

Federal Race Ethnicity Data in the Era of COVID-19: Calls for Change and Updating

Vickie M. Mays, Ph.D., MSPH

Distinguished Professor of Psychology and Health Policy & Management

University of California Los Angeles

Director of the UCLA BRITE Center on Science, Research & Policy

Special Advisor to the Chancellor

Modernizing Race and Ethnicity Data in Our Federal Health Programs

AUTHORS



Cara V. James

President and CEO, Grantmakers in Health



Barbara Lyons

Leading Expert on Medicaid and Medicare policy issues



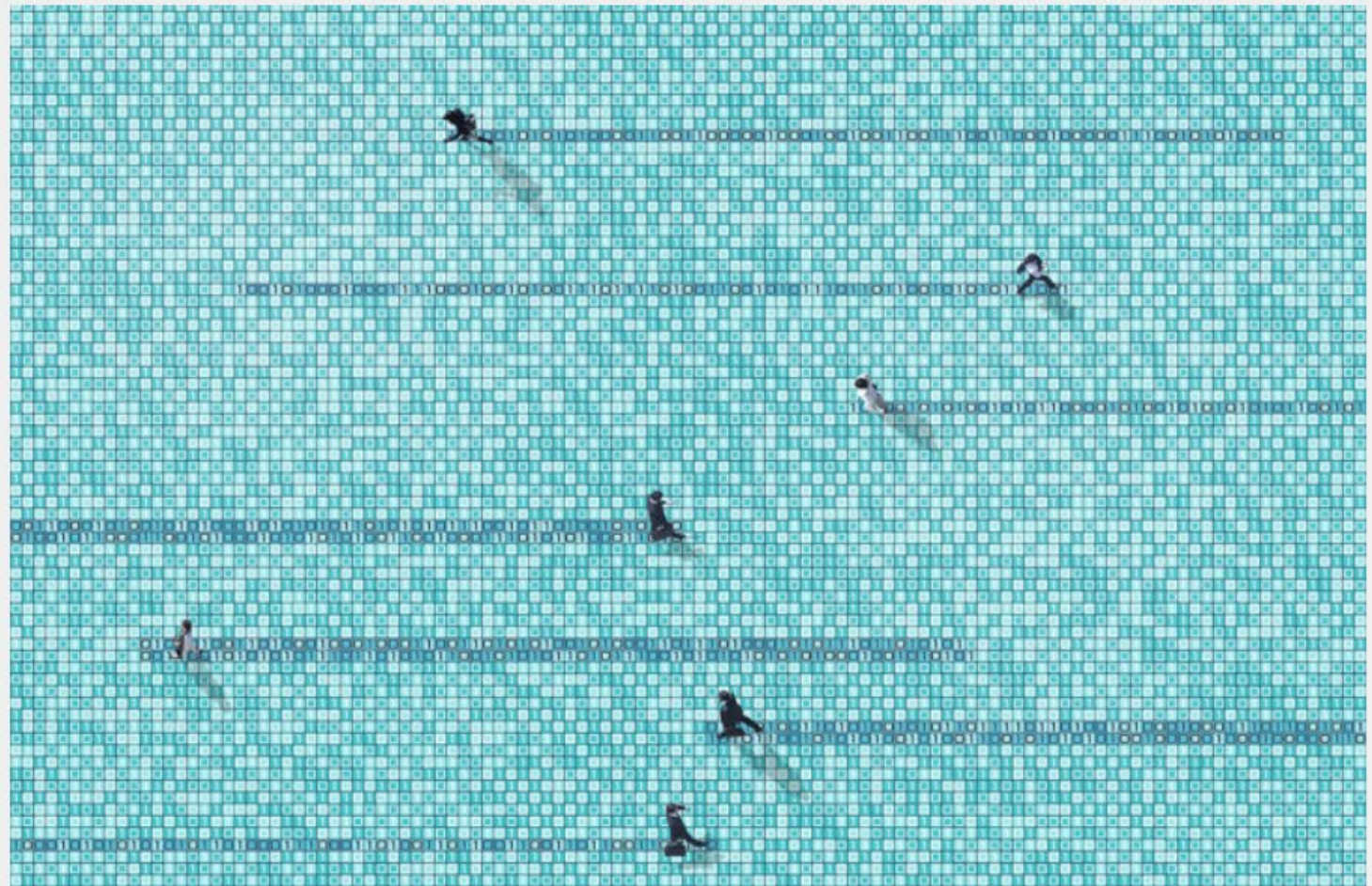
Philip A. Saynisch

Research Scientist, National Committee on Quality Assurance



Sarah Hudson Scholle

Vice President of Research and Analysis, National Committee on Quality Assurance



Race and Ethnicity Data Collected at Enrollment in Selected Health Programs

Setting	Data collection standard	Completeness	Self-reported?	Data available for research?
Medicare	Standards have changed over time	●	✓ (a)	✓
Medicaid	HHS 2011(b)	◐	✓	✓
Federally-Facilitated and State-Based Marketplaces (FFMs; SBMs)	FFMs HHS 2011; SBMs vary	◐	◐	✓
Commercial Insurance	Unknown	☾	Unknown	✗
Veterans Health Administration	OMB 1997	●	◐	✗
Indian Health Service (c)	Blood Quantum & Tribal Affiliation	◐	Unknown	✓
Federally Qualified Health Centers	OMB 1997	●	✓(d)	✓(d)
Birth Records	HHS 2011	●	✓(e)	✓
COVID-19 Vaccinations	OMB 1997	◐	Unknown	✓
Pregnancy Risk Assessment Monitoring System	OMB 1997	◐	✓(f)	✓

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Legend:

☾ Less complete ◐ Varies (by state, collection method, etc.) ● More complete ✓ Yes ✗ No

- **Lack of a clear and sufficient federal standard.** Within the U.S. Department of Health and Human Services (HHS), two standards are used. The first, finalized by the Office of Management and Budget (OMB) in 1997, includes five race categories and Hispanic as the only ethnicity. The second, finalized by HHS in 2011, includes these, plus additional categories within Asian, Native Hawaiian, and Other Pacific Islander and Hispanic. While the HHS group offers more categories, it is less commonly used; neither standard sufficiently represents the diversity of the U.S. population.
- **Misconceptions and fear.** Stakeholders noted common beliefs of legal restrictions on collecting race and ethnicity data. However, there are no federal limitations, and only a few states limit data collection in certain circumstances. Others noted that some individuals are unwilling to self-identify and providers and staff are reluctant to ask.



Comparison of Race and Ethnicity Collection Standards: Office of Management and Budget 1997 vs. Health and Human Services 2011

	OMB 1997	HHS 2011
	White	White
	Black or African American	Black or African American
	American Indian or Alaska Native	American Indian or Alaska Native
Race*	Asian	Asian Indian Chinese Filipino Japanese Korean Vietnamese Other Asian
	Native Hawaiian or Other Pacific Islander	Native Hawaiian Guamanian or Chamorro Samoan Other Pacific Islander

	OMB 1997	HHS 2011
Ethnicity*	Hispanic or Latino	Yes, Mexican, Mexican American, Chicano/a Yes, Puerto Rican Yes, Cuban Yes, another Hispanic, Latino/a, or Spanish origin
	Not Hispanic or Latino	No, not of Hispanic, Latino/a, or Spanish origin

 Download data

Note: * OMB 1997 and HHS 2011 permit the reporting of more than one race; HHS 2011 also permits people to select one or more ethnicities.

Data: Cara James et al., *Federal Action Is Needed to Improve Race and Ethnicity Data in Health Programs* (Grantmakers In Health and National Committee for Quality Assurance, Oct. 2021).

Source: Cara James et al., “Modernizing Race and Ethnicity Data in Our Federal Health Programs,” *To the Point* (blog), Commonwealth Fund, Oct. 26, 2021. <https://doi.org/10.26099/NZ4R-G375>

Federal Action Is Needed to Improve Race and Ethnicity Data in Health Programs

This project, conducted jointly by Grantmakers In Health (GIH) and the National Committee for Quality Assurance (NCQA), with support from The Commonwealth Fund, includes development of a data framework to capture how race and ethnicity is collected across federal health programs. A second report, to be released later this year, will lay out short and long-term recommendations across a range of levers at the federal and state level that could lead to better data collection, quality, and usability. The project team included Cara James and Smita Pamar, GIH; Sarah Hudson Scholle, Philip Saynisch, and Jeni Soucie, NCQA; and Barbara Lyons, consultant

- ① The federal government should review and update the Office of Management and Budget (OMB) 1997 Statistical Policy Directive on Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity to more accurately reflect the demographics of the population of the United States and provide flexibility to states and local governments to capture information reflecting the populations specific to their communities.
- ② The Centers for Medicare & Medicaid Services (CMS) should include race and ethnicity on the Medicare Part C & D application.
- ③ [The Interagency Working Group on Equitable Data \(Data Working Group\)](#) should review existing data systems and work through OMB to standardize the collection and reporting of racial, ethnic, and other demographic data across the federal government (e.g., Department of Agriculture (USDA), CMS, and Health Resources and Services Administration (HRSA) reporting requirements) while providing states, local governments, and grantees the flexibility to collect data on other population groups residing in their area.

- ④ The Department of Health and Human Services (HHS) should review and edit provider data systems to collect information on provider demographics, and work with the Bureau of Labor Statistics at the Department of Labor to help ensure that the population caring for communities reflects the demographics of those communities.
- ⑤ OMB should require all federal program reports to include data stratified by race, ethnicity, and other demographics where feasible.
- ⑥ HHS should require state and local health departments, Medicaid programs, public health, and human service programs to conduct an audit of their race and ethnicity data to identify information gaps and barriers to completion.
- ⑦ HHS and other departments should support states through technical assistance and financial assistance to improve data systems and interoperability, as well as improved analytic and reporting capacity.
- ⑧ HHS should develop educational resources on the importance of asking an individual about their race and ethnicity, and resources on why it is important to answer the questions and how the information will be used. In addition, HHS should work with myriad stakeholder groups (e.g., providers, consumer and community-based organization, public health, etc.) to disseminate the information.
- ⑨ Include community voices in the development and dissemination of materials explaining why the information is collected, how it will be used, and why it is important to collect.

- ⑩ Congress should review and amend as necessary the Health Information Portability and Accountability Act (HIPAA), the Family Educational Rights and Privacy Act (FERPA), the Patient Protection and Affordable Care Act (ACA), and other data laws to encourage the collection and sharing of information across health, human and social services, including the justice system.
- ⑪ Improving privacy protections of data captured through health apps, such as increasing the Federal Trade Commission's (FTC) authorization since they manage the health apps.

In sum, the federal government can invest resources in data system changes and education and technical assistance for expanding collection and use of race and ethnicity data. It can also increase incentives to collect and assess these data and, in cases, require that federal program participants do so. Finally, by reviewing existing regulation to assess where current policy may restrain (or create the appearance of prohibiting) collection of race and ethnicity data, the federal government can empower stakeholders to pursue these necessary efforts.