

Historical, Structural, and Social Drivers of Health Care Inequities

A Supplement to CAPC's Guide, *Advancing Equity for Black Patients with Serious Illness*

History Shapes the Present

If you're not sure how discussions about the painful history of racism against Black Americans is helpful to current-day health care delivery, we hope this monograph and CAPC's guide, [Advancing Equity for Black Patients with Serious Illness](#), will help to make the case. It's true that many forms of institutionalized racism in U.S. health care, such as racially segregated hospitals, are no longer legal. And yet, racial disparities in health and health care experiences persist for Black Americans, including those living with serious illness.

What can we take from this fact? That we still have work to do to achieve equitable care—it's not going to happen on its own.

How We Got Here: Black American History and Health Inequities

The timeline below includes a brief sample of historical events and policies that enshrined and enforced racism in the U.S., leading to current-day health inequities for Black patients. Many organizations and experts have long preserved, taught, and drawn insights from this history. The CAPC team is grateful for their work and has synthesized an educational overview for health professionals caring for Black patients with serious illness. This timeline is not comprehensive, and we recommend that readers explore the additional learning resources linked at the end of this monograph.

Timeline of Historical Events and Medical Malpractice

1619

Transatlantic Slave Trade



The transatlantic slave trade forcibly transported millions of Black people to the Americas, subjecting them to brutal conditions and dehumanizing labor. This system of exploitation laid the foundation for systemic racism and health inequities that continue to affect Black communities today. To learn more about the history and legacy of slavery in America, read [The 1619 Project](#) from *The New York Times Magazine*.

The White Lion was an English privateer operating under a Dutch letter of marque, which brought the first Africans to the English colony of Virginia.

1863-1865

Emancipation Proclamation and Juneteenth



The [Emancipation Proclamation](#) and the [Thirteenth Amendment](#) abolished slavery, and Juneteenth commemorates the date, June 19, 1865, on which news of the abolition of slavery at long last reached the Black people of Texas.

Scene in the House of Representatives on the passage of the proposition to amend the Constitution, January 31, 1865.

1896

Plessy v. Ferguson Supreme Court Decision



The [Plessy v. Ferguson](#) decision legalized racial segregation under the “separate but equal” doctrine, creating the conditions for decades of inferior and underfunded health care facilities for Black patients.

1932-1972

U.S. Public Health Service (USPHS) Untreated Syphilis Study at Tuskegee



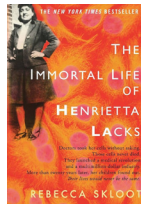
The [USPHS Untreated Syphilis Study at Tuskegee](#) saw Black men with syphilis deliberately denied treatment so that scientists could observe disease progression, reflecting blatant medical malpractice and disregard for Black lives. This atrocity eroded trust in the health care system among Black communities, a sentiment that persists today.

Tuskegee syphilis study, doctor injecting subject, 1932.



1951

Henrietta Lacks and HeLa Cells



Cells taken from Henrietta Lacks without her consent led to significant scientific advancements while her family remained unaware for decades. Learn more by reading *The Immortal Life of Henrietta Lacks*, by Rebecca Skloot.

1960s

Forced Sterilization

Black women were subjected to [coerced or forced sterilization](#) as part of eugenics programs.

1980s-Present

The HIV/AIDS Epidemic

HIV/AIDS disproportionately affected Black communities at the height of the epidemic. In 1993, [rates of AIDS cases](#) among Black Americans were 162 per every 100,000 adults—the highest of any racial or ethnic group reported by the CDC. By comparison, the rate in 1993 for white Americans was 30 per 100,000 adults. The trend continues to this [day](#), despite [advocacy efforts](#) for targeted health care interventions to decrease HIV/AIDS rates among Black Americans.

2020

The COVID-19 Pandemic



Black Americans experienced [higher rates](#) of COVID-19 infections, hospitalizations, and deaths than white Americans.

We often hear that “Black patients don’t trust the health care system,” with a common example being the [hesitancy of some Black Americans to take the COVID-19 vaccine](#) when it was first made available. And while—as with any group—there is a diversity of opinions and relationships to the health system among Black patients, the history outlined above provides insight on the earned mistrust among some Black Americans.

Present-Day Health Disparities Among Black Americans

Today, racial disparities persist across the health care landscape. As recently as 2021 the CDC declared [racism to be a serious public health threat](#). Health disparities found among Black Americans today include:

- **Chronic Diseases:** Black Americans have [higher rates of chronic conditions](#) such as hypertension, diabetes, and stroke
- **Mental Health:** According to an [APA fact sheet](#), Black people are less likely to be offered either evidence-based medication therapy or psychotherapy, compared to other racial communities.
- **Maternal and Infant Mortality:** Per the [CDC](#), Black women in the U.S. have a 2.6x higher maternal mortality rate than white women.
- **Cancer:** For many types of cancer, Black Americans have the [highest mortality rates](#) of all racial groups. For certain cancer diagnoses, Black people are [diagnosed at later stages of the disease](#), thus reducing treatment effectiveness.
- **HIV/AIDS:** As of 2022, Black Americans made up [37% of new HIV infections](#) in the U.S. despite being only 12% of the U.S. population.
- **Nutrition and Food Insecurity:** Per [CDC data collected in 2021](#), 12.2% of Black adults lived in households that had experienced food insecurity in the prior 30 days, compared with only 4.1% of white adults.

In 2021, CAPC's [Project Equity](#) workgroup conducted a [comprehensive literature review](#) to understand what is known about disparities in health care experiences and quality of life specifically for **Black people living with serious illness, and their families**. Key findings from this literature review include:

<p>↓</p> <p>Black patients living with serious illness receive poorer quality pain management from their health care providers, including less pain assessment and less pain treatment.</p>	<p>↓</p> <p>Black patients with serious illness report poor-quality clinician-patient relationships and communication.</p>
<p>↓</p> <p>Compared to other racial groups, Black patients living with serious illness tend to use more high-acuity care and have more care transitions at the end of life.</p>	<p>↓</p> <p>Black patients frequently incur higher medical costs during the course of serious illness and provide more unpaid family caregiving than other families.</p>
<p>↓</p> <p>Compared to white patients living with serious illness, Black patients are less likely to have advance care planning (ACP) discussions or documents.</p>	<p>↓</p> <p>Mistrust of the U.S. health care system may influence the decision-making of Black patients with serious illness and their loved ones.</p>

See CAPC's [comprehensive literature review](#) with citations.



Frameworks for Understanding Race-Based Health Disparities

The Social Determinants of Health

The American Medical Association defines social determinants of health as “The underlying community-wide social, economic, and physical conditions in which people are born, grow, live, work, and age. They affect a wide range of health, functioning, and quality-of-life outcomes and risks. These determinants and their unequal distribution according to social position, result in differences in health status between population groups that are avoidable and unfair.”

As we consider a history in which generations of Black Americans had limited access to housing, education, employment, and other factors critical to well-being, we develop a deeper understanding of how institutionalized racism has led to poor health outcomes today.

How do social factors impact health outcomes?

- **Housing:** For decades, [researchers have illustrated that the quality and stability of housing impact a person's health](#). For example, unstable housing is associated with increased drug use among youth, and poor housing conditions like leaky ceilings and poor ventilation are associated with poor health outcomes. People experiencing homelessness are more likely to experience trauma and associated mental health challenges. Lack of affordable housing may mean that people have to choose between paying for rent or for medications.
- **Education:** Education level influences health literacy, access to information, and job opportunities. [Higher education is associated with better health behaviors, increased income, and improved access to health care](#).
- **Employment:** [Unemployment](#) is associated with adverse health outcomes and reduced access to health care due to lack of insurance or lack of affordable care. Per 2024 U.S. Bureau of Labor Statistics data, non-Hispanic Black Americans are [more likely to be unemployed](#) than are white, Asian, or Hispanic Americans.
- **Income:** Income level determines access to basic needs such as nutritious food, health care, and safe housing. Higher income level is linked to [increased life expectancy](#).
- **Location:** Living in neighborhoods with resources like parks, grocery stores, and health care facilities can promote physical activity and well-being. Disadvantaged neighborhoods may lack these resources and have increased [environmental risk factors](#)—such as poor air quality—that impact health outcomes.
- **Criminal Justice:** Involvement with the criminal justice system can lead to [long-term health consequences](#), including chronic illness, mental health issues, substance abuse, and reduced access to employment and housing opportunities.

The Takeaway? To understand all of the factors that affect a patient's well-being, clinicians need to understand their social determinants of health. Learn more about social determinants of health by visiting the [CDC's website](#).



Racism, Discrimination, and Health

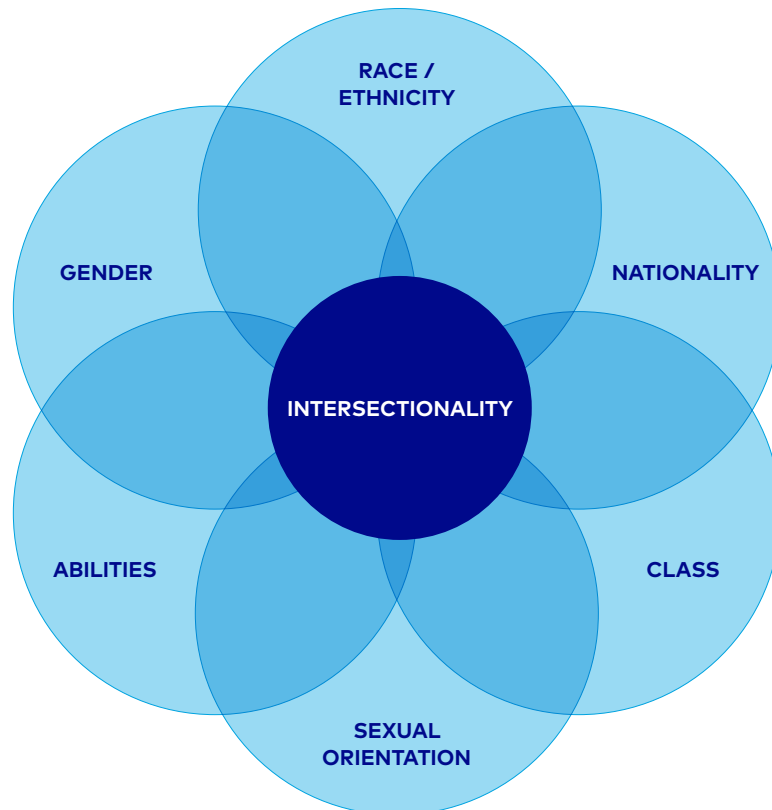
In conversations about health disparities among Black people in the U.S., the focus often centers on drivers of health and well-being such as housing, income, and education barriers. However, personal experiences of racism and discrimination are themselves a health risk.

A [number of studies](#) from the past twenty years have found an association between self-reported experiences of racial discrimination and negative health outcomes, including increased risk of [cardiovascular disease](#), [adult-onset asthma](#), and [anxiety and depression](#), among others.

Intersectionality

[Intersectionality](#) is a concept that highlights how the various aspects of a person's identity (such as race, gender, class, sexual orientation, religion, and others) intersect to create unique experiences inside of the systems we interact with. In other words, all of these identity characteristics influence our experiences, and may advantage or disadvantage us depending on the context we are in.

Health outcomes are in part shaped by this complex interplay of various identities and social factors. A patient with multiple identities that are disadvantaged in society and in health care—such as a Black woman—may be at [higher risk](#) for perceived discrimination, biased care, or worse health outcomes.



The Takeaway? Clinicians should take an intersectional approach, recognizing how their patients' experiences—and the efficacy of a care plan—may be impacted by their collective identities.

Translating Concepts into Action

The drivers of health care inequities are complex, and connected to a history of racial injustice, oppression, and discrimination. Yet despite challenges, health equity champions across the country are taking steps within their organizations and communities to deliver more equitable care to Black patients with serious illness.

CAPC's guide, *Advancing Equity for Black Patients with Serious Illness*, supports the design of health equity interventions. The guide builds upon the foundations in this monograph to help equity champions identify areas for improvement, design an equity initiative informed by patient voices, and secure resources to implement their initiatives. The guide features case examples of health equity work in all care settings and advice from seasoned health equity experts.

Join CAPC's [Virtual Office Hours](#) and [CAPC Circles \(discussion board for CAPC members\)](#) to discuss the concepts in this monograph, your experiences as a health equity champion, or your work to improve equitable care in your organization.

Additional Resources

The following resources provide additional information about the topics referenced in this guide:

- [How History Has Shaped Racial and Ethnic Health Disparities: A Timeline of Policies and Events](#), an interactive education resource from the Kaiser Family Foundation
- *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, a National Book Critics Circle Award-winning book by Harriet A. Washington
- *Just Medicine: A Cure for Racial Inequality in American Health Care*, a book by Dayna Bowen Matthew
- [A 'Forgotten History' Of How The U.S. Government Segregated America](#), a written summary of an episode of NPR's Fresh Air radio show
- [The U.S. Public Health Service Untreated Syphilis Study at Tuskegee](#), an online exhibit from the Centers for Disease Control and Prevention (CDC)

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