more than one race ($n=50$). Participants in the Spanish-speaking group were diverse, identifying as Dominican, Puerto Rican, Salvadoran, Colombian, Peruvian, or Guatemalan; in the Portuguese speaking group all identified as Brazilian. Of note, we did not conduct groups in Cape Verdean Creole, as volunteers who identified as

Cape Verdean were English-speaking. Participant ages ranged between 19 and 84 years with a mean age of 42. Participants described their experiences with acute COVID-19 and many symptoms that persisted for up to a year following COVID-19 (see Table 2).

Four salient themes emerged, which include (1) lack of awareness of Long Covid, (2) impact of Long COVID on physical health, (3) impact of Long COVID on social factors, (3) Health Care experiences, and (4) information access.

Lack of awareness of Long COVID

Awareness of “Long COVID” as a medical diagnosis was low among participants. In nine of the 11 groups, most participants had not heard of term “Long COVID”. In the two English language groups participants had heard of Long COVID but felt that it was not part of the mainstream discourse. One participant reported learning about Long COVID at a community education event and described feeling relieved to know that there was a diagnosis for what she had been experiencing.

...that was my first time ever hearing the term “Long COVID”. I’ve always felt like these symptoms happened directly after COVID, but I never had ...language to kind of express that. It wasn’t COVID, you know, [it was] like an active kind of COVID, but I felt these things, and I’d take a test, and it’d be negative. I was relieved that there was a concept of COVID kind of lingering.

Participants reflected on the notion of Long COVID and why it was not being discussed more. They described the stigma associated with COVID-19 and wondered about its implications for long COVID.

In terms of Long COVID. ...people are not, at least in my circles, ... talking about the long-term symptoms. I think COVID is one of these kind of taboo things

Table 2 Long COVID symptoms

Fatigue	Chest pain	Dizziness
Exhaustion	Vomiting	Vertigo
No stamina	Muscle and joint pain	Spinning sensation
Inability to feel rested	Spasms	Floating sensation
Headaches	Body aches	Inner ear pain
Hair loss	Memory Loss	Difficulty concentrating
Cloudy, foggy mind	Forgetfulness	Loss of sense of smell
Shortness of breath	Depression	Loss of appetite
Cough	Anxiety	Weight loss
Excess phlegm	Inability to regain balanced sugar levels	

that you really don’t talk about, because you don’t want to be alienated or stigmatized.

There was a sense among participants that the lack of public discourse related to Long COVID, had implications for their wellbeing. They reported feeling “isolated” and “alone”, as well as feeling “crazy” because they knew something was not right but did not have an explanation for what they were feeling. Because they did not have a formal diagnosis, many participants felt that they had to “push through,” which was taking its toll on them.

I’m so glad I’m on this call [referring to the focus group]. You don’t even know...this means a lot to me, because sometimes you think you’re alone, and that you’re the problem or you’re complaining, and nobody’s talking about this at work. People are going into work, not feeling well But we have to keep pushing. We have to keep moving through, and nobody has any answers....

Impact of Long COVID on physical and mental health

Participants reported that living with Long COVID is a struggle because it impacts both the body and mind (see Table 3). Further, it was described that everything is harder with Long COVID because of the exhaustion, physical pain, cloudiness, and loss of stamina. Even in cases where participants were told about Long COVID, there was little that could be done to help them. For some, over time, this has impacted their mental health.

Impact of long COVID on social factors

Across groups we heard stories of the impacts of long COVID symptoms on work and family (see Table 4). Many participants described “pushing through” because of not having paid time off. For those unable to work, the economic consequences have been steep. Participant discussed the challenges associated with acute Covid-19 when talking about Long COVID. Specifically, they talked about not having time off and its implications for health and mental health.

A broad range of socioeconomic impacts of Long COVID emerged in focus group discussions. Main impacts named were challenges with medical debt and lack of affordable care, difficulty making ends meet on medical leave due to it being only a percentage of their salary, and the lack of employer-provided time off for Long COVID which subsequently impacts the ability to pay mortgages or rent, obtain food, or access healthcare.

Participants also reported that while disability services are a resource in theory, they are difficult to access. They described having to complete complex paperwork and coordinate with physicians, which was additionally

Table 3 Health and mental health impacts of symptoms approximately here

Theme	Illustrative Quote
Struggling with impacts on the body and mind	<i>I experienced that [shortness of breath] after COVID, just headaches, and this is me now. ... it's like I'm struggling to get out [of the house] ... It's been taxing, and it's been a lot, ... I just don't have the stamina and the energy. I try to get up early and do a little workout and find some energy in a way that usually works. ... I can definitely see a shift in my mind, I'm cloudy minded like my brain is foggy, and it goes and comes. Some days are better than others. I should have been documenting this stuff, and I didn't because it's just so much going on. But it's like, why am I so foggy minded? Why can't I focus, and things like that? I'm a gym fanatic. I've been going to the gym since my twenties and I can run miles like two, three miles and feel fine. I can't even run a half a mile now without having to stop. I'm like this is not like me. I mean it blows my mind because every time I try it's like I don't have. ... I don't know if it's not enough oxygen or what it is, but the heaviness is hard.</i>
Long COVID makes life harder	<i>I would say, speaking personally for me the fatigue is a huge factor as well as the brain fog. ... My whole family got COVID after two years of avoiding it. We got it in January actually of this year and since then I have noticed a huge shift in my ability to sleep and gain rest, feel rested. It could be a nap, or it could be a good eight to ten hours of sleep on a, you know, on a weekend, or even sometimes during the week, because exhaustion is also a factor, and no matter what I do, no matter how I'm sleeping, I cannot wake up and feel rested. ... I also believe my stamina is affected as far as like how I'm able to get through tasks, and how they exhaust me faster than they previously did. Whether it's something as simple as like brushing my teeth, it can be physically like, you know. Just it's harder. Folding laundry takes longer because it's like I fold three things, and I'm like, Oh, my God! My arms hurt so much! My shoulders are like what's going on here so definitely, I notice an increase in fogginess, fatigue, and, like physical exhaustion, the exertion I did not know the term Long COVID, it seems quite appropriate, because effectively one is stuck in that [cycle], ... In the case of what happened with my father-in-law who is an elderly person, he is also a diabetic and with my niece, who is younger person, much younger, she is 20 years old, without any medical condition. ... I noticed both my father-in-law and my niece, who were left with a permanent fatigue. I mean, whatever they did, it was "I'm exhausted", "I'm tired", no matter how much they slept, it doesn't matter if they took vitamins, it doesn't matter, a constant tiredness</i>
Mental health impacts of Long COVID	<i>... after COVID, I went to my primary care doctor many times and my primary care doctor said you have long COVID, because your signs and symptoms after COVID haven't gone for a long time. The first time I felt bad about COVID was in September and December 2020. Between May and September 2021, in my body, I had pain—in my muscles and legs. I got dizzy many times, I vomited, I had headaches sometimes. My sinus symptoms never went too. ... I feel bad every day, I'm tired. Sometimes I think I'm being crazy because many days I feel bad. For almost the entire year 2021, [I felt bad].</i>

Table 4 Work, family, and socioeconomic conditions

Theme	Illustrative Quote
Impacts on work	<i>My sister has definitely been impacted in terms of her job. ... she wasn't well... she didn't have the energy and was just not well, and foggy minded, things like that. She took two short-term leaves ... Her mental health is down the drain. I can see it. We all see it.... She doesn't even have the energy to take care of the children. I go to her house, and it's like a mess, it's upside down and around, because she doesn't have the energy to do anything, and it's affecting her overall health and wellbeing and potentially her employment right. ... I just don't want her to go down the rabbit hole. You know, she has a home, and I don't want her to lose her home.</i>
Impacts on socioeconomic conditions	<i>I am sorry for my relatives with long COVID; they just had to reduce their workload. ... they reduce the number of hours they work and that led them to seek health services, which have a cost associated ... [think about] the fees and the payments that must be paid, the time that must be taken away from their work, from their leisure time to be able to go to the therapies. ... having a long COVID tends to affect all economic, social, family, and psychological aspects We had two cars, but we had to sell one. The resource we were getting to help with rent, which stopped ... I didn't recover to the point where I was able to buy a second car again. I had to sell it [the car] and I was left with one car, I didn't get back on my feet to the point of being able to get my car back, I couldn't get myself completely situated yet.</i>
The complexity of disability resources	<i>When I was out of work for three months. ... I was trying to go through the process of getting approved for disability. So, I went three months without getting paid and it was like hard to fight for disability ... I was a slow and I didn't know what I was doing, ... all this paperwork, calling this doctor and doing this and doing that, and I'm trying to get better at the same time. So uh, yeah, like I took a hit on that. I got my job back and went back to work, but it was nonsense. So, that was three months of lost income.</i>

challenging to navigate amid feeling unwell and with neurological symptoms of Long COVID.

Focus group participants made several policy recommendations. They noted the State should provide better guidance for employers and workplaces and reinstate paid time off for acute Covid and Long COVID. Participants also shared that the long-term disability process needed to be streamlined and requirements to “prove” disability should be revisited, as there are no straightforward diagnostic tests for many Long COVID symptoms. Other recommendations included expanding insurance

coverage to span a range of wellness options such as physical therapy, acupuncture, Eastern and traditional medical services, enacting state-level incentives to encourage resource sharing between healthcare institutions, and reinstating economic supports such as expanded unemployment, mortgage forbearances, eviction moratoriums, and food and utility supports.

Healthcare experiences

Participants reported varied experiences with healthcare providers and systems for both acute and Long COVID

(see Table 5). There was a perceived lack of solutions for Long COVID symptoms, with many participants reporting that healthcare providers are unable to support patients experiencing potential long COVID symptoms. Participants also alluded to racism, discrimination, and language barriers making it challenging to access care in the first place.

In the two English focus groups, participants explicitly named medical racism as an issue impacting distribution of healthcare resources, access to care, and provider attitudes and bias during visits. The few participants who reported positive experiences with their healthcare providers reported that clear treatment plans and referrals to resources from hospital and primary care physicians were helpful.

Information access

Across all groups conducted in non-English languages, language was cited as a major barrier to accessing resources for Long COVID. These language barriers include a lack of interpreter and translator services in healthcare facilities and information about COVID-19 and Long COVID being available in multiple languages online or in the news.

I think most of all, having access to information. And most, well, as immigrants. I think we're all here. We have a family member or ourselves do not have access because of the language or maybe because of shame or fear, so inform the whole community.

Regarding language barriers within healthcare settings, participants also shared a major deterrent to seeking healthcare was not being able to explain their symptoms or experience with their providers.

Participants in these focus groups also cited immigration-related barriers to accessing resources, particularly those provided by the state and federal government. They

referred to community members being afraid to seek economic support due to fear of arrest by Immigration and Customs Enforcement (ICE) and deportation or being ineligible for government assistance because of their immigration status.

One of the things that initially affected was the fear of immigration. Many people did not want to ask for help... the terror of asking for something because they have [told] a lot of people, that if you do not have papers but plan to have papers here you cannot get help from the government....

Discussion

There was a lack of awareness of Long COVID among participants. Though they were unfamiliar with the diagnosis “Long COVID,” they detailed the symptoms characteristic of Long COVID that were impacting them and their family members. Consistent with the literature, these symptoms included: fatigue, brain fog as well as respiratory symptoms, chronic pain, mental health symptoms [4–6]. Participants discussed the impacts of Long COVID symptoms and the toll they take over time on the body, mind, and spirit. Poor physical health and the lack of information and treatment was described as heightening feelings of anxiety. Many participants shared that not knowing what was wrong with their bodies caused distress.

The mental health impact of Long COVID was a thread that ran across emergent themes. The impacts on mental health were further fueled by sleep disturbances and the inability to feel rested, which is consistent with early studies indicating the need for mental health services to support patients with Long COVID [25]. The impacts of Long COVID on economic well-being, families, and work life as described as further fueling increased stress,

Table 5 Health care experiences

Theme	Illustrative Quote
Health system failure	<i>I've given up. Honestly, I don't. I don't go anymore. I've been once or twice like once in urgent care and one time to my primary care doctor, but they couldn't really do anything for me. They talked about the [long COVID] clinic at [hospital name]. And that was it. They can't give you resources. They don't know themselves right so like this is all new to everybody, and this is where organizations need to take that into consideration: how do we better... I don't think that MDs really care. At least, I had the same thing with my primary care office, I told them everything I was going through and got nothing.</i>
Racism	<i>I think that it's undeniable that in Black and Brown communities we're disproportionately impacted by COVID. I learned some really important facts from a doctor. She talks about how racism is a direct impact on people's health, because when you look at the COVID maps, it almost perfectly matches with the redlining maps. ... you know we're disproportionately impacted. ... there's a whole lot of disparities around health and accessing help even in a state that ... was the catalyst for universal health.</i>
The benefit of informed PCPs	<i>I think my PCP, she's very informative. She's the one who told me about the long term COVID department... I'm even in like a study... So, I think like she was very compassionate and understanding. Even when I got COVID-19 the first time, she had me get an infusion. I forgot it the word for it, but it was some type of infusion to make me feel better, you know. I didn't know about that infusion; they really didn't talk about it. That was the first time when she told me about it... So, my experience with my primary care, with my medical team was great.</i>

anxiety, and depression due to the financial ramifications of unemployment or disability.

Health care experiences were described as negative and in some cases were harmful. Berger, Altiery de Jesus, Assoumou and Greenhalgh (2021) argue that “the effective management of Long COVID requires, first and foremost, recognition of the condition and empathic validation of the patient’s experience.” (pg.526) [12]. Most participants in our study were not met with *empathic validation*; instead, they received dismissive responses and costly referrals, which contributed to further frustration and financial strain. This finding is consistent with the nascent literature which describes Long COVID being overlooked by providers and patients not being believed [26, 27].

Long COVID care was inaccessible for most due to factors such as high deductible plans and little to no paid time off, which is consistent with the literature [28]. Many participants reported having no paid time off and noted that paid time off for both COVID-19 and Long COVID was no longer a guarantee, which posed challenges for them because missing work was not an option. At the height of the pandemic, a series of policies emerged designed to support the health and well-being of people and families. In some industries, policies provided flexibility in worker scheduling and instituted work from home. Additional pandemic relief came with community-based programs and grassroots outreach initiatives, which were funded to disseminate health information and resources including food, gas cards and safety supplies. Most of these programs and policies have sunset, yet our participants report that Long COVID related unemployment as well as the associated medical debt remain a threat to economic security and housing stability. Moreover, when the pandemic state of emergency was lifted COVID-19 care, testing, vaccines, hospitalization are no longer guaranteed to be subsidized.

This research is not without limitations. It was a small exploratory study that relied on non-probable sampling techniques. In addition, we did not capture information about people who did not participate. Given the diversity of the populations we engaged, further within-group research is needed to examine the impacts of Long COVID and their implications for exacerbating health inequities. Despite limitations, this is among the first reports focused on this highly impacted population. It illustrates the importance of community engagement, racial equity, and language justice in health research. There is a critical need for the dissemination of information about Long COVID in communities of color that is both culturally and linguistically appropriate, which will require prioritizing investment in communities and engagement.

Conclusions

Employing qualitative methods to engage diverse Black and Latinx participants, important gaps in access to information about Long COVID were identified. For many who are aware of Long COVID and who have sought care, structural barriers such as not having paid time off and health systems barriers such as inefficient referral patterns and cost, make it difficult for them to act on their knowledge.

Recently, the National Academies of Science Engineering and Medicine released a consensus definition for Long COVID as well as a report examining the impacts of Long COVID for Social Security [1, 29]. As the definition is adopted and information about Long COVID is disseminated multilingual campaigns are critically needed to expand awareness, as are strategies to structure clinics to better meet the needs of patients, ease enrollment requirements for long term disability, and guarantee paid time off. Long COVID to ensure effective and generalizable treatments in the future. This is the one of the first studies to explore the experiences of diverse Black and Latinx populations with Long COVID more are needed.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12889-024-19567-7>.

Supplementary Material 1

Supplementary Material 2

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Author contributions

LSM: Conceptualization, Methodology, Formal analysis, Writing Original Draft, Supervision, Funding acquisition. NS: Conceptualization, Methodology, Formal analysis, Writing Original Draft, Project administration. JJ: Supervision, Conceptualization, Review & Editing, TAB: Conceptualization, Review & Editing. BPL: Writing, Review & Editing. CRC: Conceptualization, Review & Editing. LBH: Conceptualization, Review & Editing. RL: Review & Editing, GB: Review & Editing. SOOO: Formal analysis, Review & Editing. AL: Project administration, Review & Editing. RD Methodology, Review & Editing. SR Methodology, Review & Editing. IVB: Supervision, Conceptualization, Review & Editing. All authors read and approved the final manuscript.

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Data availability

Protocols and translations are available upon request by contacting Linda Sprague Martinez, lsmarti@bu.edu.

Declarations

Ethics approval and consent to participate

This research was reviewed by the Boston University Charles River Campus Institutional Review Board, Protocol number 6565X. Informed consent was

obtained from participants. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication

Not applicable.

Competing interests

Linda Sprague Martinez is an external evaluator for the Boston Public Health Commission and Action for Boston Area Development, as well as a research consultant for Boston Medical Center and The City School. All other authors have no competing interests to disclosure.

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