



# DATA FOR **BLACK LIVES**

April 2020

## Data for Black Lives COVID-19 Movement Pulse Check and Roundtable Report

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## Introduction

The Center for Disease Control and Prevention (CDC) released data on hospitalization during the first month of the COVID-19 United States epidemic.<sup>1</sup> According to this data, approximately 1 out of 3 people infected with coronavirus who require hospitalization were Black. Considering the fact that 13% of the US population is Black, Black people accounting for 33% of hospitalized COVID-19 patients is alarming. That same data reveals that white people made up 45% of hospitalizations while making up 76% of the population. Additionally, hispanics made up 8% of hospitalizations while making up 18% of the population. (Note: More recent data on COVID-19 in the Latinx community reveal disproportionate impacts) Following this initial nationwide report, US states have begun releasing COVID-19 data disaggregated by race revealing a similar disproportionate impact on Black communities.

In this critical moment where COVID-19 data is being collected, released, analyzed and interpreted, Data for Black Lives (D4BL) contemplates how this data can be used as a tool for social change instead of a weapon of political oppression in the lives of Black people. We assert that this data must be interpreted in the proper historical context considering the various elements of structural racism that inform the American public health ecosystem. We emphasize the importance of considering potential **impact** and **power** surrounding whose voices are driving the interpretations of these disparities and informing proposed solutions. We join a collective call to support Black communities and organizers working to mitigate the impact of COVID-19 on Black people.

On April 15, 2020, we convened a Data for Black Lives Movement Roundtable to serve as a pulse check for our movement. Our plan was to hear from Black public health experts who have been leading research and Black organizers leading efforts to change the conditions that make Black communities vulnerable *everyday* and especially in the COVID-19 crisis. Further, in an effort to learn how to better organize, mobilize and coordinate on behalf of Black communities nationwide and worldwide, we highlight the work of D4BL Hub Leaders, partner organizations and policymakers. This report contains a review of the content of the event and an outline of D4BL demands associated with responding to the COVID-19 pandemic.

## About the Speakers

### **Yeshimabeit Milner**

Founder & Executive Director of Data for Black Lives

### **Dr. Irene Headen**

Dr. Irene Headen is an Assistant Professor of Black Health in the Department of Community Health and Prevention at the Drexel Dornsife School of Public Health. Her research investigates the social and structural determinants of racial/ethnic disparities in adverse pregnancy outcomes. In particular, her work focuses on identifying neighborhood and community factors underlying these disparities and understanding how systems thinking can help translate these factors into multilevel interventions to improve Black maternal health outcomes. Central to Dr. Headen's work is placing pregnancy within the context of women's reproductive life course and developing ways to understand how structural racism operates over the life course to create racial/ethnic disparities during this critical window.

### **Dominique Day**

Ms. Day is the vice-chair of the UN Working Group of Experts on People of African Descent, a fact-finding body mandated by the UN Human Rights Council to investigate and report on the situation of people of African descent globally. She is a human rights attorney, leads DAYLIGHT | Rule of Law • Access to Justice • Advocacy, an access to justice platform, and maintains a civil rights practice with the boutique firm, Bledock, Levine, and Hoffman, LLP. Internationally, public policy and capacity-building work over the past two decades has focused heavily on racial justice. She has extensive experience in criminal and civil litigation on behalf of individuals and communities within the Black diaspora, including in post-conflict and transitional States. She holds a bachelor's degree from Harvard University and a juris doctor from Stanford Law School.

### **Zinzi Bailey**

Zinzi Bailey is a social epidemiologist focused on cancer health disparities as well as the health impacts of and policy solutions for structural and institutional discrimination, especially at the intersection of public health and criminal justice. She is also interested in the use of data and indicators in equitable policy and management. Bailey is currently an assistant scientist at the University of Miami Miller School of Medicine's Jay Weiss Institute for Health Equity at the Sylvester Comprehensive Cancer Center. She was the director of research and evaluation at the Center for Health Equity in the New York City Department of Health and Mental Hygiene from 2015 to 2017. Bailey received a DSc in social and behavioral sciences from Harvard T.H. Chan School of Public Health and an MSPH with a concentration in global epidemiology from Emory University.

### **Meme Styles**

Meme (mee-mee) Styles, is the President and Founder of the award-winning nonprofit [MEASURE](#), a public education & advocacy organization that empowers people to use data to tell their own story. Mrs. Styles created MEASURE in 2015 to build trust and measurable progress between people and institutions that serve them. Today, MEASURE is responsible for mobilizing communities that are furthest from opportunity to fight against systemic disparities in health, economics, criminalization & education through the CARE Model.

Meme is a global thought leader for community engagement strategies and is responsible for the annual Big Data & Community Policing Conference as well as the Innocence Initiative which seeks to protect Black Girls through the elimination of adultification bias.

Mrs. Styles holds a Bachelor's of Science in Communications, completing a Masters Of Public Administration at American Military University and a certification in Performance Measurement through George Washington University College of Professional Studies

### **Courtnei Andrews**

Courtnei is an aspiring movement scientist, data jock and public health practitioner. Born in the South and raised in Metro Atlanta, she's deeply committed to using science, medicine and healing for the greater good. While she's presently an ORISE Fellow to Minority Health and Health Equity Office at the Centers of Disease Control and Prevention and has interned with the World Health Organization, she's committed to doing the work on the ground as a founding member of the Data for Black Lives Atlanta Hub. She was a 2019-2020 Lorde's Werq Fellow with [Southerners on New Ground](#) (SONG), participated in the 2019 Georgia Statewide Organizer Academy with SONG, and participated in the 2019 Organizer Academy with Asians Advancing Justice Atlanta as a trainer/facilitator after participating in the inaugural class in 2018.

She's an alum of Young People For (YP4), a StartingBloc Fellow, and was recently accepted to the Rockwood Institute for The Art of Leadership Training. She's an alum of Emory as a double eagle, having double-majored in Neuroscience and Behavioral Biology and Psychology and later a Master's in Public Health in Behavioral Sciences and Health Education as well as becoming a Certified Health Educator, or CHES.

While she is hoping to go back to school to get a MD/PhD, when she's not working, you can find her reading books, running around Atlanta's anime/gaming conventions, scheming and dreaming over tea and weight lifting to BTS and Logic

### **Michelle Wilson**

Michelle is a native of Kansas City, Missouri, currently thriving in Atlanta, GA, with a passion for social justice and human rights. In 2013, Michelle received her BA at Philander Smith College and will complete her MA at Clark Atlanta University in Political Science this year. Currently she is the Senior Program Manager at Women Engaged a social justice nonprofit at the intersection of reproductive justice and civic engagement. She has worked in social justice and politics for over 12 years and uses data to inform her strategies with public policy and community organizing.

### **Lisa Clinton**

Lisa is a Ancestress, Sex Doula, Metaphysician, Minister, life coach, [SONG](#)'s Regional Bailout Coordinator & Case Manager, an Antagonist of the system, and a Spiritual Gangstress amongst other things. Born and raised in San Francisco CA. She loves black people because she grew up being nurtured and taught by black people struggling through oppression. She struggled four decades in the same systems of oppression and she believes that one of the many reasons she's here is to be a voice for formerly incarcerated people whose voices and experiences need to be uplifted.

Lisa was brought into movement through the Black Mama Bail Out Action founded by Mary Hooks. Lisa has survived decades of trauma due to the prison industrial complex only to become a medicine woman of truth and compassion. Lisa is always ready to be a shit starter for her people... so let's start some shit!!

“If you don't love the people, sooner or later you're going to betray the people” – Nehanda Isoke Abiodun

### **Nchedochukwu Ezeokoli**

Nchedochukwu Ezeokoli was born in Nigeria and raised in Oakland, California. Nchedo is a healer, strategist, and creative committed to social change and justice for marginalized groups with a deep focus on health and well-being, community building, and art/music. In their free time they write poetry and stories, engage in community and the arts, explore healing modalities, hang with their two kittens, and around the people they love exploring the complexities of the world. They recently graduated with their MPH in Global Health with a focus in Community Health and Development at Emory University's Rollins School of Public Health and holds a BS from Stanford University in Science, Technology, and Society in Life Sciences and Health with a minor in African Studies. Nchedo currently works as a senior healthcare strategy consultant.

## Moment of Silence

Offering respect and remembrance to those who have lost their lives to COVID-19, we began the event with a moment of silence. Many of us have been directly impacted by COVID-19 and that deserves space and acknowledgement in this movement. The loss of life is far too familiar for Black folks due to the daily realities of state sanctioned violence and structural racism. Now, we face the exponential impact of a global pandemic: COVID-19. In this moment, we are reminded that everyone lost has now joined the realm of ancestors who have always and will continue to guide us.

*"If there is any call to action in this moment, it is to ensure that their lives and their deaths are not in vain and that we make this about more than temporary reform but about long term systemic change."*

**-Yeshimabeit Milner**

We challenge ourselves to recognize and remember that our collective future survival depends on our ability, our courage and our willingness to make bold demands in this moment and we invite you to join us as we do just that. This is a movement pulse check to contemplate how we might make this moment about more than temporary relief or reform but about lasting structural change.



## About Data For Black Lives

Data for Black Lives (D4BL) is a movement of activists, organizers, and mathematicians committed to the mission of using data science to create concrete and measurable change in the lives of Black people. Since the advent of computing, big data and algorithms have penetrated virtually every aspect of our social and economic lives. These new data systems have tremendous potential to empower communities of color. Tools like statistical modeling, data visualization, and crowd-sourcing, in the right hands, are powerful instruments for fighting bias, building progressive movements, and promoting civic engagement.

But history tells a different story, one in which data is too often wielded as an instrument of oppression, reinforcing inequality and perpetuating injustice. Redlining was a data-driven enterprise that resulted in the systematic exclusion of Black communities from key financial services. More recent trends like predictive policing, risk-based sentencing, and predatory lending are troubling variations on the same theme. Today, discrimination is a high-tech enterprise.

Data for Black Lives is working to make data a tool for social change instead of a weapon of political oppression in the lives of Black people. When it comes to the disproportionate impact of COVID-19 on Black people, we assert that race on its own is not a risk factor but that racism is; that racism is above all, a technology aimed at deciding who will live and who will die. Our work at Data for Black Lives is to expose and dismantle these forces especially as COVID-19 becomes a compounding force in making structural racism ever more present and even more deadly.

## Defining the Problem: Structural Racism in Public Health

As more data reveals the disproportionate impact of COVID-19 on Black communities, people are largely considering the question: why are Black people particularly vulnerable and overrepresented among COVID-19 cases and deaths? Many articles are being written about this question and we are seeing a mainstream discussion about how to understand and formulate solutions.<sup>2-11</sup> The proposed solutions depend on how the problem is defined. It is critical to place this public health crisis in its proper historical context, which challenges us to explore COVID-19 in the framework of anti-Black structural racism.

We look to Black scholars in public health and epidemiology to outline a framework for our collective understanding of the root causes. This will ground us as we strategize and organize around the COVID-19 pandemic. We hear from Dr. Irene Headen and Dr. Zinzi Bailey to outline this framework.

## COVID-19 and Black Folks: Systems of Racism as a Root Cause

Dr. Irene Headen

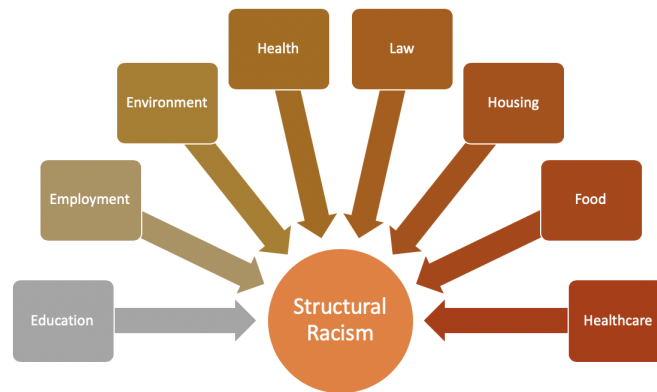
Dr. Irene Headen is currently an Assistant Professor of Black Health at Drexel Dornsife School of Public Health. On the topic of COVID-19 and the disproportionate impact on Black communities, her work offers lessons on how to approach structural racism from a systems lens. One of the most widely mentioned reasons currently being offered as an explanation of the drastic racial disparities in COVID-19 centers around Black people having high rates of chronic pre-existing conditions.<sup>12, 13</sup> But this particular explanation does not capture the fundamental problem at the root of these disparities. Racism, not race, lies at the root of these disparities; operating in its many forms to impact black health. For example, three particularly relevant manifestations of racism in our current pandemic include:

### Highlighting three public health manifestations of racism:

1. **Unequal access to care:** Black communities do not have equal access to quality healthcare often due to being overwhelmingly uninsured or underinsured.
2. **Racially biased referral for testing:** Racial bias impacting referral for testing once health care is accessed can result in delayed diagnosis. Both anecdotal and research data has shown that Black people experiencing symptoms are more likely to be turned away and told to return later.<sup>14</sup> This results in Black people on average returning to the healthcare system at more advanced stages of the disease.
3. **Lower quality of care:** Research also identifies how implicit bias impacts COVID-19 treatment and resources distribution once treatment is initiated.

All of these mechanisms are important and critical to consider in identifying the full magnitude of racism on COVID-19. However, in order to understand how racism operates in the public health sector, we have to understand racism more broadly and how it is embedded in many of the spaces and places that Black folks navigate daily.<sup>15</sup>

### Domains of Structural Racism



*Domains of structural racism visualized here represent a subset of the many domains that are relevant.*

“Racism across these different domains doesn’t operate in silos. In fact, racism across these domains creates an interactive system that expands the burden of racism on Black communities.”

**-Dr. Irene Headen**

#### Racism as an interactive system:

Racism across these spaces and places connect in ways that reinforce and amplify the impact of oppression. For example, racism in the employment sector feeds into racism in the housing sector, which further feeds into racism in the neighborhood environment. This includes how neighborhood environments in the US are structured to position Black people with unequal access to healthcare, food, and service resources as a result of socially embedded practices and policies. The Black community on average has less access to these resources that are known to support overall health and well-being. In this way, neighborhood environment is connected to how health disparities emerge and persist. Similarly, we can highlight the connection between regulations related to transportation systems and how Black and Brown communities may be disproportionately exposed to high risk environments in transit to their essential jobs.

In short, we must carefully consider the way structural racism informs social systems and how those systems are connected when framing a narrative around public health and disparate outcomes for Black people. This should also inform responses as well as data collection and analysis in relation to the impact of COVID-19 on black communities.

Envisioning how we might realistically take future action to incorporate this structural racism lens and the systemic ways it manifests and operates, we can also learn from the work of D4BL. Below are lessons by the community and for the community that are even more critical to uplift in pandemic:

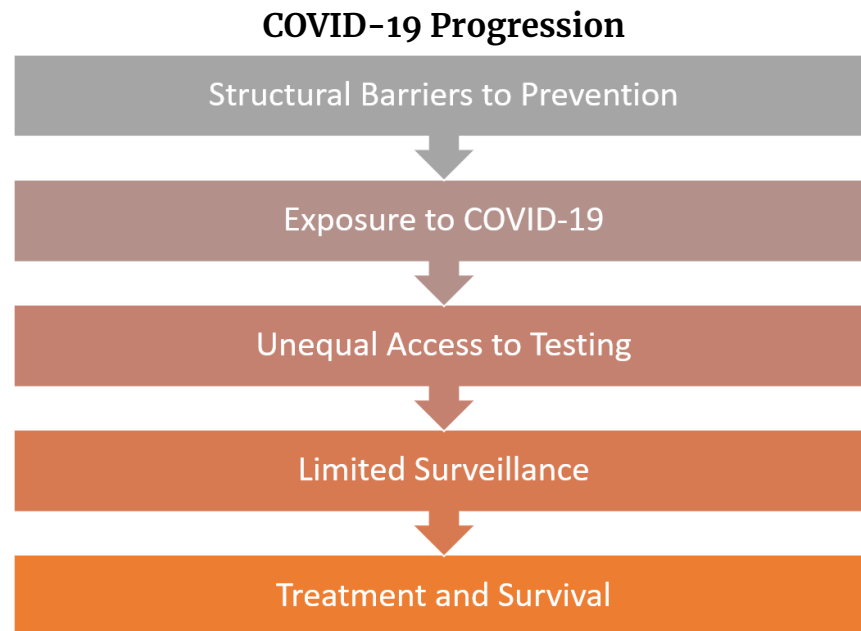
D4BL best practices for COVID-19 data on Black health outcomes:

1. Black folks must be involved in data collection efforts and inform data usage
2. The work of Black organizations must be uplifted as we collect data and move from data analysis to collective action
3. Black communities must not only be heard but centered in how we take on dismantling the disproportionate impact of COVID-19 on the Black community

## How Racism Impacts COVID-19 Prevention to Survival

Dr. Zinzi Bailey

Dr. Zinzi Bailey outlines the public health elements of COVID-19 and describes the impact of racism for each.



1. **Structural barriers to prevention:** The prevention measures that have been broadly suggested (handwashing, self-isolation, quarantine, etc) present structural barriers for those most marginalized. We must consider the barriers faced by many Black communities when it comes to participating in prevention measures. For instance, Black, indigenous and other people of color are over-represented in racially and economically segregated communities experiencing substandard housing conditions, unsafe or limited water access and often crowded housing conditions.
2. **Exposure to COVID-19:** Recently released mobility data shows that staying at home to avoid exposure to the coronavirus is in fact a privilege reserved for the wealthy.<sup>16,17</sup> Many low-income workers must continue to move around while folks with higher incomes can stay home and limit exposure. Public health experts also identify that wealthier and presumably more educated people also have a better awareness of risk or better access to information, which add to their decreased exposure.<sup>16</sup> Additionally as COVID-19 has progressed, with inequitable testing, people of color are more likely to be less protected ‘essential’ workers unable to self-isolate.

3. **Unequal access to testing:** People of color have been turned away from testing sites due to lack of insurance or inadequate criteria capturing risk and a reliance on hospital-based testing.<sup>18</sup> Also, the distribution of testing sites reveal a disparity in access to testing.
4. **Limited surveillance:** Undercounting of COVID-19 cases is likely more pronounced among marginalized racial groups. Most systems are not reporting race/ethnicity, socioeconomic, or other socio-demographic information, which prevents proper documentation of racial inequalities and targeted mobilization of resources.
5. **Treatment and survival:** Once someone has been able to get testing and is seeking treatment, pre-existing conditions and pre-existing bias of healthcare providers can further disadvantage people of color. With limited resources, doctors have to make decisions essentially about who lives and who dies. And historically, Black humanity has not always been deemed as valuable as that of white folks. The biased decision-making power of doctors and healthcare providers may contribute to the unequal rates of survival for Black COVID-19 patients. Additionally, hospitals in non-white segregated neighborhoods are less resourced with equipment, personnel, and financial flexibility.<sup>19</sup>

### A Few Areas of Concern

- *Disproportionate long-term public health impacts:* Much of the US Black population is in the South. In the same vein, many Black Americans (non-elderly) are concentrated in states with no Medicaid expansion.<sup>20</sup> This concentration may result in long-term healthcare costs for Black folks and hospitals serving non-white areas. There may end up being more limited hospital capacity for charity care and ER services for Black communities after COVID-19.
- *Disproportionate long-term financial impacts:* Consider the folks left out of the US coronavirus stimulus package. Many Black people will experience long-term unemployment or under-employment due to many industries that will no longer be viable after the COVID-19 pandemic.<sup>21</sup> Undocumented individuals and families will suffer alongside any Black small business owners with limited capacity to apply for funding. As COVID-19 ushers in an unprecedented economic downturn, we urge policy makers to ensure equitable recovery by taking targeted and strategic steps to minimize inequities, address systemic racism and “promote economic fairness for all”.<sup>22</sup>
- *Need for more progressive and radical criminal justice reform:* Given US mass incarceration rates and well-documented inhumane jail and prison conditions, we must address the vulnerability and exposure of incarcerated people during this COVID-19 pandemic. The incarcerated population already experiences a preponderance of underlying health conditions, structural constraints on hygiene, and close/cramped

quarters heightening the likelihood of devastating impacts. Reports are highlighting devastating conditions in jails and prisons and calling for mass decarceration.<sup>23, 24</sup>

**At D4BL, we call on local, state and federal correctional facilities to release people as quickly as possible in order to decrease infection rates, save lives and prevent a public health catastrophe.**



## Movement Building and Organizing

With our collective understanding of seeing the impact of COVID-19 through the lens of structural racism, we can strategize about collective action and methods to support the public health and well-being of Black people. We consider the questions: How can we fight back against the impact of COVID-19 on Black communities? How do we use this moment for abolition and decarceration? What does it look like to use data as a tool during this crisis?

We look to Black organizers and activists to highlight their strategies and offer up collective knowledge we can use and support in this moment. This provides a starting point for a call to action centered on uplifting and supporting Black folks during the COVID-19 pandemic. We hear from Dominique Day, Meme Styles, Lisa Clinton, Michelle Wilson, Courtni Andrews, and Nchedo Ezeokoli about their work.

## Racialization of COVID-19 Responses

Dominique Day

For some time, the medical and public health community has been aware of the ways structural racism might produce disparate outcomes in the case of a global pandemic. Dominique Day lays out the ways racial bias in decision making is impacting how Black people are surviving this crisis and interacting with the healthcare system. This is a call for the healthcare community and public health policy advocates to openly and directly discuss the prevalence of racial bias and mitigation strategies to adequately respond to COVID-19. It is a failure on the part of the healthcare community that these conversations were not happening from the start.

### **Racial Bias in Healthcare Decision-Making**

Doctors and physicians make decisions about treatment rationing: who gets ventilators, who gets hospital beds, who gets patient visits, etc. A 2016 study on racial bias in pain assessment showed that false beliefs about biological differences between racial groups can predict racial bias in pain perception and treatment recommendation accuracy.<sup>25, 26</sup> The connection between pain perception and treatment accuracy creates cause for concern when we now consider the ways racial perception informs treatment rationing during COVID-19. Further, a 2016 study supports that doctors under stress and time pressure show increased racial bias and that overcrowding at healthcare facilities can result in doctors displaying increased pro-white implicit bias.<sup>27</sup>

With the high-stress and overcrowded environments brought on by the COVID-19 pandemic, healthcare administrators and staff have to address racial bias explicitly and strategically. It is also important to challenge the practice of giving doctors unfettered sole discretion when it comes to decision making about treatment (e.g. hospitals in New York), because increased power with less guidance will also increase racial bias.<sup>28, 29</sup> Giving doctors and physicians sole discretion without being critical about implicit bias enables systemic racism.

The healthcare community knew all of this before the current pandemic, which means this particular risk could have been mitigated and at the very least discussed in time to develop tools that could be offered to healthcare workers. There could have been protocols in place to disrupt racial bias in these situations but this has not been done on a large scale.

### **Action Areas**

- **Critical Community Discussions:** We need to have these discussions with one another and these conversations need to inform community work and motivate people who are

seeking medical treatment to be assertive. Additionally, these conversations are not happening in policy spaces and among hospital administrators and they should be.

- **Position these strategies in a global context:** The disparate impact of COVID-19 on people of African descent is a global concern. Recently in France, medical leaders are proposing strategies that rely on the disposability of Black bodies.<sup>30</sup> In China, Black people are being evicted from homes and hotels, forced into testing, and thought to be importing COVID-19 to China.<sup>31</sup> There is a clear link from the global response to COVID-19 to neo-colonial ideologies that continue to inform people's biases and judgements. Make sure to contemplate the historical context of institutional racism (trade and trafficking of enslaved Africans and global colonialism) when developing responses to COVID-19.

For more information on policy recommendations from Dominique Day, visit the DAYLIGHT website: <https://www.daylyt.org/covid19-resources>

## Lessons from MEASURE

### Meme Styles

Meme Styles is the Founder and President of [MEASURE](#), which is an evidence-based, community driven non-profit that believes in people of color owning our own data narratives. MEASURE uses a [care model](#) to mobilize communities and create surveys and programming “for the people by the people”. They take care to ensure that folks with lived experience are involved in data interpretation. Meaning, the team treats storytelling and lived experience as valuable data that should help institutions create policies or in some cases, get rid of policies. Leadership at MEASURE is aware of the disparate outcomes of Black folks infected with COVID-19 and are working to meet the needs of the Black community in very intentional ways. Meme Styles offers concrete methods for taking action to support Black people in hopes that others might adapt and apply them.

- 1. Community feedback surveys**
- 2. Pivot/shift operations to meet the immediate needs of COVID-19**
- 3. Data-informed action**

“We offer solutions that are ready to disrupt and re-imagine what advocacy post-COVID-19 might look like.”

**-Meme Styles**

### **Community feedback surveys**

MEASURE has launched a community feedback survey in Austin, Texas to assess what needs are being met and not being met for marginalized communities. D4BL has highlighted the importance of data collection during this global pandemic to document COVID-19 impact. The survey launched by MEASURE went through a rigorous development process in an effort to ensure equity as a central focus. Following their care model, the goal was to be careful not to create additional harm with this survey. It is important to note the legacy of harm perpetuated by researchers throughout Black communities.

MEASURE has offered to share this specific survey with any organization that serves people of color. The survey can be made available in English, Spanish, and Korean (Arabic coming soon).

### **Pivot/shift operations to meet the immediate needs of COVID-19**

Nonprofits and existing organizations serving the Black community need to pivot and shift their operations to meet the immediate needs of the COVID-19 crisis. MEASURE has shifted its organization in multiple ways that we can all learn from.

For instance, MEASURE has added a direct service component to provide therapy and mentorship to their target population: Black girls. The most vulnerable Black girls with the highest need in this moment are those locked up in jails, those unable to socially distance, and those being held in inhumane isolation. This year, MEASURE has launched *The Innocence Initiative*, which is direct community action as a result of research done by Georgetown University in a report called *Girlhood Interrupted: The Erasure of Black Girls' Childhood* that tackled what is called adultification bias.<sup>32</sup> In response to the COVID-19 crisis, MEASURE offers therapy and mentorship to Black girls who have been recently released from jail, have a parent who is incarcerated, and/or have been negatively impacted by COVID-19.

In response to recent decarceration fueled by COVID-19, MEASURE has partnered with their local juvenile defender's office to create a clinical and mentorship program together. As we work towards decarceration, community based organizations have to be sustained in order to meet the needs of those that have been released to ensure that they stay out.

Looking forward past COVID-19, mass decarceration can and should be a new normal. The quick response to COVID-19 begs the question: If we were able to meet this quick and urgent need to remove people who have been incarcerated for so long, then why haven't we done it before and what do we need to do to make this a new normal?

### **Data-informed action**

MEASURE strives to address systemic injustice using data. All of the proposed solutions are data-driven. Some preliminary data on Harris County in Austin Texas - 1,142% increase in COVID-19 cases for incarcerated people in one week and 246% increase for people working in the jails. MEASURE is working to launch programs and surveys by Black people and for Black people that are impactful locally for Texas, but are agile enough to be transferred and scaled to other organizations. Please visit their website for more information: [measureaustin.org](https://measureaustin.org)

## Lessons from D4BL ATL Hub

Lisa Clinton, Michelle Wilson, Courtni Andrews, Nchedo Ezeokoli

The D4BL hubs program launched in late 2019 with the intention of serving leaders equipped with the technical skills, vision, and empathy to use data to make concrete and measurable change in the communities where they live. Hubs are led by volunteers and operate autonomously, though in tandem, with the D4BL mission. Enabling local chapters to determine their issue areas and campaign focus, ensures hubs have a greater ability to be responsive and drive impact in their local communities.

With a focus on deep leadership development, creating a national network of hubs allow leaders to work in the distinct historical and political contexts of their cities, while also being connected to leaders waging similar fights to use data to make concrete and measurable change in the lives of Black people where they live. D4BL is prioritizing the creation of hubs and the development of hub leaders to amplify the work of often overlooked and under-resourced organizing at the intersection of data and racial justice.

The D4BL Atlanta hub leaders offer insights for anyone looking to take action to support Black people during the COVID-19 crisis and beyond.

1. **Make sure Black people are centered:** Black folks who are directly impacted need to have a seat at the table. Specifically, when it comes to decarceration work, formerly incarcerated people have to be included.
2. **Trauma-informed attention:** With the calls for social distancing and self-isolation, mutual aid support has to be mindful of how people's trauma might impact their experience. For example, formerly incarcerated folks who have spent extensive time locked in cages and are now being told to stay home can start to feel like their walls are caving in on them. They need a specific-type of support and consideration during this time.
3. **Thoughtful language and articulation:** Sometimes the language we use may not be accessible to folks directly impacted and we have to think about ways to ensure everyone feels valued and heard in the work we do.

#### 4. Avoid tokenization

"We don't just want to collect data from you and tokenize you and harm you, we actually want to hear what you have to say. We want to invest in your leadership. We actually want to benefit from building a relationship with you."

-Lisa Clinton

5. **Power mapping in data collection and analysis:** Think about whose voices are we centering and whose voices are moving us forward.
6. **Money, funding and power:** Provide resources and support these organizations.
7. **Include Black queer and trans experiences:** Think about what Black folks are being left out of these conversations (Black folks in nursing homes, homeless, LGBTQ youth, domestic violence victims, etc.)
8. **Skill share:** We can each leverage our own expertise to support one another.
9. **Work from a Black Queer Feminist Lens with data:** This perspective is necessary to ensure that we are collecting data across the spectrum of marginalized identities (i.e. sexual, gender, disability). Ensuring we have the data we need to either triangulate the effects and strategies to support and uplift these communities.
10. **Expand our imaginations:** What could the world look like without prisons?
11. **Post-coronavirus reparations and redistribution of wealth**
12. **Community-based training:** Leverage folks on the ground who have shifted to deal with COVID-19; include these community members in data collection, analysis and interpretation. This could lend itself to shifting how data is used to craft community narratives.
13. **Community-Led research and funding:** What are the best practices for working with the community? Folks should be able to do this research themselves. There should also be funding available to fund these initiatives. The federal government has laid out funding for small businesses, corporations, and individuals. It is necessary for federal funding to be directed towards community-based organizations working primarily in Black communities. These organizations are well suited to be in the position to collect data about those being affected across Black communities.

14. **Create a registrar** of data scientists, software engineers, and technical folks who can assist our communities and empower them in this work. Creating a network that can link these skill sets with those of community-based organizations, activists, and even individuals who are seeking to further data for black lives. (D4BL is working on a project related to this goal)



## COVID-19 Data Demands

D4BL is working on developing policy demands that cover a broad range of topics. This work is particularly critical in response to the COVID-19 global pandemic. The following list of demands offers a framework for how both public and private actors should take action with COVID-19 data. Note that this list is not exhaustive and we will be developing more policy demands to be released in the future.

### **COLLECT AND DISCLOSE:**

We need data disaggregated by race that captures the spread of COVID-19. This data should include specific categories that capture a breadth of vulnerable people.

#### National Data:

1. We need publicly available national data on COVID-19 cases, hospitalizations, and deaths, disaggregated by race. To monitor the impact of how structural racism exacerbates the pandemic, this data should track those who are systematically vulnerable and include institutional data on the number of COVID-19 cases, hospitalizations, and deaths of individuals in the following:
  - a. nursing homes (or long-term care facilities),
  - b. homeless shelters,
  - c. federal, state, and local correctional facilities,
  - d. ICE detention, including those detained along the border,
  - e. public housing.
2. We also need publicly available data on COVID-19 cases, hospitalizations, and deaths of individuals who are deemed by the federal government as essential workers, including health care workers (both frontline and auxiliary health care workers), meatpacking, restaurant, retail, airlines, U.S. Postal Service workers, and government contract workers.

#### State and local data:

1. States, cities, and local health departments should also collect and publicly report data on COVID-19 cases, hospitalizations, and deaths, disaggregated by race, county, zip code, and hospital. This data should include institutional data on the number of COVID-19 cases, hospitalizations, and deaths of individuals in nursing homes, state prisons, local jails and lock-up facilities, homeless shelters, and in public subsidized housing.
2. State, cities, and local health departments should report data on the locations of their testing sites (hospitals, walk-in tests, morgues) and their respective testing capacities and utilization.

3. States, cities, and employers should collect and publicly report data on COVID-19 cases and deaths of individuals who are deemed by the state as an essential worker, including health care (both frontline and auxiliary health care workers), meatpacking, restaurant, retail, airlines, and local government workers, disaggregated by race.

**AVOID WEAPONIZING COVID-19 DATA:**

COVID-19 data should not be used to determine risk. It should not be used to surveil, criminalize, cage, and deny critical benefits.

COVID-19 data should not be used to inform any of the following automated decision making systems, for example:

- Predictive policing and enforcement of social distancing orders (i.e., COVID-19 hot spots should not be assigned greater police presence and prioritized enforcement of social distancing measures)
- Public safety assessments to determine whether a person can be released from jail or prison
- Forced testing (general and antibodies testing) that would disproportionately target Black, Latinx, and/or poor communities
- Denying a person credit
- Reinforcing historical practices of redlining in the form of denying loans, lowering property values, and reducing public and private investments
- Denying a person a job
- Denying a person housing
- Denying a person access to health care, treatment, or services (i.e., ventilators)
- Denying a person access to public services and benefits (i.e., public transportation)

**INTENDED PURPOSE OF DATA:**

COVID-19 Data should inform the implementation of the following immediate action:

- Release of individuals in jails, prisons, and ICE detention facilities
- Transparent, accountable, and community-informed protocols on automated decision systems used for contact tracing and other public health concerns
- Consistent testing protocols and workflows in Black communities
- Available and accessible testing sites and tests that meet the health needs of Black communities in light of the social determinants that cause racial health disparities,
- Moratoriums on negative credit reporting, late payment fees, rental evictions, foreclosures, and debt collection, and wage garnishments

- Suspension of rent payments in federally-subsidized housing programs and in low-income neighborhoods for one year
- Suspension of consumer and business credit payments (including mortgages, car, student, personal loans, and credit cards)

COVID-19 Data should be used to establish a reparative stimulus plan and efforts for long-term structural change.

1. COVID-19 data should be used to issue reparations tracing back to slavery. COVID-19 data offers more evidence that reparations are needed for harms tracing back to slavery. Evidence supporting the cumulative impact of structural racism on Black communities includes: Racial disparities in COVID-19 deaths, limited access to tests and health care, unemployment rates, and unequal loss of income. Reparations are the most viable option to rectify the deeply entrenched inequities that have only exacerbated the impact of the pandemic for Black communities.
2. COVID-19 stimulus plans, government loans, and other forms of government aid must account for COVID-19 racial disparities in deaths and loss of employment. Stimulus plans must account for the unique health challenges many Black folks face due to historical structural racism in the American public health system. Black communities need a tailored fix to recover from this pandemic in distinct ways. Otherwise, the pandemic will cause irreparable harm to Black communities that will make the promise of equity and equality a more distant reality. Additional COVID-19 stimulus plans should account for this in the allocation of dollars and relief aid.
3. COVID-19 data should be committed to a public data trust that would entrust the public with full agency over their data, as opposed to private or government actors. Designating the public as owners of this data would provide the highest level of transparency and accountability--not to mention give individuals greater negotiating power to use the data to achieve better outcomes.
4. Data on the economic impact of COVID-19 should inform alternatives to current discriminatory financial systems (e.g. credit scores). We anticipate that this data will reveal traditionally hidden biased decision-making that continues to disproportionately inhibit Black Communities' access to wealth in American society.
5. State and local health officials must co-develop with impacted communities protocols for general testing to protect Black communities from unethical clinical studies seeking to perform antibody and vaccine testing on poor Black communities. This would include

open and public announcements about where and when COVID-19 clinical trials will take place, ensuring Black scientists and researchers contribute to experimental planning, and providing accessible science communication surrounding experimental results.

## Conclusion

The COVID-19 pandemic is causing a tremendous loss of life and unprecedented economic devastation globally. In the face of such a public health crisis, people are seeking understanding of the immediate and long term impacts. Folks are looking to the data for insight about how to respond. Following America's long history of systemic anti-Black racism, the data already points to the disparate impact of COVID-19 on Black people. This is no surprise to Black folks. As we organize and take action, how do we collectively support one another during this time?

Our team at D4BL brought together public health experts to help collectively frame structural racism in the context of the US public health system. And with this framework in mind, we highlighted some of the work being done on the ground by Black organizations, all in hopes that this movement pulsecheck would inform collective action in support of the well-being of Black people.

We are mindful that the process of attaching narrative to data is not objective and that the tendency to blame Black folks for unequal outcomes will be appealing to the masses. Data does not exist in a vacuum isolated from social and political context. Interpreting the data through the lens of structural racism will result in solutions that are much more honest and less harmful to the Black community. In our COVID-19 data demands, we outline a call to action based on this framework. We will not tolerate the use of this data to justify the perpetuation of systems to control, police, surveil or deny critical benefits to Black communities.

This movement pulsecheck is but one component of the D4BL continued mission to uncover the fundamental problems associated with big data. D4BL, along with partner organizations, will continue to disrupt efforts to use this data as an instrument of oppression. We continue the work of reclaiming data to be used to uplift and empower Black communities.

## References

1. Garg S, Kim L, Whitaker M, et al. *Hospitalization Rates and Characteristics of Patients Hospitalized with Laboratory-Confirmed Coronavirus Disease 2019* — COVID-NET, 14 States, March 1–30, 2020. *MMWR Morb Mortal Wkly Rep* 2020;69:458–464.  
<https://www.cdc.gov/mmwr/volumes/69/wr/mm6915e3.htm>
2. Ray, Rashawn. *Why are Blacks dying at higher rates from COVID-19?*, April 9, 2020.  
<https://www.brookings.edu/blog/fixgov/2020/04/09/why-are-blacks-dying-at-higher-rates-from-covid-19/>
3. Moore, ReNika. *If COVID-19 Doesn't Discriminate, Then Why Are Black People Dying at Higher Rates?*, April 8, 2020.  
<https://www.aclu.org/news/racial-justice/if-covid-19-doesnt-discriminate-then-why-are-black-people-dying-at-higher-rates/>
4. Oliver Laughland and Lauren Zanolli. *Why is coronavirus taking such a deadly toll on black Americans?*, April 25, 2020.  
<https://www.theguardian.com/world/2020/apr/25/coronavirus-racial-disparities-african-americans>
5. Brooks, Rodney A. *African Americans struggle with disproportionate COVID death toll*, National Geographic, April 24, 2020.  
<https://www.nationalgeographic.com/history/2020/04/coronavirus-disproportionately-impacts-african-americans/>
6. West, James. *LA Times: New Data Reveals COVID-19 Is Killing Younger Black and Latino Californians at Higher Rates*, Mother Jones, April 2020.  
<https://www.motherjones.com/coronavirus-updates/2020/04/la-times-new-data-reveals-covid-19-is-killing-younger-black-and-latino-californians-at-higher-rates/>
7. Breslow, Jason. *Why Misinformation And Distrust Are Making COVID-19 More Dangerous For Black America*, NPR, April 10, 2020.  
<https://www.npr.org/sections/coronavirus-live-updates/2020/04/10/832039813/why-misinformation-and-distrust-is-making-covid-19-more-dangerous-for-black-amer>
8. Dan Verano and Kadia Goba. *Why The Coronavirus Is Killing Black Americans At Outsize Rates Across The US*, BuzzFeed, April 10, 2020.  
<https://www.buzzfeednews.com/article/danvervano/coronavirus-black-americans-covid19>
9. Gupta, Sujata. *Why African-Americans may be especially vulnerable to COVID-19*, ScienceNews, April 10, 2020.  
<https://www.sciencenews.org/article/coronavirus-why-african-americans-vulnerable-covid-19-health-race>
10. Kendi, Ibram X., *Stop Blaming Black People for Dying of the Coronavirus*, The Atlantic, April 14, 2020. <https://www.theatlantic.com/ideas/archive/2020/04/race-and-blame/609946/>
11. Walsh, Sean Collins. *At first, most Philly coronavirus patients were white. New cases are now primarily African Americans*, The Philadelphia Inquirer, April 3, 2020.  
<https://www.inquirer.com/news/philadelphia-coronavirus-race-african-american-cases-rising-20200403.html>

12. Johnson, Akilah and Talia Buford. *Early Data Shows African Americans Have Contracted and Died of Coronavirus at an Alarming Rate*. Propublica, April 3, 2020.  
<https://www.propublica.org/article/early-data-shows-african-americans-have-contracted-and-died-of-coronavirus-at-an-alarming-rate>
13. Aubrey, Allison. *CDC Hospital Data Point To Racial Disparity In COVID-19 Cases*. NPR, April 8, 2020.  
<https://www.npr.org/sections/coronavirus-live-updates/2020/04/08/830030932/cdc-hospital-data-point-to-racial-disparity-in-covid-19-cases>
14. Farmer, Blake. *Long-Standing Racial And Income Disparities Seen Creeping Into COVID-19 Care*. KHN, April 6, 2020.  
<https://khn.org/news/covid-19-treatment-racial-income-health-disparities/>
15. Bailey, Z. D., Krieger, N., Agenor, M., Graves, J., Linos, N., & Bassett, M. T. *Structural racism and health inequities in the USA: Evidence and interventions*. *The Lancet*, 389, 1453–1463, 2017.  
<https://www.ncbi.nlm.nih.gov/pubmed/28402827>
16. Jennifer Valentino-DeVries, Denise Lu and Gabriel J.X. Dance. *Location Data Says It All: Staying at Home During Coronavirus Is a Luxury*. *The New York Times*, April 3, 2020.  
<https://www.nytimes.com/interactive/2020/04/03/us/coronavirus-stay-home-rich-poor.html>
17. Magsino, Isiah. *Self-Isolating Is a Privilege Many Queer Hourly Workers Don't Have*. *them.*, March 23, 2020. <https://www.them.us/story/lgbtq-retail-restaurant-workers-coronavirus>
18. Farmer, Blake. *The Coronavirus Doesn't Discriminate, But U.S. Health Care Showing Familiar Biases*, NPR, April 2, 2020.  
<https://www.npr.org/sections/health-shots/2020/04/02/825730141/the-coronavirus-doesnt-discriminate-but-u-s-health-care-showing-familiar-biases>
19. Bailey, Zinzi, Sharrelle Barber, Whitney Robinson, Jaime Slaughter-Acey, Chandra Ford, Shawnita Sealy-Jefferson. *Racism in the Time of COVID-19*, Interdisciplinary Association for Population Health Science, April 2020. <http://iaphs.org/racism-in-the-time-of-covid-19/>
20. KFF Analysis of 2018 American Community Survey, 1-Year Estimates and KFF, Status of State Action on the Medicaid Expansion Decision, as of April 2020.  
<https://www.kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/>
21. Myers, Kristin. *Coronavirus to impact low-wage, black workers the most*, Yahoo Finance, March 12, 2020.  
<https://finance.yahoo.com/news/coronavirus-to-impact-low-wage-black-workers-the-most>
22. Connor Maxwell and Danyelle Solomon, *The Economic Fallout of the Coronavirus for People of Color*, American Progress, April 14, 2020.  
<https://www.americanprogress.org/issues/race/news/2020/04/14/483125/economic-fallout-coronavirus-people-color/>
23. Bryant, Miranda. *Coronavirus spread at Rikers is a 'public health disaster', says jail's top doctor*, *The Guardian*, April 1, 2020.  
<https://www.theguardian.com/us-news/2020/apr/01/rikers-island-jail-coronavirus-public-health-disaster>

24. Hartman, Matt. *We Should Use the Coronavirus Pandemic to Fight Mass Incarceration*, Jacobin, April 3, 2020.  
<https://www.jacobinmag.com/2020/04/coronavirus-pandemic-mass-incarceration-covid-prisoners>
25. Hoffman, Kelly M., Sophie Trawalter, Jordan R. Axt, M. Norman Oliver. *Racial Bias in Pain Assessment*, Proceedings of the National Academy of Sciences, Apr 2016.  
<https://doi.org/10.1073/pnas.1516047113>
26. Meghani, Salimah H., Eeeseung Byun, Rollin M. Gallagher. *Time to Take Stock: A Meta-Analysis and Systematic Review of Analgesic Treatment Disparities for Pain in the United States*, Pain Medicine, Volume 13, Issue 2, February 2012, Pages 150–174.  
<https://doi.org/10.1111/j.1526-4637.2011.01310.x>
27. Johnson, T. J., Hickey, R. W., Switzer, G. E., Miller, E., Winger, D. G., Nguyen, M., Saladino, R. A., & Hausmann, L. R. *The Impact of Cognitive Stressors in the Emergency Department on Physician Implicit Racial Bias*. Academic emergency medicine : official journal of the Society for Academic Emergency Medicine, 23(3), 297–305, 2016. <https://doi.org/10.1111/acem.12901>
28. Ramachandran, Shalini, Joe Palazzolo. *NYU Langone Tells ER Doctors to ‘Think More Critically’ About Who Gets Ventilators*, The Wall Street Journal, March 2020.  
<https://www.wsj.com/articles/nyu-langone-tells-er-doctors-to-think-more-critically-about-who-gets-ventilators>
29. Mercer, Martha. *NYC Hospital Empowers ER Docs to ‘Withhold Futile Intubations’*, Daily Beast, March 2020.  
<https://www.thedailybeast.com/nyu-langone-empowers-emergency-room-doctors-to-withhold-futile-intubations-amid-coronavirus-surge>
30. Busari, Stephanie, Barbara Wojazer. *French doctors' proposal to test Covid-19 treatment in Africa slammed as 'colonial mentality'*, CNN, April 2020.  
<https://www.cnn.com/2020/04/07/africa/french-doctors-africa-covid-19-intl>
31. Su, Alice. *‘No blacks’: Evicted, harassed and targeted in China for their race amid coronavirus*, LA Times, April 16, 2020.  
<https://www.latimes.com/world-nation/story/2020-04-16/china-coronavirus-black-african-evictions>
32. Epstein, Rebecca, Jamilya J. Blake, Thalia Gonzalez. *Girlhood Interrupted: The Erasure of Black Girls’ Childhood*, Georgetown Law, 2017.  
<https://www.law.georgetown.edu/poverty-inequality-center/wp-content/uploads/sites/14/2017/08/girlhood-interrupted.pdf>