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HEALTH INFORMATION AND DATA SHARING

Fact Sheet

How Data and Data Modernization Are Essential to Reducing Health Disparities Rooted in Racism

Introduction

Public health data modernization plays a unique and crucial role in identifying and addressing health disparities that are a result of the nation's legacy of racism. The COVID pandemic brought to the surface significant health disparities—in particular how Black, Hispanic, American Indian and Alaska Native (AIAN) and other communities of color were impacted by COVID infections and deaths on a scale far different than those for White people, most notably at the onset of COVID-19. Metropolitan areas provide a vivid illustration of how these health disparities are a lasting, direct consequence of racism in, for example, government housing policies favoring White communities over others. The disproportionate impact of COVID on racial and ethnic communities spanned the entire country. COVID also highlighted how efforts to identify and reduce these disparities were significantly hindered by shortcomings in the U.S. public health data infrastructure. This fact sheet highlights health disparities rooted in racism and explores how public health data modernization is crucial to reducing them.

Public Health Data is the Key to Understanding Health and Health Disparities that Are Deeply Rooted in Racism

Data is unquestionably vital to identifying and understanding health disparities. For example, life expectancy in the U.S. dropped by 2.7 years between 2019 and 2021. Digging deeper into the data, however, shows a considerably worse picture for racial and ethnic minorities, with life expectancy for AIAN people showing a dramatic decrease of 6.6 years, followed by Hispanic people losing 4.2 years and Black people losing 4 years. Similarly, hundreds of women die of pregnancy related causes in the U.S. every year and thousands experience poor outcomes during pregnancy. Further analyzing the data shows that Black women face a risk of pregnancy-related deaths three times that of White women. And, while the Affordable Care Act's (ACA's) coverage expansion reduced coverage disparities to a degree, a deeper look at the data shows "state uninsured rates are

generally higher and more variable for Black, Hispanic, and AIAN adults compared to [Asian American, Native Hawaiian and Pacific Islander populations] and [W]hite adults."

Public health data shows us, beyond doubt, that these health inequities are the product of racist norms and practices, grounded, in large part, in past government policy. Author Richard Rothstein, in his book the Color of Law, posits "[t]oday's residential segregation in North, South, Midwest and West is not the unintended consequence of individual choices and of otherwise well-meaning law or regulation but of unhidden public policy that explicitly segregated every metropolitan area in the United States." These same segregated areas experience major health disparities.

The City of Chicago, the country's third largest city, is one such example. With an unquestionable history of segregation, the city is a case study of how former racist policies laid the foundation for the deepening racial and ethnic health disparities of today. Chicago PBS station, WTTW, has found "[t]he system that first forced Black Chicagoans to live separately from White Chicagoans and then later expanded to exclude Latino Chicagoans remains deeply entrenched, in part because it is a home-grown structure crafted by some of the city's earliest power brokers who wanted to shape Chicago into a haven for White people through the force of violence supplemented by the weight of the law." WTTW concludes Chicago's segregation, perversely achieved through restrictive covenants and deeds, redlining and other government policy, was exported across the northern United States. It further points to a "dissimilarity index"—a measure of how unevenly demographic groups are distributed in a given area—and notes Chicago actually ranks *fifth*, behind Newark, Milwaukee, New York City, and Detroit. Miami, Philadelphia, Cleveland, St. Louis, and Nassau-Suffolk, New York round out the list of America's ten most segregated metropolitan areas, according to a study from Brown University.

Today, racial and ethnic health disparities in Chicago are stark and, sadly, correlate squarely with the city's racial and ethnic community lines. To put it succinctly, average life expectancy in Chicago's predominantly Black neighborhoods is now as much as a decade lower than Chicago's predominantly White neighborhoods. Chicago is not alone in this regard. Life expectancy in predominantly Black west Louisville, Kentucky is 67 years compared to 82 years in the nearby 70%-White eastern half of Jefferson County. And, New York City, in March, 2022, reported that COVID hospitalizations during the Omicron wave "were disproportionately higher in neighborhoods with a high percentage of Black residents." The report also found anti-Black structural racism drives health inequities "through a cascade of factors."

Health disparities across groups characterized by race and ethnicity are, of course, not unique to urban centers. COVID data shone a bright light on health inequities in all parts of the country, leading to stories like this one from the New York Times in July 2020, concluding "Black and Latino people have been disproportionately affected by the coronavirus in a widespread manner that spans the country, throughout hundreds of counties in urban, suburban and rural areas, and across all age groups." And, later, this one also from the New York Times in July of 2022: "across the small towns and farmlands, new research has found, C[OVID] killed Black and Hispanic people at considerably higher rates than it did their [W]hite neighbors. […] Black and Hispanic people in rural areas suffered an exceptionally high toll, dying at far higher rates than in cities during that second year of the pandemic."

Health disparities are, of course, not limited to communicable diseases, such as COVID. Rates of chronic diseases, such as diabetes, also expose racial disparities, with Black, Hispanic and Native American populations experiencing higher rates of the disease.

Racist law and policy created shocking disparities that have compounded over time resulting in much poorer health outcomes for people of color. Public health data makes the case for just how clear and deep these disparities are and how urgently they must be addressed.

Siloed Data Systems, Outdated Skillsets, a Patchwork of Data Policies and Other Barriers Resulted in an Incomplete Picture of Public Health and Health Disparities

The pandemic highlighted major gaps in data reporting, delays in data, incomplete data and other shortcomings. During the initial response to COVID, jurisdictions struggled to collect accurate data relating to race and ethnicity. In April 2020, only 25 states even reported confirmed COVID cases by race and only 15 reported cases by ethnicity. At the same time, only 21 states reported COVID deaths by race and 11 reported these deaths by ethnicity. Cities like Chicago, states like Colorado and Massachusetts, and the federal government, scrambled to mandate reporting and/or collection of race and ethnicity data during the initial response to the pandemic through the use of public health authority.

When COVID vaccination began, race and ethnicity data was still only available for 51% of those vaccinated. That number rose to 75% by July 2022. But even at that time, Kaiser Family Foundation found "significant gaps in data remain to help understand who is and is not getting vaccinated. [In July 2022] CDC is not publicly reporting state-level data on the racial/ethnic composition of people vaccinated or receiving booster doses. Moreover, CDC is not reporting racial and ethnic data for vaccinations among children."

These shortcomings in data provided signs of an outdated national public health data infrastructure, that made it difficult to paint a full picture of who is hardest hit by public health threats and where limited resources should be deployed. Researchers highlighted lagging data standardization, a lack of uniformity in how data was collected, an absence of interoperability across data systems, outdated methods to collect and transmit data, and unmet needs of the state and local health department informatics workforce, among other structural weaknesses in public health data collection and use. A report by the Counsel for State and Territorial Epidemiologists (CSTE) identified several factors significantly limiting the collection of more complete race and ethnicity COVID data in case surveillance, laboratory report, vaccine administration, and syndromic surveillance data, including:

- information system limitations
- insufficient guidance, requirements, or standards for collection and coding, and
- limited resources or staffing at public health agencies.

In an April 2022 Report to Congressional Committees, the U.S. Governmental Accountability Office (GAO) found "CDC faces several challenges to collecting accurate and timely data..., such as outdated methods to collect and transmit data and lack of interoperability among key surveillance systems. CDC officials also noted that, among these challenges, the agency generally lacks authority to require reporting of public health data."

The identified system-level barriers to collection and use of public health data, including race and ethnicity data, at all levels of government, are thus numerous, complex and difficult to solve. Simply put, to adequately manage contemporary public health threats and reduce health disparities, significant modernization of public health data systems is imperative.

Data Modernization Aims to Bring Public Health Data into the Two-Thousand Twenties and Holds the Key to Measuring and Reducing Health Disparities

The CDC's data modernization initiative was a response to this lagging public health data infrastructure. The GAO's April 2022 Report to Congressional Committees further found "[t]he pandemic highlighted limitations in both the data that CDC collects and in the public health surveillance systems CDC uses to collect and share these data. […] CDC's Data Modernization Initiative… aims to improve data collection and sharing, strengthen data reporting and analytics, and advance surveillance of future public health threats, among other goals."

The direct line between data modernization and health equity is clearly marked. CDC has highlighted DMI-related efforts to, for example, automate race, ethnicity and other demographic data collection. It has also launched multiple initiatives focused on data's role in promoting health and racial equity, including a dedicated webpage for health equity data. It has further explained "DMI is bridging the gap between the data we have now and the data we need to fully understand and address the drivers of health disparities. We are taking action toward more equitable public health by making data more complete, higher quality, more accessible, and more representative of all people."

Shedding more light on the link between data modernization and health equity, the Association of State and Territorial Health Officials (ASTHO) has explained "as the COVID-19 response demonstrated, national data collection was not representative and highlighted gaps—especially in race and ethnicity data. […] Data modernization can improve the public health response to emerging health threats in the United States by allowing more comprehensive and accurate data collection across diverse populations."

Conclusion

Racial and ethnic health disparities, rooted in racism, span the country. And, while COVID shone a light on stark health disparities, such inequities are not limited to communicable disease. Data modernization initiatives, aimed, for example, at creating interoperable data systems, developing our public-health-data workforce, and standardizing data formats, hold the key, not just to better data infrastructure, but identifying and reducing health disparities. You can find a brief outline of the nuts and bolts of the data modernization initiative in this CDC article.

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