

Implementing Revised Federal Race/Ethnicity Data Standards Won't Sufficiently Address Health Inequities



In March 2024, the Office of Management and Budget (OMB) released much-anticipated revisions to [Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity \(SPD 15\)](#), which had last been updated in [1997](#). Building on recommendations from the [OMB's Interagency Technical Working Group on Race and Ethnicity Standards](#) and more than 20,000 [public comments](#) in response to initial

proposals in 2023, the new standards combine questions on racial and ethnic identities and now require a separate Middle Eastern and North African (MENA) response category, among other updates. The standards also incorporate widely accepted best practices for data collection such as encouraging detailed response categories beyond these minimums, allowing individuals to opt out of sharing race and ethnicity, and promoting self-reporting of racial and ethnic identity. The changes have been [applauded](#) for their potential to improve use of race and ethnicity data for addressing health inequities.

SPD 15 requires use of the new standards by federal agencies such as the [Census Bureau](#) and the [Centers for Medicare and Medicaid Services \(CMS\)](#)—potentially improving the quality, accuracy, and consistency of demographic data for measuring variation in health care access, use, and quality, which currently [vary](#) widely. For instance, the OMB's revisions could bring more consistency in available data across states and subgroups of [Medicaid](#) and [Medicare](#) enrollees, for whom large racial and ethnic inequities in health care access and experiences persist. However, improving federal data collection standards on race and ethnicity will be far from sufficient for equipping the health sector to meaningfully address health inequities.

Federal Agency Planning For Revised

Data Standards Should Incorporate Health Plans And Other Private-Sector Organizations

As of 2021, most Medicaid enrollees nationally and in the majority of states [were in managed care plans](#); as of 2023, half of Medicare enrollees nationally [were in Medicare Advantage plans](#). Moreover, racial and ethnic inequities exist in commercial plans as well, including [employer-sponsored insurance](#). This highlights the key role of private-sector entities, including [employers](#) and health plans, in addressing health inequities using demographic data.

Based on interviews with more than 50 experts and a summit attended by more than two dozen multisector stakeholders in 2022, [research](#) conducted by the Urban Institute, the American Benefits Council, and Deloitte focused on the role of health plans in using data to measure and address health inequities. Findings from that research indicate that health plans are in a unique position not only to assess members' health care access, use, quality, experiences, and outcomes by a variety of demographic categories, but also to use these data to tackle health inequities—such as through directing resources to groups of members experiencing health inequities, incentivizing providers to reduce inequities, identifying and removing bias from treatment algorithms, and publicly reporting on

progress to establish accountability for reducing gaps. But data available to plans may derive from a variety of sources, including self-report, employer sponsors of coverage, providers, electronic health records, and Medicaid and Marketplace applications. They may also vary widely in level of detail, quality, and completeness. Moreover, individuals are not required to report their race and ethnicity to their health plans, employers, providers, or on Medicaid and Marketplace applications.

Given the opportunities for health plans to play a key role in using data collected under the new standards, federal agencies should coordinate with private-sector entities, including health plans, employers, and providers, as they design implementation of the revised standards. SPD 15 requires federal agencies to submit an action plan within 18 months of publication of the revisions (making the due date September 2025) and implement the revised standards within five years. Thus, now is the time to ensure that agency action plans incorporate coordination with health plans. Specific actions could include encouraging private-sector data collection that aligns with the new federal standards; ensuring consistency in collection strategies across health plans' different lines of business; and training providers, health plan representatives, and others who may administer the new race and ethnicity questions.

Revision Of Race And Ethnicity Data Collection Standards Is Only A Step Toward Using Data To Address Health Inequities

Implementing the OMB's revised race and ethnicity standards will require changes to data systems, and integrating new standards into fragmented, outdated, and complicated systems will be no easy task. Problems with [Medicaid unwinding](#), for example, have illustrated the challenges of underresourced state workforces using [outdated eligibility, enrollment, and renewal systems](#). Federal and state agencies, employers, and health plans alike will need to dedicate staff capacity and resources toward smooth implementation of the new standards, highlighting the need for [detailed federal guidance, funding, and technical assistance](#).

Revisions to data systems will also need to be accompanied by broader action to support health plans and other entities in not only collecting race and ethnicity data but also using these data to address health inequities. Several barriers to the use of demographic data by health plans to address health inequities arose in [our research](#). These included lack of understanding by individuals and employers, and insufficient communication by plans, of the opportunities of improved data collection by health plans to advance health

equity; legal concerns and uncertainty regarding the collection and sharing of race and ethnicity data; insufficient organizational and resource prioritization; and individuals' low trust in how data will be used and safeguarded.

[Multisector coalitions](#) are building momentum toward using data to address inequities. But more fundamentally, the new data standards will not realize their potential if individuals do not trust the health system enough to share their information. It is important that people feel seen in the racial and ethnic categories provided, a problem that may be partially addressed by the requirement of including a [MENA option](#) (although some [commenters](#) did not support the combining of the ethnicity and race questions due to concerns such as that doing so would lead to an undercount of racial identities among those with Hispanic ethnicity). But given the voluntary nature of reporting, individuals may still be unwilling to share their information if they experience discriminatory treatment, have privacy concerns, do not trust that their providers and health plans are committed to health equity, or do not understand how their data will be used. [Summit participants](#) emphasized the important role of community partners in building trust and of community-developed solutions to address low trustworthiness of the health system.

Moreover, while collection of race and ethnicity data may be

improving, there are [few examples of use of such data to meaningfully reduce health inequities](#). Federal action should extend beyond data standards to establish accountability, such as holding health plans, states, and providers accountable for reducing inequities. At the same time, there is a large role for private entities such as employers, providers, and plans to play, such as piloting efforts to use data to close gaps in care.

Finally, a large role for researchers remains. The new standards acknowledge additional research that is needed, such as understanding ideal racial identity terminology and response category order, best practices for data processing, and how respondents interpret various racial and ethnic category descriptions. Insights from research could inform additional updates to the standards, ideally more frequently than the 25-plus years that have passed since the past update and the nearly five decades since a new racial/ethnic category was added to the standards. Moreover, while societal responses to race and ethnicity are fundamental sources of inequities, collection standards for other characteristics, such as [disability](#) and [sexual orientation/gender identity](#), as well as overlaps between these characteristics, will also be needed to identify and tackle a broader array of inequities in our health system.

Authors' Note

Elevance Health funded the 2022 research cited in this *Forefront* piece. We thank Jennifer Kowalski for helpful comments on this article.