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# Research in the USA on COVID-19's long-term effects: measures needed to ensure black, indigenous and Latinx communities are not left behind

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Received 23 March 2021

Accepted 13 March 2022

Published Online First

1 April 2022

## ABSTRACT

The SARS-CoV-2 (COVID-19) pandemic continues to expose underlying inequities in healthcare for black, indigenous and Latinx communities in the USA. The gaps in equitable care for communities of colour transcend the diagnosis, treatment and vaccinations related to COVID-19. We are experiencing a continued gap across racial and socioeconomic lines for those who suffer prolonged effects of COVID-19, also known as 'Long COVID-19'. What we know about the treatment for Long COVID-19 so far is that it is complex, requires a multidisciplinary approach and there is still much research needed to fully understand the effects. In this paper, we discuss pragmatic considerations for including affected communities, relevant stakeholders, and leaders from communities of colour in the planning and implementation of Long COVID-19 research.

## EMERGING LONG-TERM EFFECTS OF COVID-19

As the SARS-CoV-2 (COVID-19) pandemic progresses, evidence continues to emerge on the long-term clinical effects of COVID-19, Post-Acute Sequelae of SARS CoV-2 infection (PASC), or 'Long COVID-19'. Studies identified persistent, long-term respiratory, functional and psychological comorbidities in patients 3–6 months after initial diagnosis.<sup>1</sup> Long COVID-19 symptoms include, but are not limited to, fatigue, shortness of breath, heart palpitations, loss of smell or taste, memory and concentration issues, psychosocial distress and chest, muscle and/or joint pain.<sup>2,3</sup> Current data suggest that Long COVID-19 severity is related to increased age and pre-existing conditions. However, few studies address inequities in Long COVID-19 outcomes in the context of material resource deprivation caused by low socio-economic status, chronic stress brought on by racial/ethnic discrimination or place-based risk.<sup>4</sup>

The overall lack of complete data for cases, deaths and, vaccine uptake by race and ethnicity complicates the ability to understand the aetiology and factors associated with mitigation of Long COVID-19 in the USA.<sup>5</sup> While local and state governments have implemented tracking measures for demographic data related to COVID-19, current Centers for Disease Control and Prevention (CDC) COVID-19 tracker data continue to show gaps in race/ethnicity reporting with approximately 65% of the COVID-19 weekly cases per 100 000 population reporting race/ethnicity in the USA.<sup>6</sup>

## WHO IS MOST AT RISK FOR LONG-TERM CONSEQUENCES OF COVID-19? THE UNEQUAL BURDEN FOR COMMUNITIES OF COLOUR

Racial, ethnic and socioeconomic disparities in the USA have disproportionately affected communities of colour, further exacerbating health inequities during the pandemic. For example, a significant proportion of front-line workers in healthcare, service industries and municipalities during the pandemic are workers from black, indigenous and Latinx communities, putting them at greater risk of exposure to COVID-19.<sup>7</sup> According to a 2020 study, 37.75% of black or African American individuals, 26.16% of Asian individuals and 27.2% of Hispanic individuals are likely employed in essential industries such as healthcare and social assistance, and hospitals or animal slaughtering and processing, compared with 26.89% of white individuals.<sup>7</sup>

Black, indigenous and Latinx communities also have a higher prevalence of comorbid conditions such as hypertension, cardiovascular disease, diabetes, obesity and asthma, which increases the risk of contracting severe COVID-19, which may lead to delays in recovery, prolonged symptoms, increased hospitalisations, and increased rate of mortality.<sup>5,8</sup> In New York, a cohort study (n=5902) of COVID-19 patients at a single academic medical centre observed that non-Hispanic black and Hispanic patients had a higher rate of two or more underlying comorbidities than their non-Hispanic white counterparts.<sup>9</sup>

Racial disparities also exist for COVID-19 testing, diagnosis and acute morbidity and mortality outcomes for black, indigenous and Latinx communities compared with predominantly non-Hispanic white communities.<sup>9–11</sup> A national study of US veterans found that black and Hispanic individuals were more likely to be tested and to test positive for COVID-19 than white individuals, even after adjusting for underlying health conditions, other demographics and geographical location.<sup>10</sup> In Louisiana, where black individuals comprise 31% of the health system's patient population, another cohort study (n=3481) found that 76.9% of hospitalised patients and 70.6% of those who died were black.<sup>11</sup>

## THE GAP IN COVID-19 DATA FOR BLACK INDIGENOUS AND LATINX COMMUNITIES

There is a long-standing history of concerns related to incomplete data collection and reporting on US racial and ethnic disparities in health. As an example, a review of the federal history in the collection and reporting of race/ethnic health statistics found the



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**To cite:** Medeiros M, Edwards HA, Baquet CR. *J Med Ethics* 2023;**49**:87–91.

landmark ‘Secretary’s Task Force on Black and Minority Health’ published in 1985. The Task Force’s work brought attention to the limitations of federal data on “minority health”.<sup>12</sup> The report highlighted the need to improve data collection and reporting to strategically characterise the problem and develop and implement programmes designed to mitigate racial and ethnic inequities in many chronic and other diseases. Some of these diseases are the underlying diseases/disorders which increased predisposition to COVID-19 cases, hospitalisations, and deaths in these communities. In the years since this landmark report, important advances in research, clinical care and policy actions were developed to address the disproportionate burden of morbidity and mortality in communities of colour. Yet we are again, reporting the pandemic exposed disparities and inequities in the same communities with incomplete data and ethical issues resurfacing regarding equity in healthcare access, bias in healthcare delivery and questions regarding the equitable allocation and uptake of COVID-19 vaccines.

In the earlier stages of the pandemic the persistent need for reporting of COVID-19 data by race/ethnicity led to the development of the ‘COVID-19 Racial Data Tracker’, a project of the COVID-19 Tracking Project and the Boston University Center for Antiracist Research.<sup>13</sup> As they stated, ‘We began the work out of necessity and planned to do it for a couple of weeks at most, always in the expectation that the federal public health establishment would make our work obsolete.’<sup>14</sup> Unfortunately, as funding ended, this important volunteer collective discontinued data collection and reporting on 7 March 2021. In their closing messages, they were encouraged by some improvements in the public health and federal data collection and reporting infrastructures but noted that deficits remain.

These inequities lead to continuous disparities in contemporary healthcare access and COVID-19 pandemic response.<sup>4</sup> For example, diversity and inclusion in early mRNA vaccine trials was suboptimal, with Pfizer reporting early on participation rates of black and Latinx individuals of 10% and 13%, respectively.<sup>15</sup> Additionally, as the vaccines entered later stage trials, public opinion on COVID-19 vaccine uptake also decreased from 54% to 32% among black and from 74% to 56% among Latinx individuals, respectively.<sup>15</sup> Reported data on race and ethnicity for COVID-19 cases and deaths continue to lag, 65% and 85%, respectively, while data on age and gender are reported for 98% of cases and 99% for deaths (see table 1).<sup>16</sup> Similar gaps in data exist for vaccine dose administration with race/ethnicity available for 74% of people who received at least one dose.<sup>16</sup>

In an unprecedented effort to mitigate the disproportionate impact COVID-19 has had on black, indigenous and Latinx communities, the National Academies of Sciences, Engineering and Medicine (NASEM) released its consensus report, Framework for Equitable Allocation of COVID-19 Vaccine in October 2020, which recommends ‘a four-phased approach to allocation built on widely accepted foundational principles and guided by evidence to maximise a societal benefit by reducing morbidity and mortality.’<sup>17</sup> The role inequity plays in the disproportionate

impact on communities of colour was front and centre in the report:

In embarking on our task, the committee started with equity. Inequity has been a hallmark of this pandemic, both locally and globally. Inequities in health have always existed, but at this moment there is an awakening to the power of racism, poverty, and bias in amplifying the health and economic pain and hardship imposed by this pandemic. Thus, we saw our work as one way to address these wrongs and do our part to work toward a new commitment to promoting health equity that is informed by but lives beyond this moment.<sup>17</sup>

Accordingly, the consensus report calls on jurisdictions to use a vulnerability index, in particular the CDC’s Social Vulnerability Index (SVI), to mitigate the impact of systemic racism and socio-economic adversity which correlate with the disproportionately higher rates of COVID-19 morbidity, mortality and transmission in black, indigenous and Latinx communities.<sup>17</sup> Indices such as the SVI are geographical based statistical tools that capture the relative average advantage and disadvantage of those living in an area. These tools incorporate metrics such as income, levels of education completed and housing quality.<sup>18</sup> Using the data collected with the tools, entities can identify population groups who may benefit more from the COVID-19 vaccines. According to a review conducted by Schmidt *et al*, by 30 March 2021, 37 of the CDC’s 64 jurisdictions (50 states, the District of Columbia, 5 cities and 8 territories) adopted disadvantage indices in their respective vaccine allocation plans, when including those that used zip code-based measures, nearly two-thirds of jurisdictions (n=43) used a place-based measure.<sup>18</sup>

Efforts to use disadvantage indices to combat racial inequities regarding vaccine efforts are to be praised and is a step in the right direction. Building on this success, we recognise there is opportunity to continue to refine these measures. As noted in the comments on equity in the NASEM report, concern was expressed about the practicality and feasibility of implementing disadvantage indices. Per Schmidt *et al*, ‘...even if all states had set aside a 10% reserve of their allotted vaccines as additional amounts for the most disadvantaged quartile, under the NASEM framework populations of colour would be offered vaccines below their population share until the beginning of phase 3, except for the very first phase.’ Additionally, with only 4 of the 64 jurisdictions using an index to monitor vaccine receipt, there is room to expand this initiative in future vaccine roll outs.<sup>18</sup>

#### WHAT IS THE STATUS OF RESEARCH ON LONG COVID-19?

Efforts are underway to better understand the long-term effects of COVID-19, including the development of clinics and centres specifically dedicated to treating and evaluating these effects.<sup>19</sup> Given the complexities associated with caring for these patients, a multidisciplinary approach is deployed with practitioners ranging from pulmonary medicine, cardiology and infectious diseases to behavioural and mental health, primary care, social

**Table 1** Centers for Disease Control and Prevention (CDC) COVID-19 Data Tracker (as of 21 January 2022)<sup>6</sup>

Category	Overall No of COVID-19 cases	No COVID-19 cases reported by category	% of cases reported by category	Overall No of deaths	No of deaths by category	% of deaths reported by category
Race/ethnicity	52 445 493	34 427 939	65	727 126	620 964	85%
Age	52 445 493	51 631 182	98	727 126	726 983	99%
Sex	52 445 493	51 900 352	98	727 126	724 493	99%

workers and pharmacists. These clinics and centres are in their initial stages and recognise the need for continued research.

The novel nature of COVID-19's long-term effects lends itself to a systematic research approach that collects a breadth of data. This method is often accomplished by building registries and following patients for several years to learn how the postdisease sequela may progress and how the disease affects overall health and well-being. Registries often ask patients' permission to collect health data and biospecimens to aid researchers in designing future research. Long-term effect registries will house valuable data that, if properly maintained and equitably shared, could serve as an integral tool in understanding, treating, and possibly mitigating the severity of COVID-19 long-term effects. Such registries create an opportunity to proactively report long-term effects specifically for black, indigenous and Latinx communities on physical health, mental health and social determinants of health.

Given the complexities of long COVID-19, non-traditional approaches to research also serve as a platform to unlock the mysteries. One such platform is the Patient-Led Research for COVID-19 group, which is comprised of citizen scientists experiencing 'Long COVID-19'. Highlighting the value of patient-led research, National Institutes of Health (NIH's) Director Dr. Francis Collins referenced the group's survey study of 3762 self-described COVID-19 'Long Haulers'.<sup>20</sup> The survey found that approximately 65% of respondents experienced symptoms for 6 months or longer, with an average of 14 different symptoms. Almost half of the respondents indicated the side effects were serious enough that they had to work fewer hours and 22% said they were not able to work at all.<sup>21</sup> The NIH director noted this study demonstrated the urgency of Long COVID-19 as a public health issue, impacting lives and livelihoods of people around the world, with the vastness of its implications still unknown. Recognising the need for answers, Dr Collins initiated the Researching COVID-19 to Enhance Recovery Initiative which is a collaborative effort to understand, prevent and treat PASC, which includes Long COVID-19.<sup>22</sup>

## RECOMMENDATIONS FOR INCLUSIVE PLANNING AND IMPLEMENTATION

While the aforementioned survey brought the patients' voice to the research forefront, the respondents were not proportionally reflective of the communities most affected by COVID-19. Respondents represented 56 countries, 42% from the USA, yet less than 8% identified as black, indigenous or Latinx.<sup>21</sup> The lack of representation reiterates the need to have an inclusive approach deployed before the gap continues to widen. The current challenge is to design research on interventions in a manner that meets patients 'where they are'—physically and mentally—and learn how to incorporate those interventions into clinical models of care. US President Biden signed an executive order on 21 January 2021, entitled, Ensuring an Equitable Pandemic Response and Recovery, outlining measures that are to be taken to 'remedy differences in COVID-19 care and outcomes within communities of colour and other underserved populations',<sup>23</sup> including the creation of the COVID-19 Health Equity Task Force, whose membership includes individuals members with lived experience regarding inequity in public health, healthcare, education, housing and community-based services.<sup>24</sup>

In October 2021, the Task Force published two documents that provide cohesive recommendations for equitable resource allocation: its Final Report and Proposed Implementation Plan and Accountability Framework. The Final Report notes that

while COVID-19 affects all Americans, these effects are not equal, that:

to this day, roughly one-half of the nationally reported data on cases and deaths have no associated race or ethnicity data...data should be disaggregated by a core set of standardized socioeconomic and demographic characteristics to help understand the impact of COVID-19 on local communities and guide improvement and expansion of resources for behavioral health supports and services, especially for communities of color and other underserved populations.<sup>24</sup>

Additionally, the Framework provides recommendations for approaching Long COVID-19 healthcare and research in a manner that promotes equity, which includes setting a national research agenda on health equity and COVID-19, understanding the impact of healthcare provider bias and discrimination, supporting insurance coverage and treatment, particularly at Long COVID-19 care centres, and 'executing a robust communications campaign and information resource centre to educate the public on Long COVID-19 in ways that are culturally and linguistically appropriate and accessible'.<sup>25</sup>

These recommendations echo voices from communities of colour and stakeholders historically left behind in research and resource allocation. As Long COVID-19 research continues to evolve, instead of the traditional approach of doing research 'on' black, indigenous and Latinx communities, researchers need to make a concerted effort to conduct research 'with' the community. Before making the ask, researchers should be willing to meet community members 'where they are', contribute in a meaningful way to the community and demonstrate active listening. Building trust through transparent communication is part of the collective process wherein communities and stakeholders are included in the development, not just the collection, of research. Approaching research as a partnership to be conducted with communities of colour begins to open the doors of collaboration. As researchers actively demonstrate a careful and transparent approach to engagement, communities of colour will begin to embrace research during acute periods of distress such as a pandemic.<sup>26</sup>

Another key consideration for inclusive planning is to include researchers and team members who are representative and inclusive of black, indigenous and Latinx communities to begin to break down historic cultural barriers. The negative effects of the under-representation of black, indigenous and Latinx scientists in the scientific workplace are a critical limitation for research across the research continuum and is a well-established focus of systematic initiatives, programmatic and policy changes at the US NIH. Contributions from black, indigenous and Latinx scientists can increase innovation and science quality and advance medicine and public health. The contributions of investigators with diverse cultural perspectives enhance research, assist in systemic bias mitigation activities, and support diversity and inclusion of diverse and underserved communities, who continue to be underrepresented in clinical trials and in research in general.<sup>27</sup>

A meaningful increase in the funding of, and contributions from black, indigenous and Latinx scientists is well aligned with established ethical frameworks and benchmarks for research. Emanuel *et al* propose a framework of eight principles, the application of which by black, indigenous and Latinx investigators could serve as a foundation to bring a culturally and socially valid context to the research, its methods, and social and scientific values, and is arguably required to assure scientific benefit, contributions to research inclusion and diversity as



**Table 2** Adapted Ethical Framework and Benchmarks for Inclusive Research<sup>12 25</sup>

Guiding ethical principle	Impact of black, indigenous and Latinx Scientists
Collaborative partnership	Breakdown historical barriers to sharing responsibilities between researchers and communities; respect for community's values, culture, traditions and social practices
Valuable scientific question	Create open dialogue to validly assess the community's prospective value on the proposed research
Valid scientific methodology	Evaluate the feasibility and sustainability within the local healthcare and physical infrastructure
Fair subject selection	Emphasise the need to identify and protect vulnerable populations, particularly communities with historical maltreatment who are subject to continued mistreatment
Favourable risk-benefit	Assess risk-benefit ratio considering community specific considerations (eg, values, social practices)
Independent review	Relay the results of reviews (eg, Institutional Review Board, Federal Drug Administration) in a transparent and culturally appropriate manner
Informed consent	Involve the community in developing recruitment procedures, incentives, and linguistically appropriate materials
Respect for enrolled subjects	Provide timely communications in a transparent manner throughout the duration of the research, from initiation of study conduct to dissemination of results

well as translation and dissemination of benefits of research (see table 2).<sup>28</sup> Future research is needed to validate if this framework sufficiently addresses the needs of black, indigenous and Latinx scientists.

## CONCLUSION

It is critical that affected communities, relevant stakeholders and leaders review and provide input into the planning and implementation of Long COVID-19 research. Continuous patient and community engagement in the design, implementation, science communication and dissemination of these studies will help to ensure health equity is a part of the response to Long COVID-19. Research results are important if implemented and communicated with communities as the driver. The novel nature of the virus and disease demonstrates the need to proactively plan for surveillance, reporting and culturally relevant healthcare. These efforts can ensure black, indigenous and Latinx communities are not left behind compounding further historical and underlying inequities due to COVID-19 by including them now as active participants in the design and decision-making process.<sup>26</sup> Long COVID-19 research is already repeating past missteps. It is imperative that researchers, clinicians, policymakers and the like make a concerted effort to address pitfalls that negatively affect black, indigenous and Latinx communities by:

- ▶ Valuing patient-reported symptoms and providing unbiased, medically appropriate interventions.
- ▶ Ensuring equitable care and resource allocation.
- ▶ Reporting race and ethnicity accurately.
- ▶ Codeveloping community-based sustainable solutions.
- ▶ Providing equity-focused funding opportunities in research and healthcare initiatives.
- ▶ Supporting the contributions of black, indigenous and Latinx investigators to include their diverse cultural perspectives to enhance research.

**Correction notice** This article has been corrected since it was first published. The open access licence has been updated to CC BY. 17th May 2023.

**Contributors** All authors conceived the project and contributed equally to the drafting and writing of the manuscript. All authors approved the final manuscript. MM serves as the guarantor and accepts full responsibility for the finished work, had access to the data, and controlled the decision to publish.

**Funding** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient consent for publication** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available in a public, open access repository.

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