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## Racial Differences in Perception and Experiences of Adverse Treatment by Healthcare Providers: A Cross-Sectional Analysis of the *All of Us* Data

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### **Abstract**

Health disparities among racial and ethnic groups in the US remain well documented. Among the non-medical issues, including discrimination, language barriers, and low health literacy, the patient-provider relationship has been identified as a factor driving health disparities. Negative interactions with healthcare providers and the healthcare system produce poor health outcomes, exacerbating health inequalities and reducing the likelihood of patients adhering to recommended treatments and therapies. This study intends to examine racial differences in perceptions and experiences of adverse treatment by healthcare providers. It performs a cross-sectional analysis of select variables from the *All of Us* research program basic and social determinants of health survey data. The study sample included 57,107 participants, 60% were females, and 83% were White. There were significant differences in the perceptions of provider treatment between White and Black participants. The data revealed that in all categories, Black participants perceived their experience as negative or less favorable compared to White respondents. These findings may spur interest in fostering and strengthening the patient-provider relationship and increasing awareness of and eliminating practices that demoralize and devalue the patient, particularly those of differing backgrounds.

**Keywords:** *All of Us* data, health disparities, biases, discrimination, patient-provider relationships, provider communication, racial disparities, quality of care

## Introduction

Evidence has shown inequity in the quality of care received by Black patients compared to their White counterparts. The Institute of Medicine (IOM) led a study commissioned by Congress to assess the differences in the healthcare quality received by non-minorities and US racial and ethnic minorities (IOM, 2022). Findings from the study revealed persistent disparities across a wide range of disease areas and clinical services. For example, in oncology, African Americans with breast cancer were less likely to receive radiation in combination with radical/modified mastectomy. Additionally, for all age groups, twice as many Black as White patients (12.5% vs. 6.6%) received no treatment for prostate cancer (Eastman, 2002). Even when clinical factors such as stage of disease presentation, co-morbidities, age, and disease severity were accounted for, disparities in treatment and services offered were still found. Although minorities have seen substantial improvements in healthcare quality, disparities persist. As noted in the National Healthcare Quality and Disparities Report 2021 key findings, even when the rates of healthcare quality improvement exceed those of White patients, they have not been enough to eliminate disparities (Agency for Healthcare Research and Quality, 2022).

Researchers have described several reasons health inequalities among racial and ethnic minorities occur, such as discrimination, language barriers, minorities subjected to adverse social determinants of health, and lower health literacy (Betancourt & Maina, 2004; Correll, 2020; U.S. Department of Health and Human Services, 2011, 2020). Ha and Longnecker (2010), through a literature review of patient and doctor communication, found that much of patients' dissatisfaction and complaints are due to doctor and patient breakdown in communication. However, many doctors overemphasize their ability to communicate with their patients effectively. Similarly, findings from a new survey conducted by The Commonwealth Fund revealed that minorities were more likely to report having difficulties communicating with their physicians, not being listened to, being disrespected, or being devalued. All rudiments could lead to receiving poor quality healthcare (The Commonwealth Fund, 2022).

Additionally, several landmark studies identified the phenomenon of implicit bias as an explanation for the poor quality of healthcare received among racial and ethnic minority populations. Structural racism rooted in the current US healthcare system model could be the undercurrent of health inequalities (FitzGerald & Hurst, 2017; Hamel, Lopes, Munana, Artiga, & Brodie, 2020; Heckler, 1985; IOM, 2002). Hamel et al. (2020) conducted a study as a joint project with the Kaiser Family Foundation and ESPN titled "Survey on Race and Health." Findings from this study revealed that Black and Hispanic adults are more likely to report difficulty finding doctors with a shared background and who treat them with respect, and Black adults (22%) were more likely to report that their provider did not believe they were telling the truth compared to White adults (17%).

For almost every quality measure, there is a sharp divide between the healthcare experience of Whites and minorities in America. By 2060, minorities will comprise 58% of the population, with the Black population increasing along with the Asian and Hispanic populations (Olden, 2019). As the US becomes more diverse, the number of racial and ethnic minority healthcare professionals is not simultaneously growing. In 2008, the American Medical Association (AMA) reported that Hispanics make up 16% of the US population but accounted for less than 6% of all

physicians (American Medical Association, 2010). Likewise, African Americans accounted for a similar proportion of the population, yet they accounted for less than 6% of physicians (AMA, 2010). Evidence suggests that minority physicians are more likely to provide culturally appropriate needed services, such as primary care for the poor and underserved minority populations (Kington, Tisnado, & Carlisle, 2001). Patients' experiences with the healthcare system and providers have implications for their healthcare-seeking behaviors and treatment outcomes. Therefore, it is imperative to research the minority population's perceptions and experiences when interacting with the healthcare system.

Findings may help to shed light on points of intervention to improve all quality health measures. Prior studies used surveys, focus groups, key informant interviews, and systematic reviews to gain information (FitzGerald & Hurst, 2017; Hamel et al., 2020). However, these studies focused on specific geographic regions and had limited reach. The National Institute of Health (NIH) *All of Us* Research Program's diverse health database provides a unique opportunity to learn about participants' experiences from people of all backgrounds across the US. The information gained from this study may help healthcare professionals, academics, faith-based organizations, and non-profit organizations devise strategies to reduce inequalities in the quality of care in treatment and services for minority populations. It was hypothesized that Black participants in this study, compared to Whites, would likely experience more adverse outcomes in the quality of treatment and services when visiting doctors' offices and other healthcare providers.

## Methods

### **The *All of Us* Research Hub**

The data from the *All of Us* program has been categorized into domains – namely surveys, physical measurements, wearables (PM), genomics, and electronic health records (EHR) – all of which are available to researchers with access to the data on the cloud-based researcher workbench. All four domains (Survey, PM, Genomics, and EHR) are mapped to the Observational Health and Medicines Outcomes Partnership (OMOP) common data model v 5.2 maintained by the Observational Health and Data Sciences Initiative collaborative. The basic demographic survey is mandatory for all participants while optional surveys include: Personal medical history, Family health history, Overall health, Lifestyle, Social determinants of health, Healthcare access and utilization, and COVID-19 participant experience. Each of the surveys has a branching logic and an option to either answer or skip a question. Although the social determinants of health survey include questions on many variables, this study focused on the participants' perception of adverse experiences when they visited the doctor or other healthcare providers. For the protection of the privacy of *All of Us* participants, various data transformation techniques are used including date shifting by a random number of days (< 365 days) across each participant record.

Researchers from institutions with access to either the Registered or Controlled Tier data can register for a workbench and create a workspace for each research project using the *All of Us* data. In the workbench, researchers select the participants of interest (Cohort builder), identify and save the health data for the selected participants (Concept set), and build a complete dataset about the selected participants/cohort of interest (Dataset builder) before exporting the data to the

Jupyter Notebook for analyses using either R or Python programming languages in the cloud environment.

### **Sample Selection and Data Extraction**

For this cross-sectional study, we used version 6 of the *All of Us* Registered Tier dataset with a total of 369,297 participants at the time of analysis for this study. Our cohort of interest for this study included 57,107 participants, 18 years of age and above who answered both the basic demographic and the social determinants of health (SDH) survey questions. The SDH survey questions included the type of neighborhood, type of housing, proximity to stores, how participants are treated at the doctor's office or health facilities, and more. Concepts of interest were selected from the *All of Us* workbench to build a complete dataset. The concepts included date of birth and survey date, from which age was calculated, race, sex at birth, the highest level of education, household income, and SDH concepts. Using a Likert scale, participants responded (Never, Rarely, Sometimes, Most of the time, and Always) to the following SDH questions:

- *"You are treated with less courtesy than other people."*
- *"You are treated with less respect than other people."*
- *"You receive poorer service than others."*
- *"A doctor or nurse acts as if he or she thinks you are not smart."*
- *"A doctor or nurse acts as if he or she is afraid of you."*
- *"A doctor or nurse acts as if he or she is better than you."*
- *"You feel like a doctor or nurse is not listening to what you were saying."*

This study, being a secondary analysis of deidentified data from *All of Us*, is exempt from IRB approval since it's considered non-human subject research.

### **Demographic Variables**

Age was calculated by subtracting the date of birth from the date the survey was taken and recorded as a continuous variable. The race variable was categorized as Black or African American, White, Others (Asians, more than one population, and another single population), and Unknown (I prefer not to answer, None indicated, None of these, and Skip). Sex at birth was recorded as Male and Female with deletion of those that answered either "intersex," "none of these describe me," or "prefer not to answer." The highest education was categorized as high school, some college, and college or advanced degree. For household income, participants were put into three categories: less than \$50,000, \$50,000-100,000, and above \$100,000 annually.

### **Exposure and outcome variables**

The exposure of interest in this study is race (White, Black, Others, and Unknown) with White as the reference group. The outcomes of interest were each of the seven social determinants of health questions regarding how participants perceived their treatment when visiting a doctor's office or health facility. The Likert scale (Never, Rarely, Sometimes, Most of the time, and Always) responses to the outcomes were collapsed into two (Yes and No). All those who answered the outcome questions with "Never," "Rarely," and "Sometimes" were considered as "No" and those who answered, "Most of the time," and "Always" were considered "Yes."

### Statistical Analysis

The descriptive statistics of study participants were summarized using the demographic variables race, sex at birth, age, educational level, and household income. Age, being a continuous variable was expressed as mean (SD), while the rest of the demographic variables were summarized by frequency and percentages. Both crude and multivariable logistic regression, adjusting for some demographic variables were used to assess the association between the exposure (race) and each of the seven SDH outcome variables of interest. The crude and adjusted odds ratios (OR) and their 95% confidence intervals were recorded for each outcome variable with a significance level set at  $p < 0.05$ .

### Results

The following results were realized upon analysis of the *All of Us* Research SDH survey data. The questions of interest focused on the participant's perceptions of the healthcare providers' attitudes toward and treatment of the patients. Experiences of discrimination and bias toward patients can affect their willingness to seek and receive care as well as their health outcomes. The results were stratified by race and adjusted for confounding variables (i.e., highest education level and annual household income). The hypothesis was accepted; Black participants in this study, compared to White participants, perceived and experienced more adverse outcomes in the quality of treatment and services when visiting doctors' offices and other healthcare providers.

### Participant demographics

The study sample included 53,973 individuals of which 60.6% were females and 34% were males. Approximately 83.6% of the respondents self-reported as White and 6% were Black, which includes African Americans, or African lineages such as Ethiopian, Haitian, Jamaican, Nigerian, Somali, and more. The category of others or unknown made up 10.4% of the sample. Those with some college education or higher totaled 48,621, which was more than 90% of the respondents. A third of the respondents (33.1%) earned less than \$50,000, and 35.3% had a household income ranging from \$50,000 to \$100,000. Those with households of \$100,000 or more were 31.6% or 13,665 in total. Table 1 presents the demographic characteristics of the survey respondents.

Table 1  
*Study Participants' Demographic Characteristics*

Variable	N (%)
Age in years (mean, SD)	57.86 (15.52)
Gender	
Female	34650 (60.6)
Male	19323 (33.8)
Self-reported race	
White	44804 (83.6)
Black	3231 (6.0)
Others	2341 (4.4)
Unknown	3236 (6.0)
Education	
High school	5180 (9.6)
Some college	12214 (22.7)
College or advanced degree	36407 (67.7)

Household income	
Less than \$50k	14298 (33.1)
\$50k-100k	15264 (35.3)
More than \$100k	13665 (31.6)

### Outcome variables

The data revealed that in all categories Black respondents perceived their experience to be negative or less favorable when compared to White respondents. When comparing the percentage of Black adults to the percentage of White adults who experienced these negative encounters with their healthcare providers, the difference between the groups was significant, obtaining a p-value of 0.001 for each outcome variable. More than 5% of the Black respondents compared to only 1.6% of the White respondents believed they received poorer service from their healthcare providers than others. Black participants were 2.5 times more likely to believe that they receive poorer service than others when compared to White patients. The results are presented in Tables 2 and 3.

Table 2  
*Outcomes Stratified by Race*

Outcome	Response N (%)	White	Black	Others	Unknown	P-value
Provider not listening to me	Yes	2058 (4.7)	271 (8.8)	134 (5.8)	214 (6.9)	<0.001
	No	42056 (94.3)	2817 (91.2)	2178 (94.2)	2902 (93.1)	
Provider thinks I'm not smart	Yes	1092 (2.5)	147 (4.8)	79 (3.5)	132 (4.3)	<0.001
	No	42598 (97.5)	2909 (95.2)	2206 (96.5)	2930 (95.7)	
Provider afraid of me	Yes	424 (1.0)	64 (2.2)	24 (1.1)	44 (1.5)	<0.001
	No	41907 (99.0)	2904 (97.8)	2207 (98.9)	2914 (98.5)	
Provider thinks better than me	Yes	1128 (2.6)	138 (4.4)	91 (3.9)	128 (4.1)	<0.001
	No	43046 (97.4)	2977 (95.6)	2217 (96.1)	3020 (95.9)	
Receive poorer service	Yes	705 (1.6)	160 (5.2)	51 (2.2)	106 (3.4)	<0.001
	No	43138 (98.4)	2917 (94.8)	2241 (97.8)	2977 (96.6)	
Less courtesy from provider	Yes	819 (1.8)	164 (5.2)	57 (2.5)	110 (3.5)	<0.001
	No	43480 (98.2)	2981 (94.8)	2256 (97.5)	3030 (96.5)	
Less respect from provider	Yes	759 (1.7)	150 (4.8)	58 (2.5)	98 (3.2)	<0.001
	No	43344 (98.3)	2955 (95.2)	2245 (97.5)	2999 (96.8)	

There was a statistically significant difference ( $p < 0.001$ ) between the Black and White respondents when asked if the healthcare provider listened to them during the office visit. When compared to their White counterparts, Black participants were 35% more likely to perceive the provider as not listening to them. More than 5% of the Black respondents acknowledged that their provider treated them with less courtesy than others, and 4.8% reported the healthcare providers as showing them less respect than others. When compared with their White counterparts, Black respondents were two times more likely to perceive themselves as being treated with less courtesy than others. Only 2% of White respondents reported being treated with less respect (than others) by their providers.

Additionally, 4.8% of the Black respondents acknowledged that the provider thought of them as not being as smart as others, compared to 2.5% of the White respondents. Black respondents were 45% more likely to report that their healthcare provider acted as though they were not smart. Only 1% of the 42,000 White respondents felt that the provider was afraid of them along

with 2% of the over 3,000 Black respondents believed this to be the case. They were nearly twice as likely to acknowledge that the providers act afraid of them in comparison to their White counterparts. Four percent (4%) of the Black respondents felt as though their healthcare provider acted as though he or she was better than them; White participants were 68% less likely to perceive the provider as acting as though he or she were better. The bivariate and multivariable odds ratios are presented in Table 3.

Table 3  
*Crude and Adjusted Odds Ratios for Each Outcome by Race*

Outcome	Race	Crude OR (95% CI)	P value	Adjusted* OR (95% CI)	P value
Provider not listening to me	White	1 (Referent)	-	1 (Referent)	-
	Black	1.96 (1.71-2.23)	< 0.001	1.38 (1.19-1.60)	< 0.001
	Others	1.25 (1.05-1.49)	0.0125	1.29 (1.05-1.57)	< 0.001
	Unknown	1.51 (1.29 - 1.73)	< 0.001	1.09 (0.92 - 1.29)	0.32
Provider thinks I'm not smart	White	1 (Referent)	-	1 (Referent)	-
	Black	1.96 (1.65 - 2.34)	< 0.001	1.45 (1.19 - 1.78)	< 0.001
	Others	1.39 (1.09-1.75)	< 0.05	1.48 (1.14 - 1.92)	< 0.001
	Unknown	1.76 (1.45 - 2.10)	< 0.001	1.42 (1.15 - 1.75)	< 0.001
Provider afraid of me	White	1 (Referent)	-	1 (Referent)	-
	Black	2.17 (1.65 - 2.81)	< 0.001	1.93 (1.39 - 2.67)	< 0.001
	Others	1.07 (0.69 - 1.58)	> 0.05	1.30 (0.82 - 2.05)	0.26
	Unknown	1.49 (1.07 - 2.01)	< 0.001	1.44 (0.99 - 2.10)	0.05
Provider think better than me	White	1 (Referent)	-	1 (Referent)	-
	Black	1.76 (1.47 - 2.11)	< 0.001	1.32 (1.09 - 1.61)	0.01
	Others	1.57 (1.25 - 1.94)	< 0.001	1.73 (1.36 - 2.19)	< 0.001
	Unknown	1.62 (1.33 - 1.94)	< 0.001	1.22 (0.99 - 1.51)	0.06
Receive poorer service	White	1 (Referent)	-	1 (Referent)	-
	Black	3.36 (2.80 - 3.99)	< 0.001	2.49 (2.04 - 3.05)	< 0.001
	Others	1.39 (1.03 - 1.83)	< 0.05	1.50 (1.09 - 2.07)	0.01
	Unknown	2.18 (1.76 - 2.67)	< 0.001	1.79 (1.41 - 2.27)	< 0.001
Less courtesy from provider	White	1 (Referent)	-	1 (Referent)	-
	Black	2.90 (2.43 - 3.44)	< 0.001	2.08 (1.69 - 2.54)	< 0.001
	Others	1.34 (1.01 - 1.74)	< 0.05	1.50 (1.10 - 2.03)	0.01
	Unknown	1.92 (1.57 - 2.34)	< 0.001	1.57 (1.25 - 1.99)	< 0.001
Less respect from provider	White	1 (Referent)	-	1 (Referent)	-
	Black	2.90 (2.41 - 3.46)	< 0.001	1.95 (1.58 - 2.41)	< 0.001
	Others	1.47 (1.11 - 1.91)	< 0.001	1.55 (1.14 - 2.11)	0.01
	Unknown	1.87 (1.49 - 2.29)	< 0.001	1.36 (1.06 - 1.74)	0.02

\*Adjusted for highest educational level and annual household income.



## Discussion

While this section of the NIH Study is under the umbrella of the social determinants of health, the questions extrapolated and analyzed for this study dealt strictly with participants' perceptions of how they were treated at the doctor's office or with other healthcare providers. Black participants from this study noted that when they interacted with the doctor's office or other health care providers they were disrespected, devalued, frightened of them, received poor quality care, were treated as if they were not intelligent, and were not listened to.

### **Providers not Listening to Patients**

Doctors must gather information from patients to facilitate accurate diagnosis and to provide healthful instructions while establishing a caring relationship with the patient (Ha & Longnecker, 2010). The goal of this bidirectional exchange is important for the delivery of high-quality healthcare yielding the best health outcome for the patient. A majority of the Black participants in the study believed they were not listened to when interacting with the doctor's office or other healthcare providers. Findings from this study imply that even when access to healthcare is not a barrier, having access does not necessarily equate to a substantial level of understanding by the patient or patient satisfaction. These findings aligned with Hamel, Lopes, Mufiana, Artiga, and Brodie's (2020) study, where Black patients tried to get physicians to order specific tests or treatments that they believed were essential to their well-being but were denied. According to Ha and Longnecker (2010), "doctors with better communication and interpersonal skills to detect problems earlier can prevent medical crises and expensive interventions and provide better support to their patients" (p. 42). These improved skills could lead to higher-quality outcomes and better patient satisfaction; lower costs of care, greater patient understanding of health issues, and better adherence to the treatment process (Ha & Longnecker, 2010). Therefore, findings from this study could help inform points of intervention to improve doctor and patient communications, thereby improving quality measures.

### **Providers showing Disrespect to Patients**

Black participants in this study reported feeling disrespected, treated with less courtesy, and devalued, for example, as if they were not smart. Black participants also reported that the provider acted fearful when interacting with them. Explicit or implicit bias may be the cause of this behavior. Findings from the Institute of Medicine Report "Unequal Treatment Confronting Racial and Ethnic Disparities" implied that bias rather explicit or implicit among healthcare providers might influence the treatment and services given to patients by healthcare providers (IOM, 2022). The researchers described bias as beliefs about certain groups of people that healthcare providers bring into the workspace based on their personal experiences. These beliefs may manifest themselves when the provider is under pressure, must deal with complex problems, or require high cognitive demand. Researchers further noted that these biases might shape physicians' interpretation of this information and their expectations for treatment, such as the likelihood of patients' compliance.

Most healthcare providers find biased behavior at odds with their professional values. Still, like other members of society, they may not recognize the manifestations of prejudice in their behavior (IOM, 2002). To reduce bias in patient encounters with healthcare providers and the healthcare system, organizations must embed Cultural Competency and Implicit Bias Training on a

continuous basis. Additionally, organizations must assess their organizational policies and practices to ensure they are culturally and linguistically appropriate so that quality of care is provided as a default and prepare their organization to provide tailored services to the growing diverse population (IOM, 2002).

### **Providers Rendering Poorer Healthcare Services**

Black participants in this study felt they received poorer healthcare services. The IOM report (2002) highlighted the unequal treatment of care of minorities compared to their White counterparts in various quality measures. Evidence has shown that African Americans of low social economic status may have limited access to quality health care. Uniquely, 90% of the participants in this study had, at a minimum, a college degree or higher but still felt like they received poorer quality of care. This information may be similar to the information disclosed by the IOM report (2002) in that even when factors such as insurance, education, and income were not barriers, minorities still received less quality care. As the demographics in the US continue to shift, causing the populations to grow more diverse, paying attention to those areas where minorities are most at risk, could help improve the quality of care, for example, by eliminating barriers such as languages, insurance, and literacy (The Commonwealth Fund, 2022).

### **Limitations**

While data were provided for the respondents in other racial and ethnic groups, this work only examines the results from the Black and White populations. The *All of Us* Social Determinants of Health survey data included numerous variables, race was the primary variable examined in the current work. The original survey collected data using a five-item Likert scale. These results were condensed into two-level outcomes (Yes and No). This may have some non-differential effect on these measures of association.

### **Strengths**

A strength of the current study is its reliance on a large sample size for the comparison. A large sample is often not available to investigate the patient-provider relationship and communication, particularly in the areas of biases, discrimination, and mistreatment.

### **Implications for practice**

The findings may spur interest in fostering and strengthening the patient-provider relationship and increasing awareness of and eliminating practices that demoralize, demonize, and devalue the patient, particularly those of differing backgrounds. Additionally, these insights may drive providers to seek out training and preparation that enables them to serve diverse communities more effectively. At the organizational level, these findings could inform health interventions and policy and system changes. The changing landscape of the US population warrants future research that examines the healthcare provider encounters experienced by other minority populations included in the *All of Us* data. The research should investigate other non-medical variables such as lack of insurance, acceptance and inclusion, language barriers, and literacy proficiency, as it relates to the quality of treatment and care resulting from the patient-provider encounters experienced by other minority populations.

## Conclusion

Individuals will rely upon their perceptions and past experiences as motivators for engaging in health care services. For Black patients, traditionally marginalized and often neglected by the healthcare system, patient-provider interaction is essential and can contribute to reducing healthcare disparities. When perceptions of and experiences with the health system, its providers, and the care provided are inadequate, it can impede their willingness to adhere to recommended treatments and therapies, maintain visits and check-ups, and share and engage with stakeholders in the system. A bi-directional relationship requires that the healthcare provider and the system remain aware of biases that are injected into the encounters via their comments and practices. In this study, Black participants were more likely to have accounts of negative interactions with doctors and other healthcare providers. The current findings support the need for strategies and programs that ensure patients feel respected, listened to, and appropriately cared for, to prevent these non-medical issues hindrance of the desired positive health outcomes.

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