The Case for Data Visibility

Marcella Nunez-Smith

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Bias is ingrained within the fabric of American society, and as we strive toward healthy communities, we must strive toward equity. To do so, it is essential that we consider not only the most obvious forms of bias, but also the embedded, often unconscious, prejudices that permeate every workplace, institution, and policy. Within the fight for health equity, efforts to counter implicit bias must be ever present. The history of medicine is rife with discrimination, oppression, and exploitation of marginalized populations. This is evident through well-known instances of racism in medicine such as the U.S. Public Health Service Study of Untreated Syphilis in the Negro Male or Henrietta Lacks, but even more so, this remains clear throughout the lived experiences of patients of color who face daily disproportionate discrimination in medical encounters.[1] This history, along with the systemic structures that it intersects, generates contemporary health disparities. To achieve health justice, we must address systemic and embedded biases.

To move the needle on health equity, we cannot only analyze the presence of bias in existing policies; we must also proactively counter ongoing impacts of bias and discrimination. For this reason, the Biden-Harris administration prioritized health equity in the fight against COVID-19. The COVID-19 pandemic underscored and exacerbated deep health disparities in this country. To address this and to ensure equitable access to COVID-19 therapeutics and vaccines, President Biden signed an Executive Order establishing the COVID-19 Health Equity Task Force on his first full day in office.[2] As Chair of the Presidential Task Force and Senior Advisor to the White House COVID-19 Response Team, I worked in partnership with community, academic, government, and industry leaders to advance access and equity in the national response to COVID-19.

Data is imperative to driving public health responses, yet implicit bias pervades our public health and medicine data ecosystems. This includes invisibility and erasure in data, which hide the depth of health inequities in this country and enable the ongoing structural violence perpetuated by health disparities. To achieve health equity, accurate and comprehensive data collection on wide-ranging demographics and social determinants of health – including race and ethnicity – is fundamental.

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https://doi.org/10.1162/daed_a_02046

Thus, in combatting COVID-19 health disparities, we were dedicated to collecting data for the hardest hit communities and identifying data sources that would support the execution of equitable access to personal protective equipment, testing, vaccines, and therapies. To accomplish this, the Biden-Harris administration took a multipronged approach, which included assessing the nationwide collection of demographic and socioeconomic variables; expecting that all government entities collect, analyze, and share information on demographic and socioeconomic variables; leveraging the Centers for Disease Control and Prevention's Social Vulnerability Index (SVI) to guide vaccination venue location; and identifying data shortfalls and challenges to better prepare and respond to future pandemics.

By centering partnerships and data equity to address implicit and explicit bias in the COVID-19 response, we were able to change the course of COVID-19 health disparities. For example, in May 2021, at the beginning of the COVID-19 vaccine rollout, only 53 percent of eligible Black Americans had received the first dose of the vaccine compared to 63 percent of white Americans. Through leveraging the SVI, addressing social determinants of health, and centering trustworthy community messengers, the administration intervened and made vaccinations more accessible to communities disproportionately impacted by the pandemic. Coordinated and collective partnerships resulted in historic vaccination parity by January 2022, eliminating racial/ethnic gaps in adult COVID-19 vaccination rates.

To have far-reaching impact, we must confront implicit bias at every level and across every sector. Changemaking also demands an unequivocal focus on marginalized populations. Thus, as we address existing frameworks and develop new ones, we must place historically marginalized and minoritized communities at the forefront and align incentives toward health equity. Only with this intentional consideration can we advance health justice.

ABOUT THE AUTHOR

Marcella Nunez-Smith (MD, MHS) is the Associate Dean for Health Equity Research, C.N.H Long Professor of Internal Medicine, Public Health, and Management, and Director of the Equity Research and Innovation Center at the Yale School of Medicine. An elected member of the National Academy of Medicine, she was the Chair of the Presidential COVID-19 Health Equity Task Force and Senior Advisor to the White House COVID-19 Response Team, Cochair of the Biden-Harris Transition COVID-19 Advisory Board, and Chair of Governor Ned Lamont's Reopen Connecticut Advisory Group Community Committee.

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ENDNOTES

[1] For information on the U.S. Public Health Service Study of Untreated Syphilis in the Negro Male, see "About the USPHS Syphilis Study," Tuskegee University, https://www.tuskegee.edu/about-us/centers-of-excellence/bioethics-center/about-the-usphs-syphilis-study (accessed December 22, 2023). For information on Henrietta Lacks, see Denise Grady, "A Lasting Gift to Medicine that Wasn't Really a Gift," *The New York Times*, February 1, 2010, https://www.nytimes.com/2010/02/02/health/02seco.html.

[2] Exec. Order No. 13,995, 86 Fed. Reg. 7193 (Jan. 21, 2021).

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