



# **BREAKING BARRIERS:**

## **SURVEYING COMMUNITY PERSPECTIVES OF COVID-19 VACCINE RESEARCH**

MAY 2021

**TAG**

Treatment Action Group  
[www.treatmentactiongroup.org](http://www.treatmentactiongroup.org)

## **Breaking Barriers: Surveying Community Perspectives of COVID-19 Vaccine Research**

*This paper was prepared by Abraham Johnson with editorial input from  
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*The authors of this report bear sole responsibility for the content.*

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*Treatment Action Group (TAG) is an independent, activist, and community-based research and policy think tank committed to racial, gender, and LGBTQ+ equity; social justice; and liberation, fighting to end HIV, tuberculosis (TB), and hepatitis C virus (HCV).*

*TAG catalyzes open collective action by affected communities, scientists, and policymakers to ensure that all people living with or impacted by HIV, TB, or HCV -- especially communities of color and other marginalized communities experiencing inequities -- receive life-saving prevention, diagnosis, treatment, care, and information.*

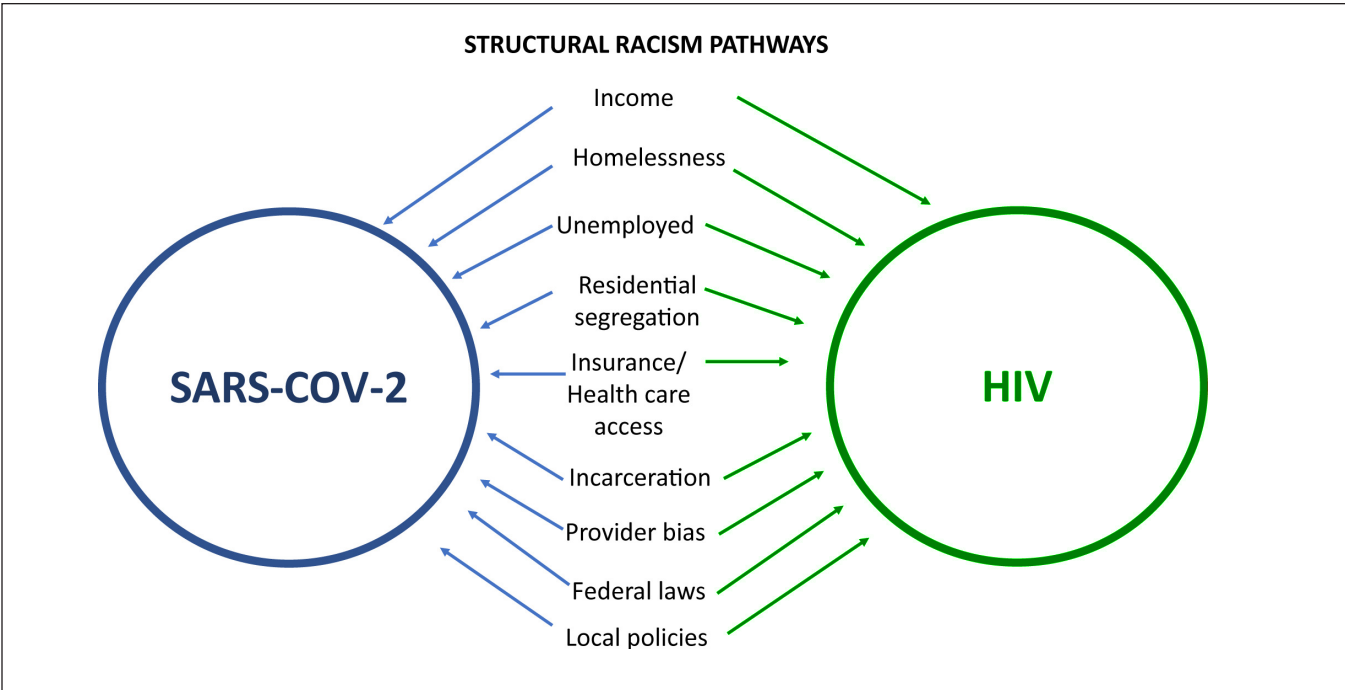
*We are science-based activists working to expand and accelerate vital research and effective community engagement with research and policy institutions for an end to the HIV, TB, and HCV pandemics.*

### **THE PRIMARY AIMS OF THIS REPORT ARE:**

- To raise the profile of discussions that have been taking place regarding community understanding and involvement in COVID-19 vaccine research.
- To describe results from a survey of diverse community members put together by TAG, the Black AIDS Institute (BAI), and the COVID-19 Prevention Trials Network (CoVPN) that solicited feedback on community experiences with COVID-19, knowledge of the vaccine development process, and perceptions of COVID-19 vaccines.

# INTRODUCTION AND BACKGROUND

The COVID-19 pandemic has placed a spotlight on health care disparities in the United States. The SARS-CoV-2 virus swept across the country resulting in severe disease outcomes, including hospitalization and death. These consequences have manifested differently across communities based on race, ethnicity, socioeconomic status, and location. The disparities are grimly familiar to those involved in work addressing HIV, where the epidemic has been clearly driven by issues such as structural racism, racial segregation, and poverty. In many ways both diseases have traveled along the same faultlines in our society; in a series of published papers, Gregorio Millett of amfAR recently highlighted the parallels between disparities in HIV and COVID-19.<sup>1</sup>



Part of the effort to address disparities in HIV has involved broadening and diversifying community partnership in the response, including promoting meaningful and intentional engagement in the research necessary to improve and increase accessibility of preventive and therapeutic interventions. With the sudden onset of the COVID-19 pandemic, a lack of information and trustworthy communication from political leaders fueled concerns of individual safety, uncertainty, and skepticism around participation in research—particularly in the vital effort to develop and roll out COVID-19 vaccines.

In an effort to capture these tensions with COVID-19 research, the Treatment Action Group (TAG), Black AIDS Institute (BAI), and the COVID-19 Prevention Network (CoVPN) designed an online survey that garnered feedback on community experience with COVID-19, as well as the communities’ knowledge of the vaccine development process and perceptions of COVID-19 vaccines. By better understanding community perspectives, we hope to inform efforts to bridge the gap between community and research as

*Nearly half of African American respondents (48%) reported that they have experienced racial discrimination in a health care setting, compared to 8% of White respondents.*

<sup>1</sup> Millett, GA. New pathogen, same disparities: why COVID-19 and HIV remain prevalent in U.S. communities of colour and implications for ending the HIV epidemic. J Int AIDS Soc. 2020 Nov; 23(11):e25639.

our organizations have historically done within the field of HIV. The results of this survey cover community familiarity with the research process, perceptions of bias within research, concerns about vaccine uptake, trusted sources of information, and several other key areas. With nearly equal responses from Black and White participants, we focus primarily on differences in responses between the two groups. The report ends with recommendations on how the survey might inform community-facing messaging going forward.

## SURVEY METHODOLOGY

An online Qualtrics survey, containing 49 questions in English or Spanish, was administered from October 28, 2020, until December 11, 2020. An email announcement was shared with HIV-related listservs, and organizational contacts of TAG, BAI, and CoVPN encouraged recipients to distribute it further. The survey received 306 responses. Responses were analyzed in sum and by self-reported demographic categories.

**Table 1: Background on Respondents**

Race/Ethnicity	%	Gender Identity	%
White non-Hispanic	41%	Cisgender male	23.8%
Black/African American	40%	Cisgender female	59.4%
Hispanic/Latino/Latinx	7%	Nonbinary	4.2%
Asian	6%	Transgender women	1%
American Indian or Alaska Native	3%	Transgender men	1.9%
Native Hawaiian or Pacific Islander	1%	Chose not to share	9.4%

Employment Status	%
Gainfully employed, working 30 hours or more a week	72%
Reported being considered essential workers	36%
Health care workers who had direct contact with patients	41%
Health care workers with no direct patient contact	16%

Responses were received from people in Alabama, California, Colorado, Connecticut, District of Columbia, Florida, Illinois, Indiana, Louisiana, Maryland, Mississippi, North Carolina, South Carolina, Tennessee, and Texas.

The respondents were composed of (as self-identified) 59.% cisgender women, 23.8% cisgender men, 1% transgender women, 1.9% transgender men, and 4.2% nonbinary people (9.4% of respondents opted not to share their gender identity). The group tended to have more formal education, with 50% of respondents having an advanced degree. Forty-one percent identified as White; 40% as Black, African American or African, 7% as Hispanic, Latinx, or Spanish, 6% as Asian; and 3% as American Indian or Alaska Native 1% as Native Hawaiian or Pacific Islander. The average age for participants was 50 (range 21 to 79), with 54% reporting living in a home or townhouse and 42% in an apartment or condominium. Seventy-three percent of participants reported living with at least one other person, for 46% this included a spouse or significant other. Twenty-seven percent lived in a household with three or more people. Seventy-two percent of respondents reported that they were gainfully employed, working 30 hours or more a week, and 36% of respondents reported being considered essential workers. Many of these essential workers (41%) were health care workers who had direct contact with patients, and 16% were health care workers with no direct patient contact. More than half

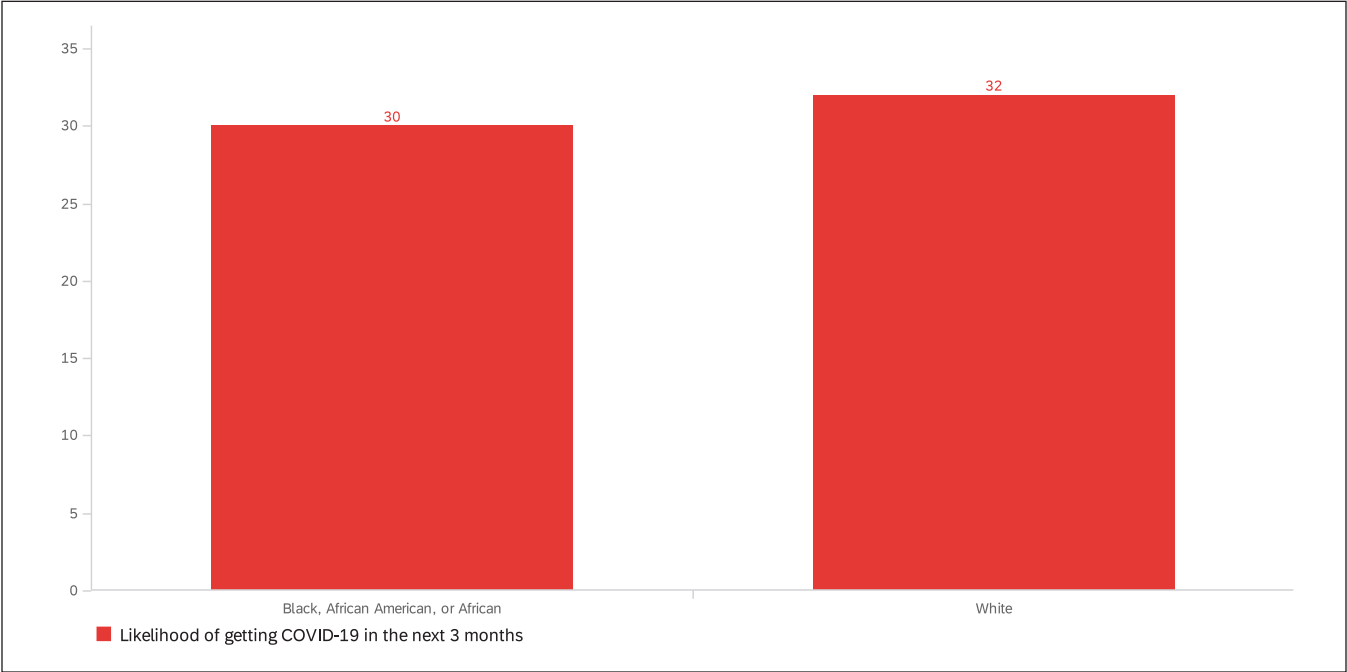
*When asked whether people of color will benefit from COVID-19 vaccine research as much White people, 49% of African American respondents either somewhat or strongly disagreed.*

of the respondents (52%) rated their health as “good.” A slight majority of respondents (55%) reported having underlying health issues, with 32% citing multiple conditions and 23% a single condition. The most common conditions were HIV (18%) and hypertension (18%); 40% were on daily medication for a health condition (22% for a single condition, 18% for multiple conditions).

**Risk of Contracting the Virus**

Participants were asked how likely they are to get COVID-19 in the next three months. This question was on a sliding scale with 0 being “not at all likely” and 100 being “extremely likely.” There was also an option for participants to say they had already contracted SARS-CoV-2/the virus. The average answer to this question was in the 30th percentile, meaning that the majority of respondents did not think they would contract the virus in the next three months. In terms of racial composition, both African American and White respondents averaged in the 30th percentile. The same held true for cisgender women and men, with too few transgender and nonbinary respondents to allow for meaningful comparisons. No notable differences in assessments of risk of acquiring the virus were evident among different age groups (over or under 30, over or under 50).

**Graph 1: Risk of Contracting the Virus By Race**



**COVID-19 Impact on Community**

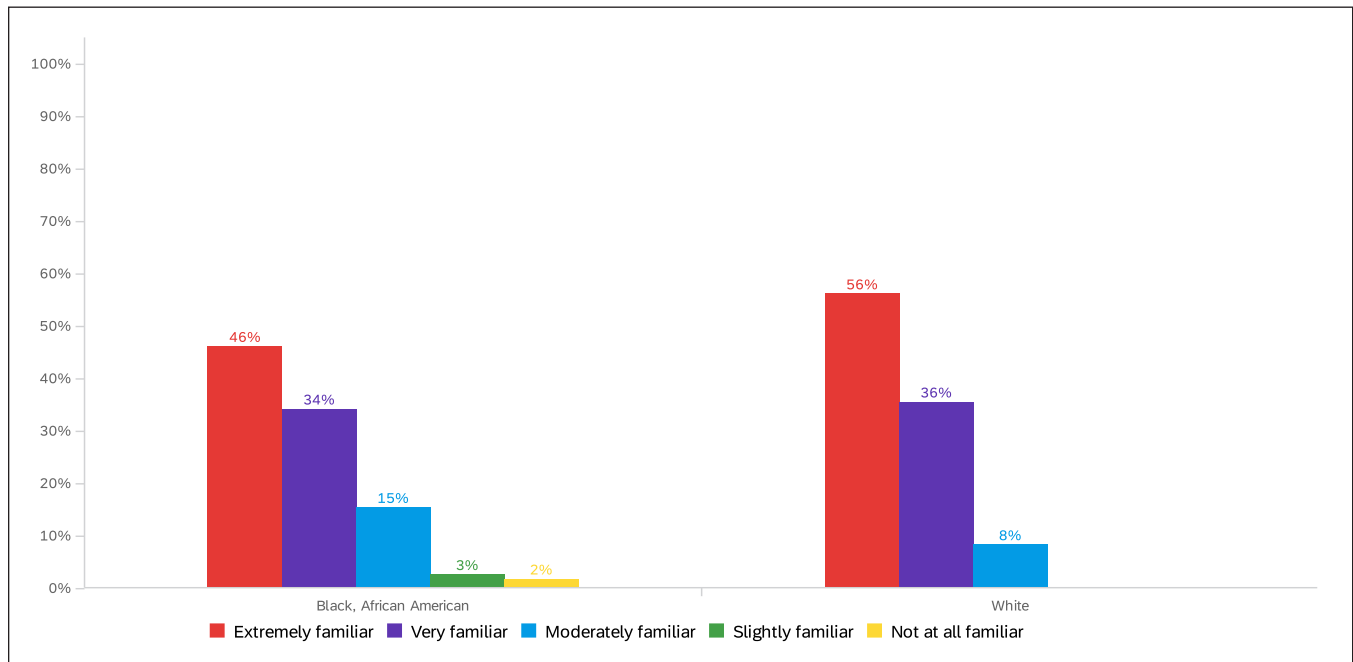
The COVID-19 pandemic interrupted communities’ ability to access health care services because of stay at home orders. Additionally, the pandemic greatly affected community members’ personal lives, resulting in negative impacts professionally, financially, and socially.

The survey asked participants, “How has the COVID-19 pandemic affected your ability to access healthcare services including mental health providers, general healthcare, specialist healthcare and complimentary or holistic healthcare?” Overall, 34% of respondents reported that the COVID-19 pandemic somewhat affected their ability to access mental health providers, while 44% of respondents reported that the COVID-19 pandemic affected their ability to access general health care.

## Knowledge of COVID-19 in Community

Knowledge of COVID-19 infections, deaths, and local and state restrictions slightly varied between African Americans and Whites. Participants were asked if they knew someone who had tested positive for COVID-19. Most respondents (87%) said yes, and a small percentage (3%) were unsure. Responses were similar by race; most African Americans (87%) and Whites (88%) reported that they knew someone who had tested positive. Additionally, 52% of African Americans reported knowing someone who died from complications related to COVID-19 compared 34% of White respondents. In terms of familiarity with local and state restrictions, overall 48% of respondents reported being extremely familiar with local and state COVID-19 restrictions; however, the percentage was higher for White respondents (47%) compared to African American (37%).

**Graph 2: Familiarity with COVID-19 Restrictions by Race**



## Protection Against COVID-19

From the start of the COVID-19 pandemic, there has been official governmental guidance regarding ways to protect yourself against COVID-19, including frequent hand washing, social distancing, and wearing a mask or face covering. The survey asked respondents what they had done in the last seven days to keep themselves safe from the virus. Participants were able to choose from 13 options. Ninety-four percent of respondents reported frequently washing their hands, 99% said they had worn a mask to stay safe, and 86% of respondents had avoided large gatherings. Overall, 42% of respondents reported that they had canceled travel plans, and 77% worked or studied from home. A qualitative section was included for participants who said they wanted to but were unable to adhere to the safety measures. Here are a few of their responses:

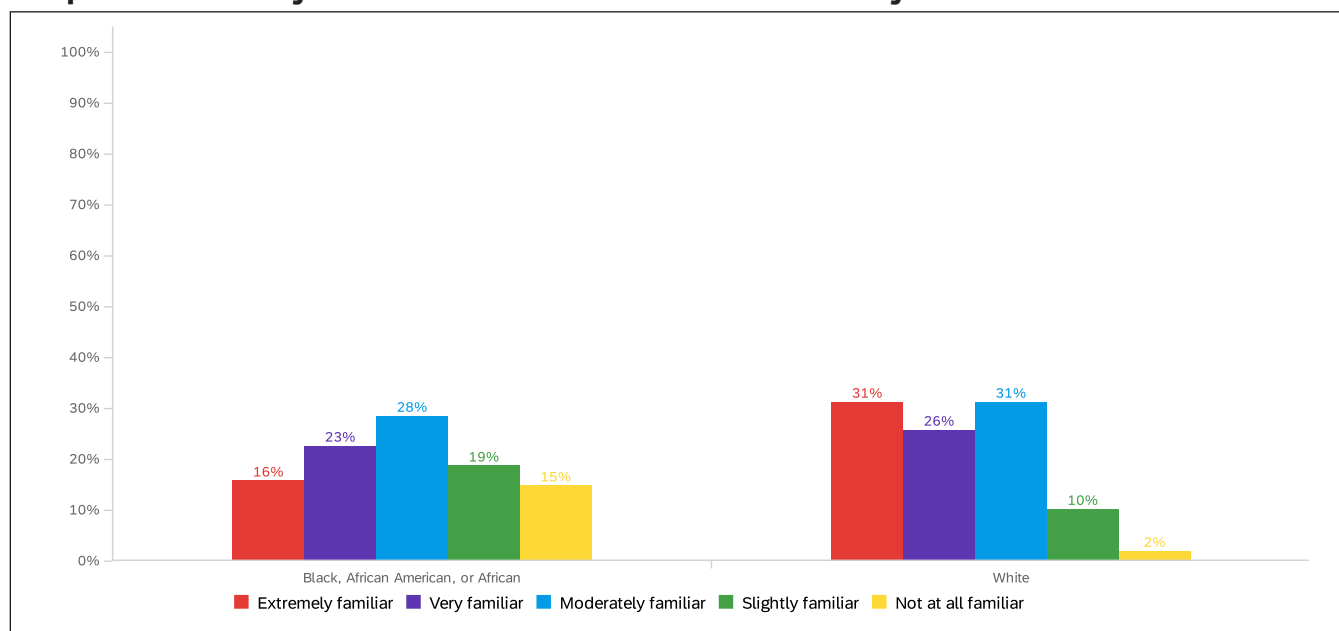
- “I’m currently about 2 months pregnant so I need to continue to attend doctor’s appointments, and unfortunately living in NYC has made it extremely difficult when leaving my apartment to stay 6 feet away from others who may be at high risk.”
- “I wasn’t permitted to work from home by management at my organization. My mom and my niece passed away from health complications, so we had to gather for the funerals. I have cancelled many family outings because of COVID and also fell behind in school. I am in the final year of grad school and had to turn in a few assignments late because of not being in the classroom. It is hard to be engaged in school as there is no separating work from home or home from school.”

- “I cannot afford a car and ride transit. My transit trips are to work and to grocery stores located outside of my food desert neighborhood. Cannot afford grocery delivery. Cannot avoid coworkers/the public we serve.”
- “I wanted to stockpile medicine, but my insurance company won’t allow it.”
- “Although I would like to, given the nationwide surge in infections currently underway, my insurance permits me to do 90-day refills of only 1 or 2 of my least essential meds, none of my ARVs and no other brand-name drugs.”

### Questions on COVID-19 Vaccine Development and Opinions on a COVID-19 Vaccine

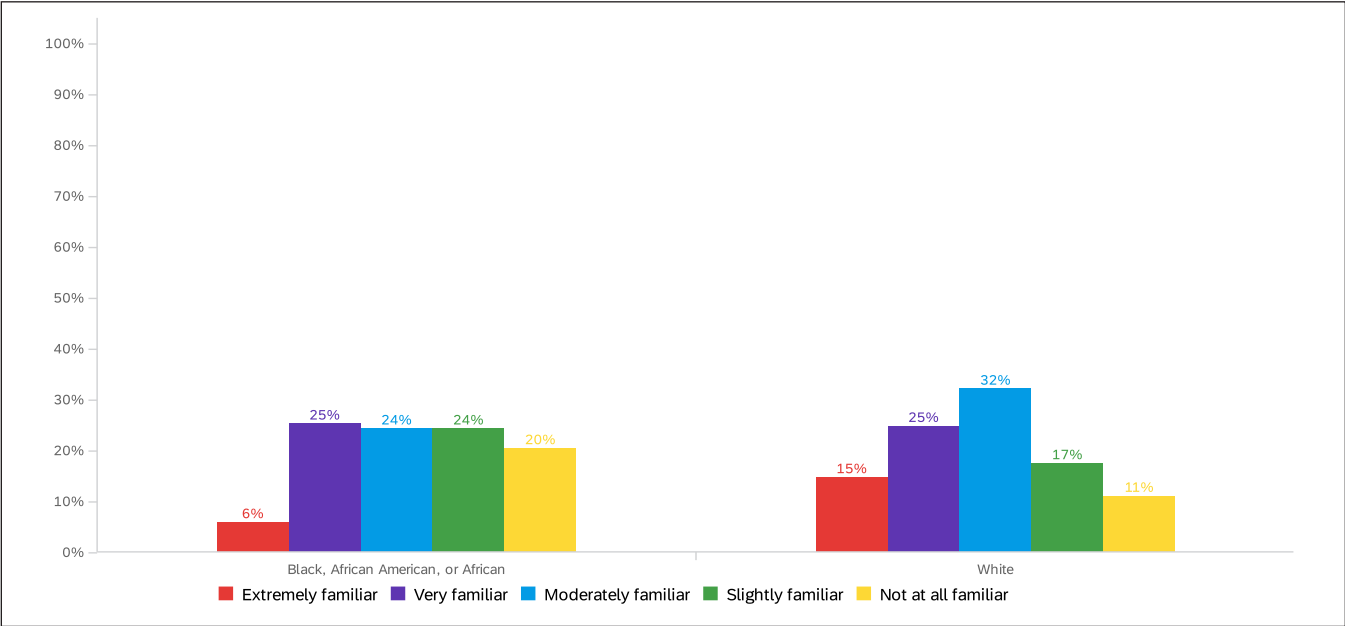
In order to successfully fight back against SARS-CoV-2, there must be an uptake in vaccines among communities most affected by the pandemic — and, ideally, herd immunity. Historically, marginalized communities have higher mistrust in the vaccine development process, with abuses such as the Tuskegee syphilis study having been found to contribute to that mistrust.<sup>2</sup> An additional aim of the survey was to gather the opinions of community members on COVID-19 vaccines and to gain an understanding of their knowledge and familiarity with the scientific process. Overall, only about a quarter of the respondents (24%) said they were extremely familiar with the scientific research process. Among respondents identifying as African American, 25% responded that they were extremely familiar with the scientific research process, 10% of Hispanic respondents said they were extremely familiar with the scientific research process, and 54% of White respondents said they were extremely familiar with the scientific research process. The survey also addressed familiarity with vaccine development. Only 11% of respondents said they were extremely familiar with vaccine development. Moreover, 31% of participants identifying as non-White said they were extremely familiar with vaccine development, compared with 55% of White respondents.

**Graph 3: Familiarity with the Scientific Research Process by Race**



<sup>2</sup> Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. J Health Care Poor Underserved. 2010 Aug;21(3):879–97. doi: 10.1353/hpu.0.0323.

**Graph 4: Familiarity with Vaccine Development by Race**



### **Structural Barriers**

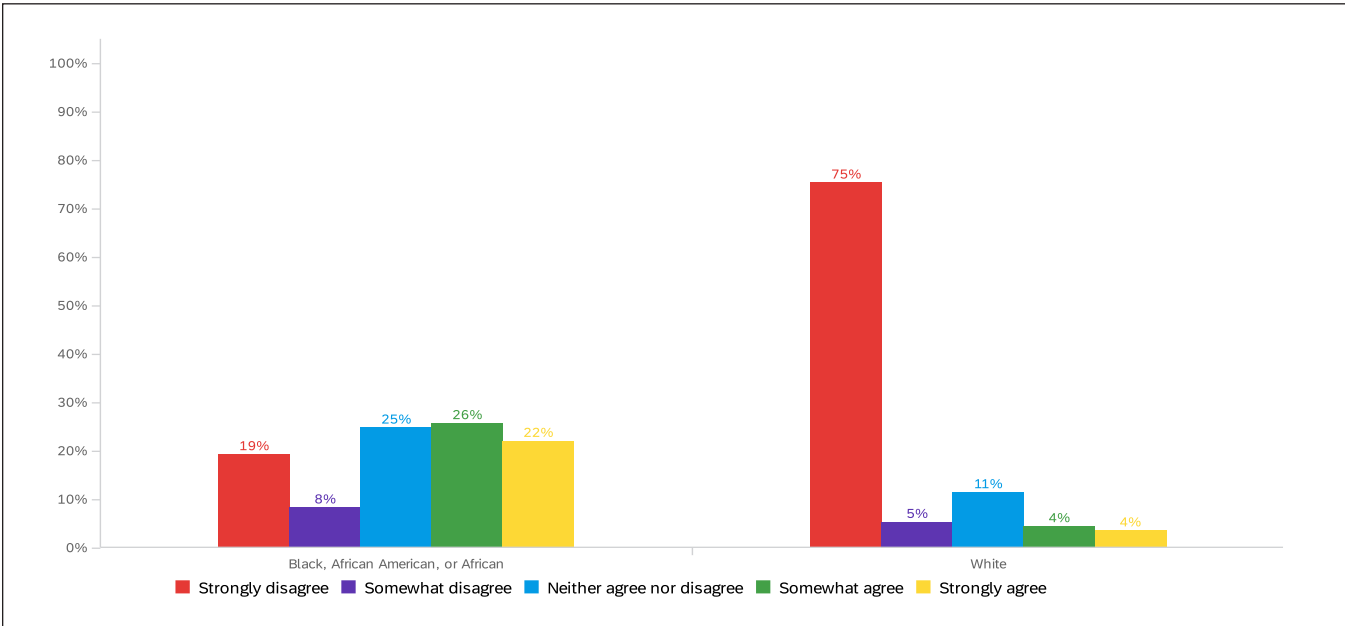
Structural barriers including racism and racial inequities have to be considered when addressing the COVID-19 pandemic. Survey respondents were asked a series of questions on a Likert scale ranging from *strongly disagree* to *strongly agree* regarding representation in clinical research, whether racism makes a difference in getting access to certain medicines or treatments, and whether they had experienced racial discrimination in a health care setting. When asked if their race is represented in clinical research, 61% of African American respondents strongly disagreed; only 7% of White respondents strongly disagreed. When asked whether racism makes a difference in getting access to certain medicine or treatment, a majority of both African American (68%) and White respondents (64%) strongly agreed. Nearly half of African American respondents (48%) reported that they have experienced racial discrimination in a health care setting, compared with 8% of White respondents.

**Sixty-one (61%) of African American respondents strongly disagreed that African Americans are represented in clinical research.**

When asked whether racism makes a difference in getting access to certain medicine or treatment, both African American and White respondents (40%) strongly agreed. When asked whether people of color will benefit from COVID-19 vaccine research as much White people, 49% of African American respondents either somewhat strongly disagreed.



**Graph 5: Racial Discrimination Experiences**



Note: Forty-eight percent of African Americans report experiencing racism when percentages from “strongly agree” and “somewhat agree” are combined.

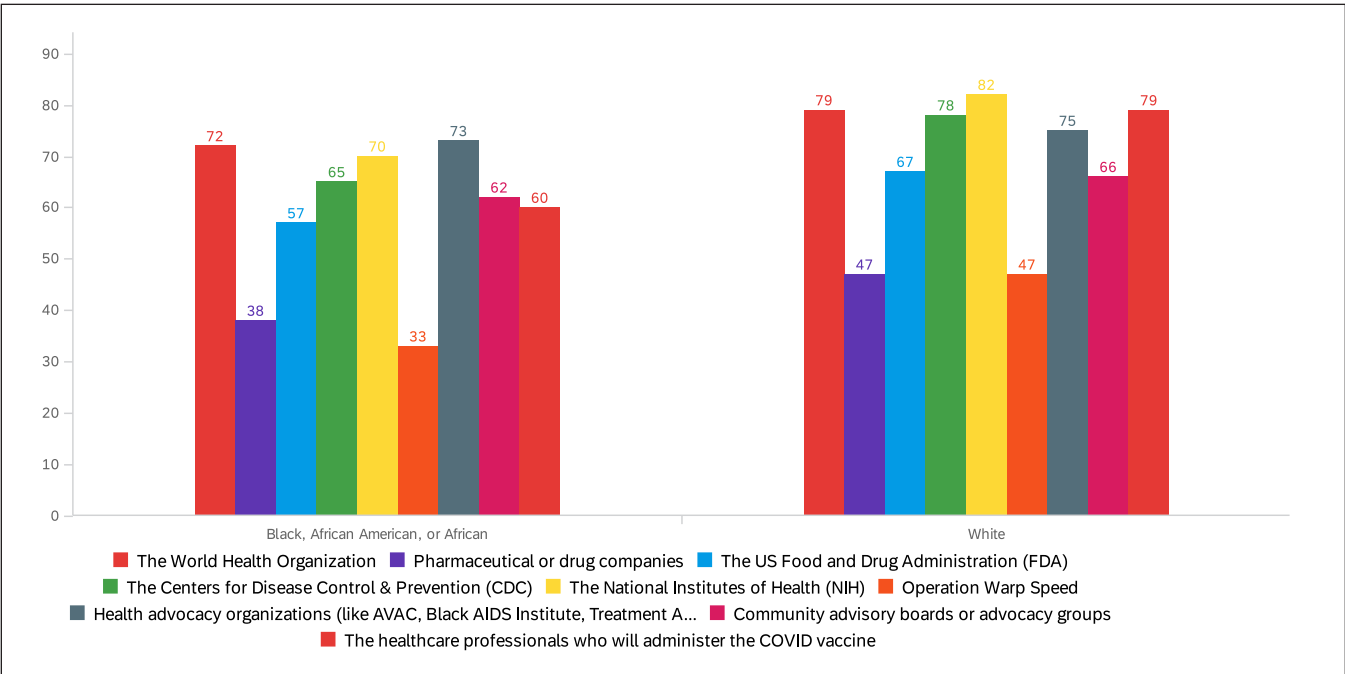
### **Knowledge of Vaccine Development**

Understanding of vaccine development can lead to successful uptake of available vaccines. Participants were asked how familiar they were with the vaccine development process. Only 29% of participants reported that they were moderately familiar; 14% reported not being at all familiar with the vaccine development process. This question was further broken down by race, and 60% of African Americans reported having no familiarity with the vaccine development process, compared to 34% of White respondents. Respondents were also asked to respond to true or false questions about the vaccine development process. A common myth heard within communities is that participants in COVID-19 vaccine studies will be given SARS-CoV-2 (the coronavirus) as part of the study. Seventy-one percent of participants responded “false” to this statement; however, answers differed by race. Fifty percent of African Americans responded “true” to this statement; 32% of White participants responded “true.”

### **Trust in Vaccine Development**

Medical misinformation is filtered through marginalized communities. There are many mediums that allow communities to get the latest information on vaccine development. Survey participants were asked to rate on a scale of 0–100 how much they trust the following sources when it comes to vaccine development: the World Health Organization (WHO), pharmaceutical or drug companies, the U.S. Food and Drug Administration (FDA), the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), Operation Warp Speed, health advocacy organizations (like AVAC, Black AIDS Institute, Treatment Action Group), community advisory boards or advocacy groups, and the health care professionals who will administer COVID-19 vaccines. African American trust was highest in health advocacy organizations with a mean score of 73 and the lowest trust in the Operation Warp Speed with a mean score of 33. White respondents trust was highest in The World Helath Organization and healthcare professionals who administer the COVID-19 vaccines both mean score of 79. Conversely, White respondent trust was lowest in Operation Warp Speed and Pharmaceutical and pharmaceutical or drug companies (mean score of 47).

**Graph 6: Trusted Sources for Information on Vaccine Development Process by Race**



Note: Scores are averages on a scale of 0 to 100 where higher scores indicate greater trust

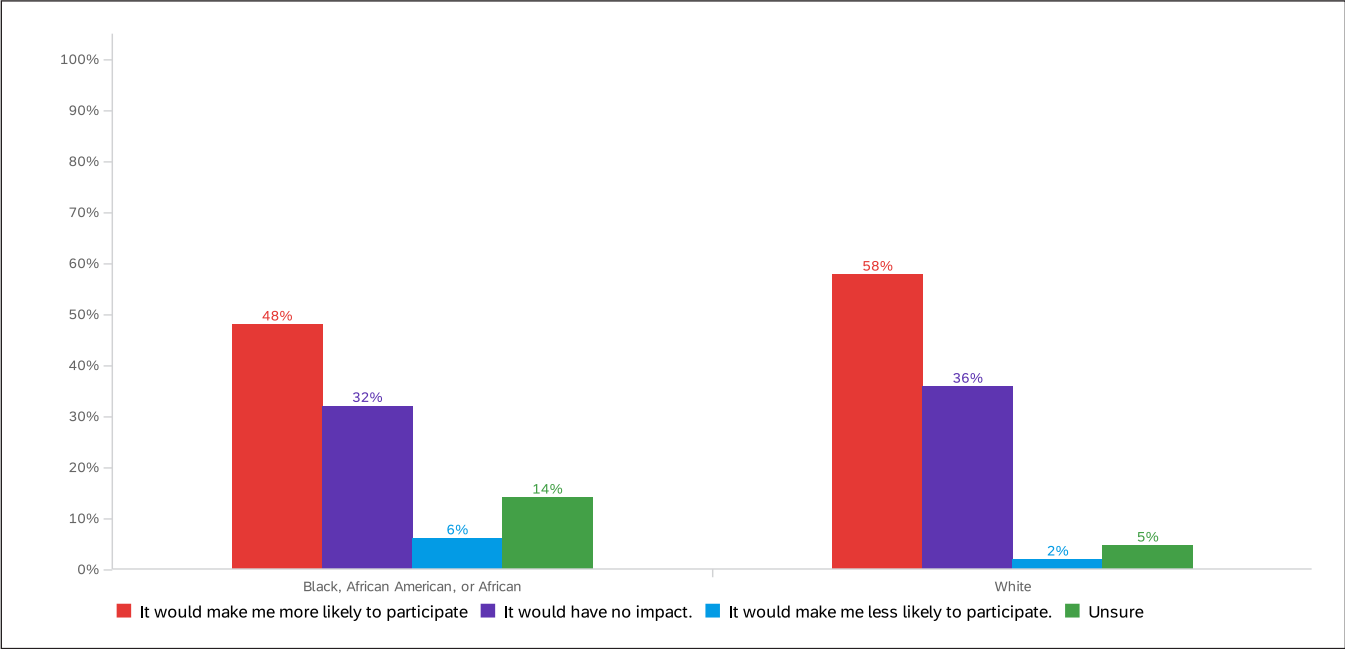
### ***Deciding Whether to Participate in a COVID-19 Vaccine Trial***

COVID-19 vaccine trials must have diverse representation. However, members of marginalized communities are far less likely to participate in clinical research trials. An additional aim of the survey was to understand community members' willingness to participate in COVID-19 vaccine trials. Participants were provided 12 possible factors that might affect their willingness to participate. The three factors that most positively affected the willingness to participate were: "having frequent COVID-19 testing and health monitoring" (68%), "knowing someone who had participated in a COVID-19 vaccine trial" (55%), and "my doctor or healthcare provider recommended that I join a COVID-19 vaccine trial" (55%). The three factors least likely to affect the decision to participate were: "political leaders encouraged participation in COVID-19 clinical trial" (12%), "payment for participation" (39%), and "knowing someone who died from COVID-19" (43%).

The effect of knowing someone who had participated in a COVID-19 vaccine trial differed slightly by race: 48% of African Americans said they would be more likely to participate in a COVID-19 vaccine trial if they knew someone who participated in such a trial, compared to 58% of White respondents.

***Community-based organizations should be funded to foster community engagement on vaccine development and the scientific research process. This includes the development and dissemination of educational materials for communities.***

**Graph 7: The Effect of Knowing Someone who had Participated in a COVID-19 Vaccine Trial by Race**

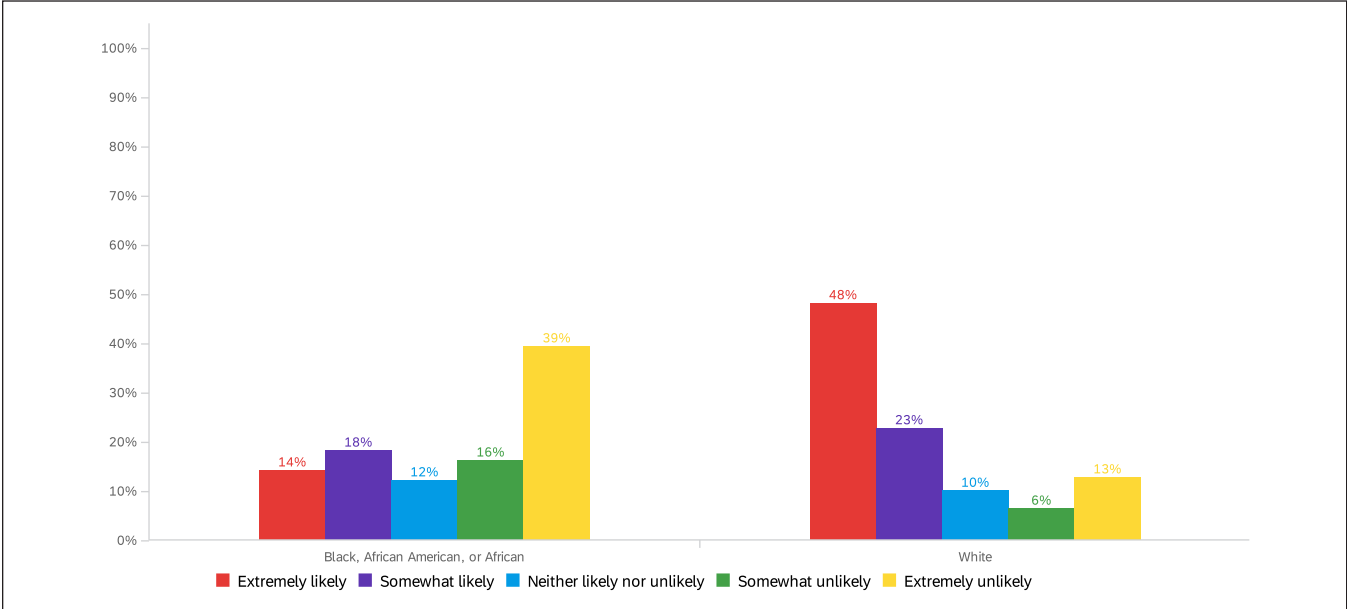


### ***Likelihood of Getting Vaccinated***

Participants were asked about their likelihood of getting vaccinated “if a coronavirus vaccine were available now.” Note that the survey was first distributed before the Emergency Use Authorizations for the Pfizer and Moderna vaccines, and response collection continued for about a month after those EUAs were issued. Thirty-three percent of participants said they would be extremely likely to get vaccinated if a vaccine were available at that time, and 25% of participants said they would wait at least six months, or until many others had been vaccinated, to see how safe and effective the vaccination was. Only 14% of African American respondents said they would be extremely likely to get vaccinated if a vaccine were available, and 39% said they were extremely unlikely to get vaccinated. Of participants identifying as White, 48% said they were extremely likely to get vaccinated, and 13% said they were extremely unlikely to get vaccinated. Thirty-six percent (36%) of African American respondents said they would wait at least six months, or until many others had been vaccinated, to see how safe and effective the vaccination was.

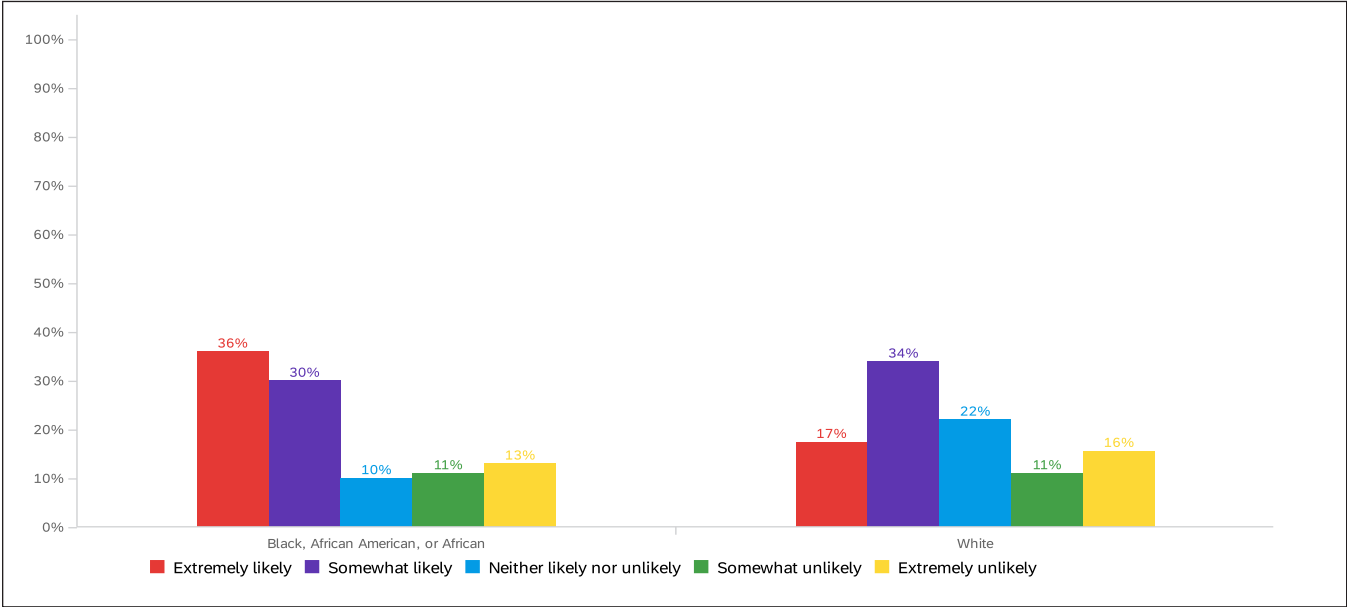
***Thirty-six percent (36%) of African American respondents said they would wait at least six months, or until many others had been vaccinated, to see how safe and effective the vaccination was.***

**Graph 8: Likelihood of Getting Vaccinated by Race**



Note: The survey was first distributed before the Emergency Use Authorizations for the Pfizer and Moderna vaccines, and response collection continued for about a month after those EUAs were issued.

**Graph 9: Likelihood of Waiting Six or More Months, to Get Vaccinated or Until Many Others Had Been Vaccinated, to See How Safe and Effective the Vaccination Is**



## Survey Limitations

The development and promotion of the survey was not without limitations. The survey was disseminated to minority groups that were disproportionately affected by COVID-19. An intentional oversampling of populations known to have higher health disparities would have aided in providing proper representation for more groups; while African American respondents were highly represented, we did not see that same level of response from other racial and ethnic minorities. Respondent demographics were skewed in other ways: The survey lacked representation from gender and sexual minority groups, the majority of respondents reported having an advanced degree, and there was an oversampling of frontline health workers who had direct contact with patients. During the survey period, there were advances in the development of vaccines, as well as a shift in the political climate. This meant that respondents who weighed in at different points over the survey period had different information, possibly affecting their responses.

An additional limitation of the survey was that respondents geographically located in the deep or rural South were underrepresented. The survey included a disproportionate number of responses from people in New York because of TAG's strong network there.

## DISCUSSION

### Community Engagement in the Scientific Process

Community engagement is an integral part of the scientific research process and vaccine development. Successfully engaging the community in these processes increases knowledge, resulting in community trust and buy-in. Survey results showed that many participants had minimal familiarity with the research process and vaccine development, particularly when we looked at the results broken down by race. This highlights the importance of community education broadly across communities, whether there is a global pandemic or not. Communities must be engaged during every phase of any research trial. Additionally, resources must be allocated to the development and maintenance of a community engagement infrastructure that focuses on educating the community on all aspects of clinical research. Racism (in all of its forms and manifestations) is the main driver of marginalized communities' being less likely to participate in clinical research, especially when we consider the legacy of leaving these communities out of research. The responsibility for community engagement must be placed on the medical community. Medical professionals must partner with community stakeholders and community-based organizations to do the work to engage communities; they should not paint a picture suggesting that communities bear the responsibility because they are choosing not to enroll in, engage in, or learn more about clinical research.

***Community members are the most integral component for the research process. Clinical research trials should not be implemented without input and buy-in from the community.***

### Race

A theme throughout this data analysis that has been reflected in other research on community perspectives was the difference in responses between racial groups. African Americans reported having a much lower familiarity with the scientific research process and vaccine development compared to White respondents, even though the majority of respondents reported being frontline health care professionals. In total, 45% of African American respondents were frontline workers, compared to 32% of White respondents. A majority of African Americans reported that they did not feel represented in clinical research and that they had experienced discrimination in a health care setting. Proper representation of diverse populations in clinical research is critical to ensure that

interventions are proven safe and effective in all people who might benefit from them. Having diverse populations represented in clinical research can help with recruitment of populations deemed hard to reach, and it can build trust within communities that historically do not trust clinical research.

## CONCLUSION

There remains an urgent need to develop robust community engagement strategies with a racial equity framework that focuses on addressing medical mistrust. Community engagement should include health care workers, because as shown in this report, the scientific research process and vaccine development are complex subjects for those even with advanced degrees. The data from this report once again confirms that racism is indeed a social determinant of health.

## RECOMMENDATIONS

- Community-based organizations should be funded to foster community engagement on vaccine development and the scientific research process. This includes the development and dissemination of educational materials for communities.
- Public health messages developed with the intent to educate communities on vaccine development, or for recruitment of community members, should feature real people from the community.
- Mandatory anti-racism and cultural humility trainings should be offered to all non-Black employees in the health care workforce.
- Perceived risks for contracting infectious diseases are subjective, therefore an unbiased approach should be taken when discussing risk factors.
- Community members are the most integral component for the research process. Clinical research trials should not be implemented without input and buy-in from the community.
- Power lies in community, and community members must get more credit, support, and recognition for contributions made in keeping themselves and others safe during the pandemic.