Opinion Article

Real World Data to Advance Racial and Ethnic Minority Health Equity

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Information on race and ethnicity has been integral to our understanding of the health issues affecting the U.S population and support of population health outcomes. Additionally, variations associated with race and ethnicity have been correlated with risks for certain diseases, conditions, and responses to medication. Understanding these factors remains important for identifying and addressing disparities in health [1].

Interest in the use of real-world data (RWD) has increased over the past two decades [2]. The urgency of the COVID-19 pandemic has heightened interest in the use of RWD to obtain timely information, as well as to identify and monitor demographic disparities in COVID-19 outcomes [3].

While the use of RWD provides new opportunities, it also has limitations. RWD frequently is not consistent with the Office of Management and Budget (OMB) Directive "Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity" [4,5]. As with all RWD, race and ethnicity data collected in Electronic Health Records (EHRs) are not collected for research purposes [6,7]. There may also be inappropriate and sub-optimal use and/or analysis of race and ethnicity data, including aggregation and data mapping that combine categories and data elements in ways that are not consistent with OMB standards [6-8]. Additionally, while substantial efforts have been made to capture race and ethnicity data in EHRs, there is still a high frequency of missing data and misclassification [6-8].

Advancing equity requires data that are complete, standardized, and interoperable [9,10]. However, there remain many challenges to achieve these goals. Some challenges are more easily managed–for example, increasing awareness among researchers, health care administrators and professionals and policymakers, among other stakeholders of the need to collect high-quality race and ethnicity data. Other challenges will require more intentional effort, including addressing the high volume of missing race and ethnicity data. Additionally, reporting data in a standardized format will ensure data comparability and exchangeability across healthcare systems and researchers engaged in promoting and achieving health equity.

As the pandemic highlighted, data analysis by race, ethnicity, age, geographic area, education, and other socioeconomic variables provides valuable information for decision making. We see the opportunity to improve the quality of race and ethnicity data as immensely important to responding to the pandemic and other pressing public health challenges as we aim to provide equitable health care for diverse populations.

Competing interests

The authors declare that they have no competing interests.

Disclaimer

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