



The state of the science on metrics and data sources

Fernando De Maio, PhD
Vice President, Health Equity Research and Data Use
American Medical Association

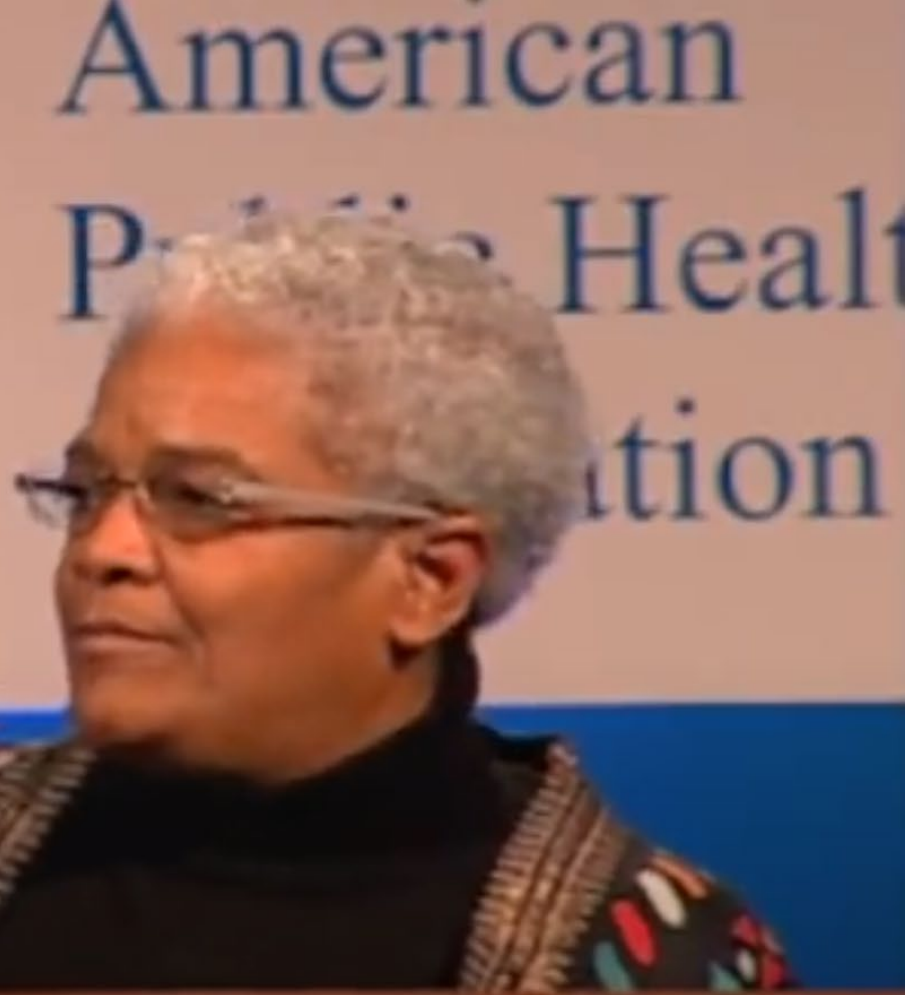
Professor, Dept. of Sociology
DePaul University

NASEM
06/21/2023

"We are not where we need to be. And it is critical that we understand why... our response ...has often been to retreat into ever more technical approaches; to believe that somehow data can protect us and that evidence-based interventions will improve the health of our nation.

...So we lie to our young. We train them in technical skills when we know policy is not determined by p values or by data, but by power and politics."

(Linda Rae Murray, APHA Presidential Address 2011)



0:39 / 13:13



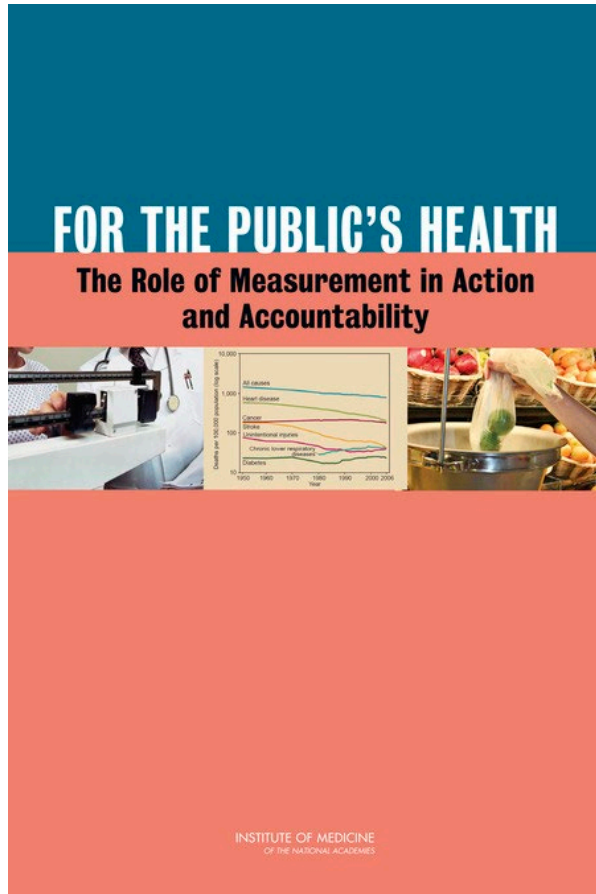
Data for Black Lives

Data as protest. Data as accountability. Data as collective action.

Sign up for our mailing list below or [Donate Now](#)

1 → First Name

Type your answer here...



“Galvanizing” Action with Data

“Concerted efforts that familiarize Americans with the meaning of the measures, such as portraying them in terms of the “GDP of health,” will be a key step in building the understanding that can galvanize action in and on behalf of populations and communities where health disparities are prominent.” (p. 84)

'Radical' Statistics


- Describes and challenges inequities (inequalities that are avoidable, unnecessary, and unfair)
- Concerned with power, social structure **and p values and data**
- Historical and political
- Objective but not detached

Two Core Assumptions

We can measure the social world (with some degree of precision).

Measurement of inequities can spur social change (with the right approach).

[←](#) [→](#) [↻](#) <https://healthequitytracker.org> [🔍](#) [☆](#) [📄](#) [⚙️](#)

 **Health Equity Tracker**

[What is Health Equity?](#) [Explore the Data](#) [Downloads & Methodology](#) [About](#)


Advancing Health Equity

We know that the data we collect can be flawed and at times even worsen health inequities many people face if not reported or analyzed correctly.

We work to change that narrative by identifying, understanding, and responding to health inequities in our communities in a way that will allow every person to live well and long from generation to generation.

Join us in powering transformational action!

[Explore the Health Equity Tracker](#)



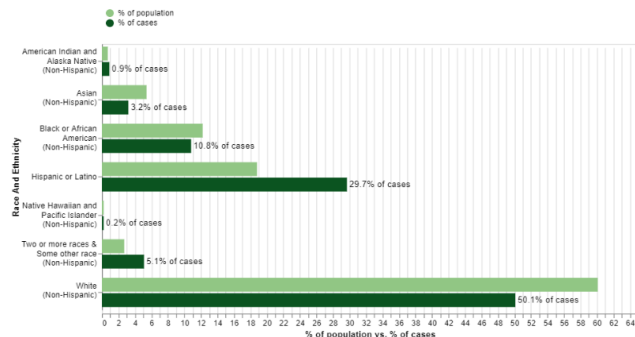
Investigate rates of COVID-19 ▾ in United States ▾

Major gaps in the data

Structural racism and oppression create health inequities, and lead to missing data. The maps and tables below reflect the best data we have, but there are major known gaps in the data. We're working to close these gaps which, in turn, will help us create more effective health policies in the United States. [Read more about missing and misidentified people.](#)

Share Of Total COVID-19 Cases vs. Population By Race And Ethnicity In United States

⚠ 38.3% of cases reported unknown race and ethnicity. The chart below only displays data for cases where race and ethnicity was known.

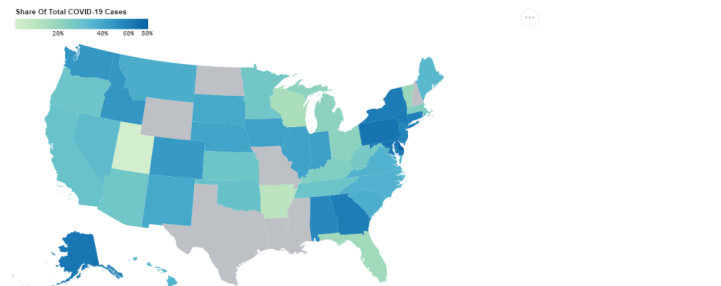


Sources: [CDC Case Surveillance Restricted Access Detailed Data](#) (updated May 2021) [American Community Survey 5-year estimates](#) (updated 2019)

Share Of Total COVID-19 Cases With Unknown Race And Ethnicity

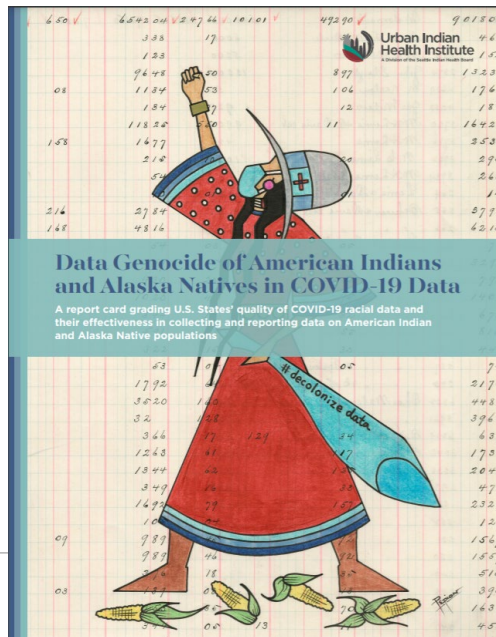
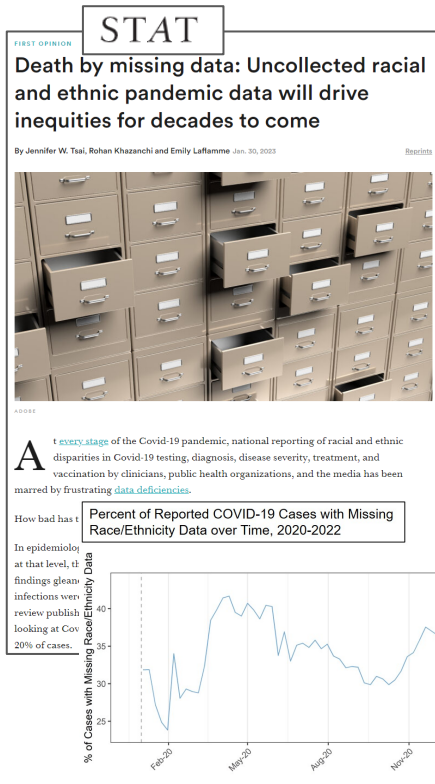
United States

⚠ 38.3% of cases reported unknown race and ethnicity. The map below displays data for cases where race and ethnicity was unknown.



Sources: [CDC Case Surveillance Restricted Access Detailed Data](#) (updated May 2021) [American Community Survey 5-year estimates](#) (updated 2019)

Lesson from COVID: Missing Race and Ethnicity Data are not an Accident



The Pandemic's Missing Data

We desperately need to release the statistics on race and ethnicity.

Opinion

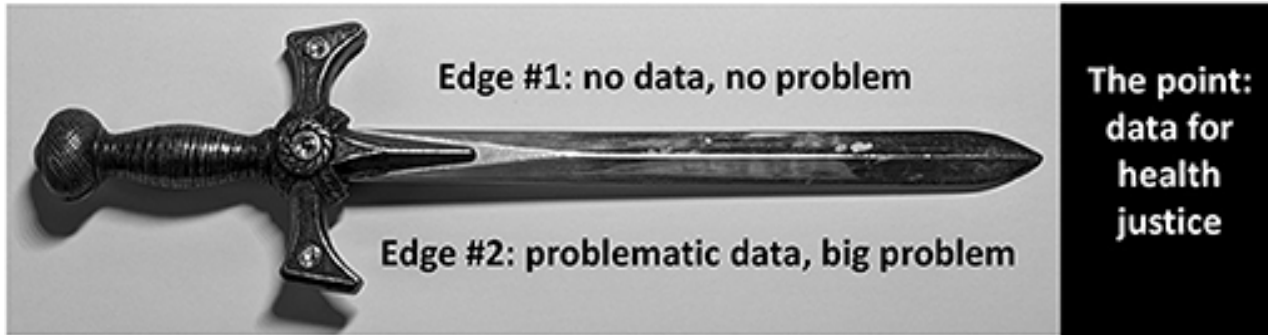
By Aletha Maybank
 Dr. Maybank is the chief health equity officer at the American Medical Association.
 April 7, 2020

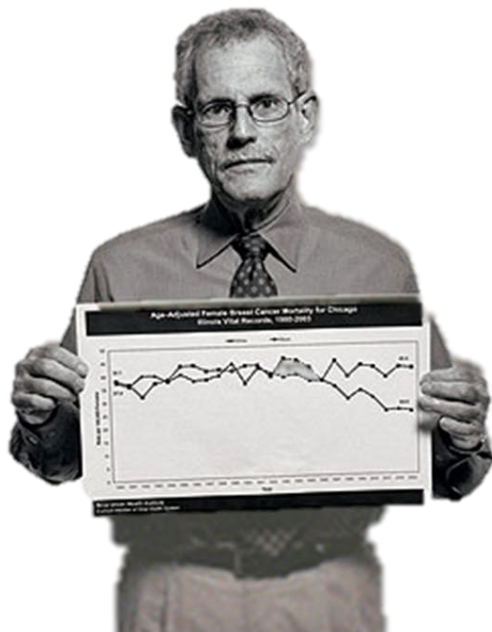
On Tuesday, [Dr. Anthony S. Fauci](#), the nation's leading expert on infectious diseases, acknowledged at a news conference that he expects black people will continue to die of the coronavirus at disproportionate rates.

Fewer than a dozen states have published data on the race and ethnic patterns of the pandemic, but the picture is becoming clear. In [Milwaukee County](#), blacks represent only one-quarter of the population, but 45 percent of the coronavirus cases and 70 percent of deaths. In Michigan, where 14 percent of the population is black, they make up a disproportionate percentage of cases (33 percent) and deaths (41 percent). And in Chicago, blacks make up [half of all cases and 70 percent of the deaths](#) even though the city is only one-

Data as a two-edged sword

- One edge of the sword is **"no data, no problem"** -- where data suppression is done by those who want to keep problems invisible and to shirk accountability.
- The other side is **"bad data, big problem"** -- where data "gets used badly," often to entrench injustice.





You know, it's one thing to talk about data.
But, I think, maybe it's possible to get lost in the data...
Remember that this is... literally a matter of life and death.

- Steve Whitman, PhD

Founding director of the Sinai Urban Health Institute

Speakers

Amy Branum, associate director for science at the National Center for Health Statistics, Centers for Disease Control and Prevention

Carolyn Liebler, associate professor of sociology at the University of Minnesota College of Liberal Arts and the Minnesota Population Center

Sam Harper, associate professor in the department of epidemiology, biostatistics, and occupational health at McGill University (virtual)



Physicians' powerful ally in patient care