

Put in context, data can help expose and fix health inequities

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Health data can do much more than describe the world's problems. It can contribute to alleviation of those problems and help build recognition of health inequities while also showing that they are avoidable, unnecessary, unfair and unjust.

"We face an onslaught of data of horrific indicators, and it's not just math, it's not just abstract numbers," said Fernando De Maio, PhD, director of research and data use for the AMA Center for Health Equity. "These are people and families and communities with a great deal of preventable suffering."

He made those remarks while moderating "Research and Data for Health Equity," a recent episode in the AMA "Prioritizing Equity" video series, in which a panel of experts discussed the power of data in understanding health inequities and the systemic issues that cause them to persist.

Learn why COVID-19 hits Latinx at nearly double overall U.S. rate.

What data should tell us

Patient data must tell more about the person besides their diagnosis, list of prescriptions or health insurance status.

"You are not your health insurance," said panelist Alyasah Ali Sewell, PhD, an associate professor of sociology at Emory University and founder and director of the Race and Policing Project scholarly research depository.

Data will show that a woman has a 10-block walk to her doctor's office, she said.

But it won't tell you that, on the sixth block, that woman may witness—or even experience herself—an unwarranted police stop-and-frisk action and the data won't show how this stress deteriorates her

health across time.

Data is always a two-edged sword, said panelist Nancy Krieger, PhD, professor of social epidemiology at the Harvard T.H. Chan School of Public Health's department of social and behavioral science.

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, she said.

The author of *Epidemiology and the People's Health*, published in 2011, Krieger cited as an example of “no data, no problem,” the lack of race, ethnicity and socioeconomic data for COVID-19 cases and deaths—despite the fact that race and ethnicity are included on death certificates as is socioeconomic data such as education status, and also ZIP Codes, which can be linked to data on community characteristics, such as poverty and racialized economic segregation.

An example of “bad data, big problems” was the reliance on death counts instead of computing death rates in initial COVID-19 reports, which suggested white people were at greater risk in the pandemic.

Using data to spark action

The work of the Sinai Urban Health Institute (SUHI) in Chicago was cited as an example of how data can be used to reduce health inequities. In 2006, SUHI released a study of showing there was large difference in breast cancer mortality rates between Black and white women in Chicago that wasn't seen in other U.S. cities.

The study led to the convening of a Chicago breast cancer summit and the creation of the still active Metropolitan Chicago Breast Cancer Task Force. Summit participants pointed to three factors for the inequities: Black women received fewer mammograms, the mammograms received were of inferior quality, and Black women had inadequate access to quality treatment once their cancer was diagnosed.

The institute is part of the Sinai Health System, the largest private safety-net health care system in Illinois. More recently, it has been studying excess death rates as a metric for understanding health inequities and stimulating action.

An institute comparison of Black and white mortality rates in the U.S. revealed that there are 70,000 excess Black deaths each year. Locally, the number is 3,500. That's up from 3,200 some 10 years ago.

"It's very clear that it's not a race difference, it's a difference due to racism," said panelist Maureen Benjamins, PhD, a senior research fellow at the institute.

Benjamins and De Maio are co-authors of new *JAMA Network Open* study that extends the SUHI's research to compare mortality rate and inequities in 30 U.S. cities.

Benjamins also noted that the institute has worked with its community to disseminate its findings in an accessible and understandable manner.

It formed a community advisory committee 20 years ago that has the power to add, remove or edit questions in the institute's health surveys. It also helps train community survey interviewers and advises on infographics that best communicate survey findings.

Historical context of chronic conditions

The importance of the data's historical context was also discussed by panelists. Sewell noted how rates of chronic disease are high in neighborhoods where home ownership is hindered by expensive mortgages with prepayment penalties from lenders who are quick to take back a property if payment is slow.

It was noted that the common chronic conditions such as diabetes, hypertension and obesity seen in these neighborhoods are also linked to higher risk of death from COVID-19. Research also makes clear, however, that health inequities in these chronic conditions do not explain the higher risk of infection in communities of color—which is instead driven by exposure at work and crowded housing due to the combination of low wages and unaffordable housing—and the prevalence of these chronic conditions also do not explain the higher risk of mortality, once infected.

"When people see all of that, they just see people dying, they see people sick," she said. "I see the actions of the predatory lending market where there was a housing boom creating the condition of disparities."

Learn more about the health equity education on the AMA Ed Hub™ featuring CME from the AMA's Center for Health Equity and curated education from collaborating organizations. To earn CME on the AMA's "Prioritizing Equity" video, visit the course page on AMA Ed Hub™.