

# Data Equity Toolkit

JUNE 2025

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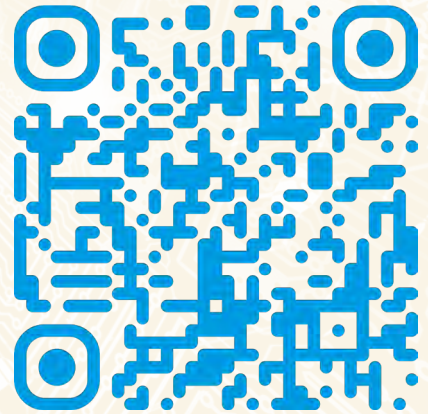
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# STANDARDIZING DATA TO ADVANCE THE HEALTH EQUITY MOVEMENT: A MULTI-SECTORIAL STRATEGY

March 28, 2023

Summary of a cross-sector dialogue sponsored by:

Blue Cross Blue Shield Association  
and National Minority Quality Forum



## INTRODUCTION

**The National Minority Quality Forum (NMQF) and Blue Cross Blue Shield Association (BCBSA)** are partners on this issue brief that describes policy challenges and recommended solutions to advance a stakeholder-informed data equity movement that includes engagement with federal agencies, employers, labor, health systems, clinicians and historically under-represented populations.

This issue brief is informed through input from stakeholder convening sessions and the report, *Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity: Opportunities, Barriers, and Solutions*, authored by the Urban Institute, the American Benefits Council, and Deloitte Consulting.



Through our partnership, NMQF and BCBSA place the highest priority on creating awareness among and eliciting input from multi-sectorial thought leaders regarding the issues that attend data collection standards and ethical use with regards to race, ethnicity and language (REL) data and sexual orientation and gender identity (SOGI) data.

More than 25 patient advocacy, health care and business leadership organizations contributed their time and expertise during three invitational stakeholder convenings in 2022 (see Appendix A). The inaugural convening occurred on Aug. 3, 2022, where data equity stakeholders participated in a facilitated discussion that touched on the priorities of key stakeholder groups. The Sept. 28, 2022, convening of the group enabled an extensive and highly informative discussion of the gaps in data specificity to support efforts to address health inequities. Of particular concern to the discussants was the variability in the types of data collected, how they are analyzed and applied. Discussants also emphasized the importance of the manner in which data are collected, noting that the highest quality data is self-reported. The objective of the Dec. 9, 2022, convening was to discuss potential engagement with the federal standards development process to help assure that a national data collection standard is created that supports equity in health care.

In our view, the process outlined above was a success – reinforcing the need for non-voluntary collection of standardized, precise data to enable insurers, health care providers, employers and patient advocates to design and implement targeted solutions to better meet the needs of perpetually underserved groups. As a result, this issue brief addresses consensus-based policy options that, when implemented, will strengthen the data foundation and accrue to the benefit of all corporate and consumer stakeholders.

## DISCUSSION

Significant health inequities plague the U.S. health care system, impacting historically marginalized racial<sup>1</sup>, ethnic, socioeconomic<sup>2</sup> and LGBTQ+<sup>3</sup> communities.<sup>4</sup> There are many causes for these inequities, including, but not limited to, systemic racial, ethnic, language and LGBTQ+ biases and their intersectional relationship to concomitant sex, gender, age, disability, socioeconomic, cultural and geographic factors. Together, these forces have created, perpetuated and exacerbated inequalities in access to the benefits of the American health services research, delivery and financing system. The consequences of these biases manifest as disparate, but preventable and amenable morbidity and mortality every year.



In June 2022, the Office of Management and Budget (OMB) announced the initiation of a formal review to revise the 1997 OMB *Statistical Policy Directive No. 15 (Directive No. 15): Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*.<sup>5</sup> Directive No. 15, first promulgated in 1977, provides minimum standards that ensure the federal government’s ability to compare information and data across federal agencies and to document the effectiveness of federal programs in serving the diverse American general population. The current (1997) iteration of Directive No. 15 encourages further disaggregation in the collection, tabulation and reporting of data, when useful. According to U.S. Chief Statistician Dr. Karin Orvis, the objective of the current OMB review and revision process is to ensure that these statistics “better reflect the diversity of the American people.” Dr. Orvis also outlined a plan to complete the revision of these data collection standards by the summer of 2024.

The well-documented disparities in access to high-quality health care **are challenging, but not insurmountable.**

The well-documented disparities in the availability of and access to high-quality health care in terms of diagnosis and treatment that could result in disparate outcomes are pervasive, multi-faceted and multi-sectorial. They are challenging, but not insurmountable. Failure to be proactive to redress these inequities compromises not only the health of families and communities, but also the financial health of employers and the bottom lines of businesses across all industry sectors.

The planned OMB update of Directive No. 15 can enable every sector of the health services research, delivery and financing system to advance the diversity, equity and inclusion plans that they have announced as priorities. Further, a case can be made that absent the Directive No. 15 update and other steps outlined below, collectively, these efforts will fail. NMQF and BCBSA stand ready to work with OMB to implement an inclusive updating process that will serve to improve the inputs and outcomes of health care, inform research and innovation, and assure that coverage and payment policies reflect and assign equitable value to the full diversity of the American general population.

## Data Quality is Critical in Addressing Health Inequities

Health disparities in the United States and its territories are indisputable and are a foundational characteristic of the U.S. health care system. These disparities are manifest in a multitude of statistics:

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The percentage of adults reporting **fair or poor health status** is **higher** among **African Americans, Hispanics, American Indian and Alaska Natives** than it is among whites.<sup>6</sup>

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Despite being younger in average age than other population groups, **LGBTQ+ individuals** more commonly report being in **fair or poor health** than non-LGBTQ+ people and report **higher rates of disability and chronic disease**.<sup>7</sup>

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**Infant mortality** in the United States is comparably **higher among several racial and ethnic minority populations** than it is among whites.<sup>8</sup>

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**Black and Native American women** are **2-3X more likely** to die from **pregnancy-related causes** than white women.<sup>9</sup>

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**Suicide rates climbed significantly** among **American Indian, Black, and Hispanic** people in 2021 in the wake of the COVID-19 pandemic even as rates of suicide among white people fell for a third straight year.<sup>10</sup>

**Only 1 in 3 Black Americans** who needs mental health care receives it, even though rates of mental illness are similar among Black, Hispanic, and white adults.<sup>11</sup>

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Cancer incidence rates are higher among white individuals compared to African Americans, and yet **African Americans** have a **significantly higher mortality rate** from the disease.<sup>12</sup>

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**African Americans** are **2X as likely** as whites to die from diabetes.<sup>13</sup>

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Research has shown that **African American and Hispanics** face **greater barriers** in trying to gain access to health care services.<sup>14</sup>

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**LGBTQ+ people** are **more likely to report difficulties** with their health care providers, such as having their health concerns dismissed or being blamed for their health problems.<sup>15</sup>

The value of comprehensive data on a full range of populations and population cohorts cannot be overstated. Standardized, precise data create opportunities for insurers, health care providers, employers and patient advocates to design and implement targeted solutions to better meet the needs of perpetually underserved groups. Through adoption of robust and comprehensive REL and SOGI data, health entities can better monitor health services access and utilization, design focused incentives for health providers to reduce inequities, track changes in health outcomes by population cohort and respond accordingly, and more accurately measure progress on reducing disparities. By incorporating a richer data set reflecting inclusive workforce composition, employers can make informed decisions on which health plan can best meet the needs of employees and their families.



High-quality, reliable data are key to measuring, monitoring and reporting changes in the care provided, in the outcomes of the care, and in the disparities associated with those outcomes. Health care and health policy professionals recognize that data collection and analysis should reflect the extraordinary diversity of the American population if genuine progress is to be achieved. However, industry and government initiatives aimed at accomplishing this objective have been pursued using a variety of methods due to lack of alignment and common equity-related collection standards, including for REL and SOGI data. To make these industry and government efforts more impactful, the adoption of national data collection standards to which public and private sector stakeholders commit is essential. Voluntary compliance, while potentially more palatable for certain stakeholder sectors, is not the best approach for a system change of enduring significance and impact.

## The OMB Standard and the Need for Improvement

The OMB's Directive No. 15 was established in 1977 to promote uniformity and comparability for data on race and ethnicity across all federal programs and fund initiatives, including monitoring compliance with civil rights laws including equal access to housing, education and employment. The standards are used in the decennial census, in household surveys, on administrative forms, and in various types of research.

In 1997, OMB updated Directive No. 15 to create standardized questions on race and ethnicity required for reporting by federal agencies and recipients of federal funds (See Appendix B<sup>16</sup>). To ensure data quality, the directive advises collecting race and ethnicity data using two questions, with ethnicity being collected first. Directive No. 15 establishes the *minimum* REL data collection standard, which includes the following five categories on race and two on ethnicity.

- **Ethnicity: Hispanic or Latino; and Not Hispanic or Latino**
- **Race: American Indian or Alaska Native\*; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; and white.**

\* Tribal nations have a unique legal and political relationship with the United States as affirmed by the U.S. Constitution, treaties, statutes, and case law. Thus, the legal and political status that Tribal nations have is fundamentally distinct from race-based classifications.

OMB Directive No. 15 (1997) encourages the collection of more granular data that is enhanced by categorization that can be aggregated back to the minimum REL data noted above. While more granular and disaggregated data can be collected, there is currently no national industry standard.

There is a distinct contrast between the minimum categories established by OMB, and, for example, the current code set maintained by the Centers for Disease Control and Prevention (CDC) that contains 900-plus categories for race and ethnicity data collection.

SOGI data collection has been far less developed than the work that has taken place on race and ethnicity. In the SOGI field, there is very little standardization. Health Level Seven International, commonly known as HL7, the data interoperability standardization organization, has initiated the “Gender Harmony” project that can serve as a building block for future SOGI data collection and dissemination.

In the SOGI field, there is **very little standardization.**

OMB Directive No. 15 (1997) is silent on the issue of SOGI data.

## The Patient Protection and Affordable Care Act Data Standard Provision

The passage of the Patient Protection and Affordable Care Act (ACA) in 2010 created an opportunity to improve the collection of data that can be utilized to address health equity. One provision of the ACA requires the Department of Health and Human Services (HHS) Secretary to establish new data collection standards for race, ethnicity, sex, primary language and disability status.<sup>17</sup> The law requires that these standards be used, to the extent practicable, in all national population health surveys. For purposes of the 2018 implementation process, the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE) in conjunction with the HHS Office of Minority Health (OMH) developed a set of uniform data collection standards to be applied to surveys conducted or sponsored by HHS. The criteria developed by ASPE/OMH require that:

- Data standards are evidence-based and demonstrated to have worked well in practice for national survey data collection.
- Data standards are framed as minimum data standards, with agencies permitted to include as many additional questions on these topics as desired as long as the minimum standard is included. Agencies are also permitted to include additional response categories for data standards *with as much additional detail and granularity as desired*, provided that the additional detail can be aggregated back to the minimum standard and that the sample design and sample size support that level of granularity.
- Data standards comply, at a minimum, with any standards already mandated by OMB.
- Data standards are for person-level data collected in population-based health surveys, where subjects either self-report information or a knowledgeable proxy provides information about the subject or responds for all persons in a household.



The ASPE/OMH standards represent an opportunity to collect more robust, granular and disaggregated data. The concern is that the ASPE/OMH standards have yet to be uniformly adopted by either government or the commercial health care delivery and financing sectors. Although some electronic medical record vendors offer an option to use the ASPE/OMH code set in collecting data, current adoption of the ASPE/OMH standards appear to be primarily limited to collecting REL data on the Affordable Care Act's individual health insurance exchanges.

As the OMB seeks options to improve Directive No. 15 standards for race and ethnicity data collection, of note is the ASPE/OMH model, implemented and tested in the field, as a current available and primed resource for utilization.

## The Imperative: National Industry Standards and Mandatory Adoption Across the Health Care Ecosystem

Collecting and exchanging data with the right level of detail necessitates a multi-stakeholder effort. No single sector has sufficiently robust and precise data to redress systemic inequities in health care. The collaboration between health care leaders, social service agencies and community-based organizations supports working together to address data equity challenges. Because such inequities are universal, it is imperative the health care research, delivery and financing enterprise coalesce around adoption of national data collection and standards for health equity data sets. The Office of the National Coordinator for Health IT (ONC) noted that advancing the use of data standards and interoperability of health equity data is crucial to improving the health and well-being of all individuals and communities. Beyond adopting a common standard for health equity data, more work is needed across the ecosystem to solve this challenge.<sup>18</sup>

Industry adoption of updated Directive No. 15 standards is essential. During the Directive No. 15 updating process, the evolving nature of SOGI data must be accommodated. Equity in access to the data collection process, as well as assuring that all population cohorts are reflected in the data is at the crux of systemic equity.

**Standards are needed** to define how best to engage with individuals and their families.

In addition to technical standards, standards are needed to define how best to engage with individuals and their families. If trust is indeed a factor that affects the ability to collect reliable data, distrust must not be triggered during the data collection process. Uniformity in the data collection tools, lexicon and framing of questions is essential.

## RECOMMENDATIONS

### **NMQF and BCBSA support the following recommendations for inclusion in the OMB Directive No. 15 update that is scheduled for completion in 2024:**

- Directive No. 15 should provide clear and consistent requirements for the collection of REL and SOGI data that include a minimum standard for disaggregated R/E collection and are consistent with industry interoperability standards (e.g., Fast Healthcare Interoperability Resources (FHIR) standards).
- OMB should incorporate the current data standards promulgated by the DHHS Assistant Secretary for Planning and Evaluation/Office of Minority Health into Directive No. 15 and require that these be the minimum standard categories for collecting disaggregated REL data.
- OMB should intentionally and proactively elicit and accept additional input from diverse stakeholders regarding SOGI data collection and utilization into the Directive No. 15 update.
- OMB should enforce non-voluntary, uniform and universal adoption of the updated OMB Directive No. 15 standards upon release in 2024 for all government agencies and all private sector health care stakeholders, including payers and providers.

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## ENDNOTES

- <sup>1</sup> U.S. Department of Health and Human Services Task Force on Black and Minority Health, 1985-1986. <https://collections.nlm.nih.gov/catalog/>.
- <sup>2</sup> Riley WJ. "Health disparities: gaps in access, quality and affordability of medical care." *Trans Am Clin Climatol Assoc.* 2012. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3540621/>.
- <sup>3</sup> Baptiste-Roberts K, Oranuba E, Werts N, Edwards LV. "Addressing Health Care Disparities Among Sexual Minorities." *Obstet Gynecol Clin North Am.* March 2017. <https://pubmed.ncbi.nlm.nih.gov/28160894/>.
- <sup>4</sup> Blue Cross Blue Shield Association. "The Ethical and Transparent Use of Data to Reduce Health Disparities," page 2. [https://www.bcbs.com/sites/default/files/healthequity/REL/HE\\_REL\\_Data\\_Paper.pdf](https://www.bcbs.com/sites/default/files/healthequity/REL/HE_REL_Data_Paper.pdf).
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- <sup>6</sup> Latoya Hill, Latoya, Artiga, Samantha and Haldar, Sweta. "Key Facts on Health and Health Care by Race and Ethnicity." Kaiser Family Foundation. January 26, 2022. <https://www.kff.org/report-section/key-facts-on-health-and-health-care-by-race-and-ethnicity-health-status-outcomes-and-behaviors/>.
- <sup>7</sup> Dawson, Lindsey, Frederiksen, Brittini, Long, Michelle, Ranji, Usha, and Kates, Jennifer. "LGBT+ People's Health and Experiences Accessing Care." Kaiser Family Foundation. July 22, 2021. <https://www.kff.org/womens-health-policy/report/lgbt-peoples-health-and-experiences-accessing-care/>.
- <sup>8</sup> Ely DM, Driscoll AK. "Infant Mortality in the United States, 2019: Data From the Period Linked Birth/Infant Death File." *National Vital Statistics Report.* December 2021. <https://pubmed.ncbi.nlm.nih.gov/34878382/>.
- <sup>9</sup> Centers for Disease Control and Prevention. Racial and Ethnic Disparities Continue in Pregnancy-Related Deaths. September 5, 2019. <https://www.cdc.gov/media/releases/2019/p0905-racial-ethnic-disparities-pregnancy-deaths.html>
- <sup>10</sup> Stone, D. M. (2023). Notes from the Field: Recent Changes in Suicide Rates, by Race and Ethnicity and Age Group — United States, 2021. *MMWR. Morbidity and Mortality Weekly Report*, 72(6). <https://doi.org/10.15585/mmwr.mm7206a4>
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- <sup>12</sup> Latoya Hill, Latoya, Artiga, Samantha and Haldar, Sweta. "Key Facts on Health and Health Care by Race and Ethnicity." Kaiser Family Foundation. January 26, 2022. <https://www.kff.org/report-section/key-facts-on-health-and-health-care-by-race-and-ethnicity-health-status-outcomes-and-behaviors/>.
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## ENDNOTES (continued)

<sup>15</sup> Dawson, Lindsey, Frederiksen, Brittni, Long, Michelle, Ranji, Usha, and Kates, Jennifer. “LGBT+ People’s Health and Experiences Accessing Care.” Kaiser Family Foundation. July 22, 2021. <https://www.kff.org/womens-health-policy/report/lgbt-peoples-health-and-experiences-accessing-care/>.

<sup>16</sup> Appendix B contains the official text version of the Federal Register notice which was downloaded 01-16-2023. A pdf of the Federal Register notice can be accessed [here](#).

<sup>17</sup> U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. “HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status, October 30, 2011.” (Access 01-16-2023 at <https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0>) and <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00413>.

<sup>18</sup> Blue Cross Blue Shield Association. “The Ethical and Transparent Use of Data to Reduce Health Disparities,” page 5. [https://www.bcbs.com/sites/default/files/healthequity/REL/HE\\_REL\\_Data\\_Paper.pdf](https://www.bcbs.com/sites/default/files/healthequity/REL/HE_REL_Data_Paper.pdf).

## APPENDIX A

### Stakeholder Convenings on Data Equity

#### August 3, 2022

1. American Academy of Family Physicians
2. American Benefits Council
3. American Hospital Association
4. American Medical Association
5. Association of American Medical Colleges
6. Blue Cross Blue Shield Association
7. Families USA
8. Langco Partners (facilitator)
9. National Association of Health Services Executives
10. National Rural Health Association
11. National Health Council
12. National Indian Health Board
13. National LGBTQ Taskforce
14. National Minority Quality Forum
15. Urban Institute

#### September 28, 2022

1. American Benefits Council
2. American Cancer Society
3. American College of Physicians
4. American Heart Association
5. American Medical Association
6. American Psychiatric Association
7. Asian & Pacific Islander American Health Forum
8. Association of American Medical Colleges
9. Blue Cross Blue Shield Association
10. Business Roundtable
11. Center for Law and Social Policy
12. Families USA
13. Human Rights Campaign
14. Joint Center for Political and Economic Studies
15. Langco Partners (facilitator)
16. MarylandRARE - EveryLife Foundation
17. National Academy for State Health Policy
18. National Health Council
19. National Hispanic Medical Association
20. National Indian Health Board
21. National LGBTQ Task Force
22. National Minority Quality Forum
23. National Rural Health Association
24. Urban Institute

December 9, 2022

1. Advocates for Community Health
2. American Benefits Council
3. American College of Physicians
4. American Heart Association
5. American Hospital Association
6. Asian & Pacific Islander American Health Forum
7. Association of American Medical Colleges
8. Blue Cross Blue Shield Association
9. Business Roundtable
10. Center for Law and Social Policy
11. Families USA
12. Langco Partners (facilitator)
13. Joint Center for Political and Economic Studies
14. National Health Council
15. National LGBTQ Task Force
16. National Minority Quality Forum
17. National Rural Health Association
18. Urban Institute

## APPENDIX B

### OFFICE OF MANAGEMENT AND BUDGET Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (1997)

[Federal Register Volume 62, Number 210 (Thursday, October 30, 1997)]

[Notices]

[Pages 58782-58790]

From the Federal Register Online via the Government Publishing Office [[www.gpo.gov](http://www.gpo.gov)]

[FR Doc No: 97-28653]

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Part II

Office of Management and Budget

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Revisions to the Standards for the Classification of Federal Data on  
Race and Ethnicity; Notices

Federal Register / Vol. 62, No. 210 / Thursday, October 30, 1997 /  
Notices

[[Page 58782]]

OFFICE OF MANAGEMENT AND BUDGET

Revisions to the Standards for the Classification of Federal Data  
on Race and Ethnicity

AGENCY: Executive Office of the President, Office of Management and  
Budget (OMB), Office of Information and Regulatory Affairs.

ACTION: Notice of decision.

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**SUMMARY:** By this Notice, OMB is announcing its decision concerning the revision of Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting. OMB is accepting the recommendations of the Interagency Committee for the Review of the Racial and Ethnic Standards with the following two modifications: (1) the Asian or Pacific Islander category will be separated into two categories--"Asian" and "Native Hawaiian or Other Pacific Islander," and (2) the term "Hispanic" will be changed to "Hispanic or Latino."

The revised standards will have five minimum categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. There will be two categories for data on ethnicity: "Hispanic or Latino" and "Not Hispanic or Latino."

The Supplementary Information in this Notice provides background information on the standards (Section A); a summary of the comprehensive review process that began in July 1993 (Section B); a brief synopsis of the public comments OMB received on the recommendations for changes to the standards in response to the July 9, 1997, Federal Register Notice (Section C); OMB's decisions on the specific recommendations of the Interagency Committee (Section D); and information on the work that is underway on tabulation issues associated with the reporting of multiple race responses (Section E).

The revised standards for the classification of Federal data on race and ethnicity are presented at the end of this notice; they replace and supersede Statistical Policy Directive No. 15.

**EFFECTIVE DATE:** The new standards will be used by the Bureau of the Census in the 2000 decennial census. Other Federal programs should adopt the standards as soon as possible, but not later than January 1, 2003, for use in household surveys, administrative forms and records, and other data collections. In addition, OMB has approved the use of the new standards by the Bureau of the Census in the "Dress Rehearsal" for Census 2000 scheduled to be conducted in March 1998.

**ADDRESSES:** Please send correspondence about OMB's decision to: Katherine K. Wallman, Chief Statistician, Office of Information and Regulatory Affairs, Office of Management and Budget, Room 10201 New Executive Office Building, 725 17th Street, N.W., Washington, D.C. 20503; fax: (202) 395-7245.

**ELECTRONIC AVAILABILITY AND ADDRESSES:** This Federal Register Notice and the related OMB Notices of June 9, 1994, August 28, 1995, and July 9, 1997, are available electronically from the OMB Homepage on the World Wide Web: <<<http://www.whitehouse.gov/WH/EOP/OMB/html/fedreg.html>>>.

Federal Register Notices are also available electronically from the U.S. Government Printing Office web site: <<[www.access.gpo.gov/su\\_docs/aces/aces140.html](http://www.access.gpo.gov/su_docs/aces/aces140.html)>>. Questions about accessing the Federal Register online via GPO Access may be directed to telephone (202) 512-1530 or toll free at (888) 293-6498; to fax (202) 512-1262; or to E-mail <<[gpoaccess@gpo.gov](mailto:gpoaccess@gpo.gov)>>.

This Notice is available in paper copy from the OMB Publications Office, 725 17th Street, NW, NEOB, Room 2200, Washington, D.C. 20503; telephone (202) 395-7332; fax (202) 395-6137.

FOR FURTHER INFORMATION CONTACT: Suzann Evinger, Statistical Policy Office, Office of Information and Regulatory Affairs, Office of Management and Budget, NEOB, Room 10201, 725 17th Street, N.W., Washington, D.C. 20503; telephone: (202) 395-3093; fax (202) 395-7245.

#### SUPPLEMENTARY INFORMATION:

##### A. Background

For more than 20 years, the current standards in OMB's Statistical Policy Directive No. 15 have provided a common language to promote uniformity and comparability for data on race and ethnicity for the population groups specified in the Directive. They were developed in cooperation with Federal agencies to provide consistent data on race and ethnicity throughout the Federal Government. Development of the data standards stemmed in large measure from new responsibilities to enforce civil rights laws. Data were needed to monitor equal access in housing, education, employment, and other areas, for populations that historically had experienced discrimination and differential treatment because of their race or ethnicity. The standards are used not only in the decennial census (which provides the data for the "denominator" for many measures), but also in household surveys, on administrative forms (e.g., school registration and mortgage lending applications), and in medical and other research. The categories represent a social-political construct designed for collecting data on the race and ethnicity of broad population groups in this country, and are not anthropologically or scientifically based.

##### B. Comprehensive Review Process

Particularly since the 1990 census, the standards have come under increasing criticism from those who believe that the minimum categories set forth in Directive No. 15 do not reflect the increasing diversity of our Nation's population that has resulted primarily from growth in immigration and in interracial marriages. In response to the criticisms, OMB announced in July 1993 that it would undertake a comprehensive review of the current categories for data on race and ethnicity.

This review has been conducted over the last four years in collaboration with the Interagency Committee for the Review of the Racial and Ethnic Standards, which OMB established in March 1994 to facilitate the participation of Federal agencies in the review. The members of the Interagency Committee, from more than 30 agencies, represent the many and diverse Federal needs for data on race and ethnicity, including statutory requirements for such data. The Interagency Committee developed the following principles to govern

the review process:

1. The racial and ethnic categories set forth in the standards should not be interpreted as being primarily biological or genetic in reference. Race and ethnicity may be thought of in terms of social and cultural characteristics as well as ancestry.

2. Respect for individual dignity should guide the processes and methods for collecting data on race and ethnicity; ideally, respondent self-identification should be facilitated to the greatest extent possible, recognizing that in some data collection systems observer identification is more practical.

3. To the extent practicable, the concepts and terminology should reflect clear and generally understood definitions that can achieve broad public acceptance. To assure they are reliable, meaningful, and understood by respondents and observers, the racial and ethnic categories set forth in the standard should be developed using

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appropriate scientific methodologies, including the social sciences.

4. The racial and ethnic categories should be comprehensive in coverage and produce compatible, nonduplicative, exchangeable data across Federal agencies.

5. Foremost consideration should be given to data aggregations by race and ethnicity that are useful for statistical analysis and program administration and assessment, bearing in mind that the standards are not intended to be used to establish eligibility for participation in any federal program.

6. The standards should be developed to meet, at a minimum, Federal legislative and programmatic requirements. Consideration should also be given to needs at the State and local government levels, including American Indian tribal and Alaska Native village governments, as well as to general societal needs for these data.

7. The categories should set forth a minimum standard; additional categories should be permitted provided they can be aggregated to the standard categories. The number of standard categories should be kept to a manageable size, determined by statistical concerns and data needs.

8. A revised set of categories should be operationally feasible in terms of burden placed upon respondents; public and private costs to implement the revisions should be a factor in the decision.

9. Any changes in the categories should be based on sound methodological research and should include evaluations of the impact of any changes not only on the usefulness of the resulting data but also on the comparability of any new categories with the existing ones.

10. Any revision to the categories should provide for a crosswalk at the time of adoption between the old and the new categories so that historical data series can be statistically adjusted and comparisons can be made.

11. Because of the many and varied needs and strong interdependence of Federal agencies for racial and ethnic data, any changes to the

existing categories should be the product of an interagency collaborative effort.

12. Time will be allowed to phase in any new categories. Agencies will not be required to update historical records.

13. The new directive should be applicable throughout the U.S. Federal statistical system. The standard or standards must be usable for the decennial census, current surveys, and administrative records, including those using observer identification.

The principal objective of the review has been to enhance the accuracy of the demographic information collected by the Federal Government. The starting point for the review was the minimum set of categories for data on race and ethnicity that have provided information for more than 20 years for a variety of purposes, and the recognition of the importance of being able to maintain this historical continuity. The review process has had two major elements: (1) public comment on the present standards, which helped to identify concerns and provided numerous suggestions for changing the standards; and (2) research and testing related to assessing the possible effects of suggested changes on the quality and usefulness of the resulting data.

Public input, the first element of the review process, was sought through a variety of means: (1) During 1993, Congressman Thomas C. Sawyer, then Chairman of the House Subcommittee on Census, Statistics, and Postal Personnel, held four hearings that included 27 witnesses, focusing particularly on the use of the categories in the 2000 census. (2) At the request of OMB, the National Academy of Sciences' Committee on National Statistics (CNSTAT) conducted a workshop in February 1994 to articulate issues surrounding a review of the categories. The workshop included representatives of Federal agencies, academia, social science research institutions, interest groups, private industry, and a local school district. (A summary of the workshop, *Spotlight on Heterogeneity: The Federal Standards for Racial and Ethnic Classification*, is available from CNSTAT, 2101 Constitution Avenue, N.W., Washington, D.C. 20418.) (3) On June 9, 1994, OMB published a Federal Register (59 FR 29831-29835) Notice that contained background information on the development of the current standards and requested public comment on: the adequacy of current racial and ethnic categories; the principles that should govern any proposed revisions to the standards; and specific suggestions for change that had been offered by individuals and interested groups over a period of several years. In response, OMB received nearly 800 letters. As part of this comment period and to bring the review closer to the public, OMB also heard testimony from 94 witnesses at hearings held during July 1994 in Boston, Denver, San Francisco, and Honolulu. (4) In an August 28, 1995, Federal Register (60 FR 44674-44693) Notice, OMB provided an interim report on the review process, including a summary of the comments on the June 1994 Federal Register Notice, and offered a final opportunity for comment on the research to be conducted during 1996. (5) OMB staff have also discussed the review process with various interested groups and have made presentations at numerous meetings.

The second element of the review process involved research and

testing of various proposed changes. The categories in OMB's Directive No. 15 are used not only to produce data on the demographic characteristics of the population, but also to monitor civil rights enforcement and program implementation. Research was undertaken to provide an objective assessment of the data quality issues associated with various approaches to collecting data on race and ethnicity. To that end, the Interagency Committee's Research Working Group, co-chaired by the Bureau of the Census and the Bureau of Labor Statistics, reviewed the various criticisms and suggestions for changing the current categories, and developed a research agenda for some of the more significant issues that had been identified. These issues included how to collect data on persons who identify themselves as "multiracial"; whether to combine race and Hispanic origin in one question or have separate questions on race and Hispanic origin; whether to combine the concepts of race, ethnicity, and ancestry; whether to change the terminology used for particular categories; and whether to add new categories to the current minimum set.

Because the mode of data collection can have an effect on how a person responds, the research agenda proposed studies both in surveys using in-person or telephone interviews and in self-administered questionnaires, such as the decennial census, which are filled out by the respondent and mailed back. Cognitive interviews were conducted with various groups to provide guidance on the wording of the questions and the instructions for the tests and studies.

The research agenda included several major national tests, the results of which are discussed throughout the Interagency Committee's Report to the Office of Management and Budget on the Review of Statistical Policy Directive No. 15: (1) In May 1995, the Bureau of Labor Statistics (BLS) sponsored a Supplement on Race and Ethnicity to the Current Population Survey (CPS). The findings were made available in a 1996 report, *Testing Methods of Collecting Racial and Ethnic Information: Results of the Current Population Survey Supplement on Race*

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and Ethnicity, available from BLS, 2 Massachusetts Avenue, N.E., Room 4915, Postal Square Building, Washington, D.C. 20212, or by calling 202-606-7375. The results were also summarized in an October 26, 1995, news release, which is available electronically at <<<http://stats.bls.gov/news.release/ethnic.toc.htm>>>. (2) The Bureau of the Census, as part of its research for the 2000 census, tested alternative approaches to collecting data on race and ethnicity in the March 1996 National Content Survey (NCS). The Census Bureau published the results in a December 1996 report, *Findings on Questions on Race and Hispanic Origin Tested in the 1996 National Content Survey*; highlights of the report are available at <<<http://www.census.gov/population/www/socdemo/96natcontentsurvey.html>>>. (3) In June 1996, the Census Bureau conducted the Race and Ethnic Targeted Test (RAETT), which was designed

to permit assessments of the effects of possible changes on smaller populations not reliably measured in national samples, including American Indians, Alaska Natives, detailed Asian and Pacific Islander groups (such as Chinese and Hawaiians), and detailed Hispanic groups (such as Puerto Ricans and Cubans). The Census Bureau released the results in a May 1997 report, Results of the 1996 Race and Ethnic Targeted Test; highlights of the report are available at <<<http://www/census.gov/population/www/documentation/twps-0018.html>>>. Single copies (paper) of the NCS and RAETT reports may be obtained from the Population Division, U.S. Bureau of the Census, Washington, D.C. 20233; telephone 301-457-2402.

In addition to these three major tests, the National Center for Education Statistics (NCES) and the Office for Civil Rights in the Department of Education jointly conducted a survey of 1,000 public schools to determine how schools collect data on the race and ethnicity of their students and how the administrative records containing these data are maintained to meet statutory requirements for reporting aggregate information to the Federal Government. NCES published the results in a March 1996 report, Racial and Ethnic Classifications Used by Public Schools (NCES 96-092). The report is available electronically at <<<http://nces.ed.gov/pubs/96092.htm>>>. Single paper copies may be obtained from NCES, 555 New Jersey, NW, Washington, D.C. 20208-5574, or by calling 202-219-1442.

The research agenda also included studies conducted by the National Center for Health Statistics, the Office of the Assistant Secretary for Health, and the Centers for Disease Control and Prevention to evaluate the procedures used and the quality of the information on race and ethnicity in administrative records such as that reported on birth certificates and recorded on death certificates.

On July 9, 1997, OMB published a Federal Register Notice (62 FR 36874-36946) containing the Interagency Committee's Report to the Office of Management and Budget on the Review of Statistical Policy Directive No. 15. The Notice made available for comment the Interagency Committee's recommendations for how OMB should revise Directive No. 15. The report consists of six chapters. Chapter 1 provides a brief history of Directive No. 15, a summary of the issues considered by the Interagency Committee, a review of the research activities, and a discussion of the criteria used in conducting the evaluation. Chapter 2 discusses a number of general concerns that need to be addressed when considering any changes to the current standards. Chapters 3 through 5 report the results of the research as they bear on the more significant suggestions OMB received for changes to Directive No. 15. Chapter 6 gives the Interagency's Committee's recommendations concerning the various suggested changes based on a review of public comments and testimony and the research results.

### C. Summary of Comments Received on the Interagency Committee's Recommendations

In response to the July 9, 1997, Federal Register Notice, OMB received approximately 300 letters (many of them hand written) on a

variety of issues, plus approximately 7000 individually signed and mailed, preprinted postcards on the issue of classifying data on Native Hawaiians, and about 500 individually signed form letters from members of the Hapa Issues Forum in support of adopting the recommendation for multiple race reporting. Some of the 300 letters focused on a single recommendation of particular interest to the writer, while other letters addressed a number of the recommendations. The preponderance of the comments were from individuals. Each comment was considered in preparing OMB's decision.

## 1. Comments on Recommendations Concerning Reporting More Than One Race

The Interagency Committee recommended that, when self-identification is used, respondents who wish to identify their mixed racial heritage should be able to mark or select more than one of the racial categories originally specified in Directive No. 15, but that there should not be a "multiracial" category. This recommendation to report multiple races was favorably received by most of those commenting on it, including associations and organizations such as the American Medical Association, the National Education Association, the National Council of La Raza, and the National Committee on Vital and Health Statistics, as well as all Federal agencies that responded. Comments from some organizations, such as the NAACP Legal Defense and Educational Fund, the Lawyers' Committee for Civil Rights Under Law, and the Equal Employment Advisory Council, were receptive to the recommendation on multiple race responses, but expressed reservations pending development of tabulation methods to ensure the utility of these data. The recommendation was also supported by many of the advocacy groups that had earlier supported a "multiracial" (box) category, such as the Association of MultiEthnic Americans and its affiliates nationwide. Several individuals wrote in support of "multiple race" reporting, basing their comments on a September 1997 article, "What Race Am I?" in *Mademoiselle* magazine, which urged its readers "to express an opinion on whether or not a 'Multiracial' category should be included in all federal recordkeeping, including the 2000 census." A few comments specifically favoring multiple race responses suggested that respondents should also be asked to indicate their primary racial affiliation in order to facilitate the tabulation of responses. A handful of comments on multiple race reporting suggested that individuals with both Hispanic and non-Hispanic heritages be permitted to mark or select both categories (see discussion below).

A few comments, in particular some from state agencies and legislatures, opposed any multiple race reporting because of possible increased costs to collect the information and implementation problems. Comments from the American Indian tribal governments also were opposed to the recommendation concerning reporting more than one race. A number of the comments that supported multiple race responses also expressed concern about the cost and burden of collecting the information to meet Federal reporting requirements, the schedule for implementation, and how the data would be tabulated to meet the requirements of legislative redistricting

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and enforcement of the Voting Rights Act. A few comments expressed support for categories called “human,” or “American”; several proposed that there be no collection of data on race.

## 2. Comments on Recommendation for Classification of Data on Native Hawaiians

The Interagency Committee recommended that data on Native Hawaiians continue to be classified in the Asian or Pacific Islander category. This recommendation was opposed by the Hawaiian congressional delegation, the 7,000 individuals who signed and sent preprinted yellow postcards, the State of Hawaii departments and legislature, Hawaiian organizations, and other individuals who commented on this recommendation. Instead, the comments from these individuals supported reclassifying Native Hawaiians in the American Indian or Alaska Native category, which they view as an “indigenous peoples” category (although this category has not been considered or portrayed in this manner in the standards). Native Hawaiians, as the descendants of the original inhabitants of what is now the State of Hawaii, believe that as indigenous people they should be classified in the same category as American Indians and Alaska Natives. On the other hand, the American Indian tribal governments have opposed such a reclassification, primarily because they view the data obtained from that category as being essential for administering Federal programs for American Indians. Comments from the Native Hawaiians also noted the Asian or Pacific Islander category provides inadequate data for monitoring the social and economic conditions of Native Hawaiians and other Pacific Islander groups. Because the Interagency Committee had recommended against adding categories to the minimum set of categories, requesting a separate category for Native Hawaiians was not viewed as an option by those who commented.

## 3. Comments on Recommendation Concerning Classification of Data on Central and South American Indians

The Interagency Committee recommended that data for Central and South American Indians be included in the American Indian or Alaska Native category. Several comments from the American Indian community opposed this recommendation. Moreover, comments from some Native Hawaiians pointed out what they believed to be an inconsistency in the Interagency Committee’s recommendation to include in the American Indian or Alaska Native category descendants of Central and South American Indians--persons who are not original peoples of the United States--if Native Hawaiians were not to be included.

## 4. Comments on Recommendation Not to Add an Arab or Middle Eastern Ethnic Category

The Interagency Committee recommended that an Arab or Middle

Eastern ethnic category should not be added to the minimum standards for all reporting of Federal data on race and ethnicity. Several comments were received in support of having a separate category in order to have data viewed as necessary to monitor discrimination against this population.

## 5. Comments on Recommendations for Terminology

Comments on terminology largely supported the Interagency Committee's recommendations to retain the term "American Indian," to change "Hawaiian" to "Native Hawaiian," and to change "Black" to "Black or African American." There were a few requests to include "Latino" in the category name for the Hispanic population.

### D. OMB's Decisions

This section of the Notice provides information on the decisions taken by OMB on the recommendations that were proposed by the Interagency Committee. The Committee's recommendations addressed options for reporting by respondents, formats of questions, and several aspects of specific categories, including possible additions, revised terminology, and changes in definitions. In reviewing OMB's decisions on the recommendations for collecting data on race and ethnicity, it is useful to remember that these decisions:

- retain the concept that the standards provide a minimum set of categories for data on race and ethnicity;
- permit the collection of more detailed information on population groups provided that any additional categories can be aggregated into the minimum standard set of categories;
- underscore that self-identification is the preferred means of obtaining information about an individual's race and ethnicity, except in instances where observer identification is more practical (e.g., completing a death certificate);
- do not identify or designate certain population groups as "minority groups";
- continue the policy that the categories are not to be used for determining the eligibility of population groups for participation in any Federal programs;
- do not establish criteria or qualifications (such as blood quantum levels) that are to be used in determining a particular individual's racial or ethnic classification; and
- do not tell an individual who he or she is, or specify how an individual should classify himself or herself.

In arriving at its decisions, OMB took into account not only the public comment on the recommendations published in the Federal Register on July 9, 1997, but also the considerable amount of information provided during the four years of this review process, including public comments gathered from hearings and responses to two earlier OMB Notices (on June 9, 1994, and August 28, 1995). The OMB decisions

benefited greatly from the participation of the public that served as a constant reminder that there are real people represented by the data on race and ethnicity and that this is for many a deeply personal issue. In addition, the OMB decisions benefited from the results of the research and testing on how individuals identify themselves that was undertaken as part of this review process. This research, including several national tests of alternative approaches to collecting data on race and ethnicity, was developed and conducted by the professional statisticians and analysts at several Federal agencies. They are to be commended for their perseverance, dedication, and professional commitment to this challenging project.

OMB also considered in reaching its decisions the extent to which the recommendations were consistent with the set of principles (see Section B of the Supplementary Information) developed by the Interagency Committee to guide the review of this sensitive and substantively complex issue. OMB believes that the Interagency Committee's recommendations took into account the principles and achieved a reasonable balance with respect to statistical issues, data needs, social concerns, and the personal dimensions of racial and ethnic identification. OMB also finds that the Committee's recommendations are consistent with the principal objective of the review, which is to enhance the accuracy of the demographic information collected by the Federal Government by having categories for data on race and ethnicity that will enable the capture of information about the increasing diversity of our Nation's population while at the same time respecting each individual's dignity.

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As indicated in detail below, OMB accepts the Interagency Committee's recommendations concerning reporting more than one race, including the recommendation that there be no category called "multiracial," the formats and sequencing of the questions on race and Hispanic origin, and most of the changes to terminology.

OMB does not accept the Interagency Committee's recommendations concerning the classification of data on the Native Hawaiian population and the terminology for Hispanics, and it has instead decided to make the changes that follow.

**Native Hawaiian classification.**--OMB does not accept the recommendation concerning the continued classification of Hawaiians in the Asian or Pacific Islander category. Instead, OMB has decided to break apart the Asian or Pacific Islander category into two categories -- one called "Asian" and the other called "Native Hawaiian or Other Pacific Islander." As a result, there will be five categories in the minimum set for data on race.

The "Native Hawaiian or Other Pacific Islander" category will be defined as "A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands." (The term "Native Hawaiian" does not include individuals who are native to the State of Hawaii by virtue of being born there.) In addition to Native Hawaiians,

Guamanians, and Samoans, this category would include the following Pacific Islander groups reported in the 1990 census: Carolinian, Fijian, Kosraean, Melanesian, Micronesian, Northern Mariana Islander, Palauan, Papua New Guinean, Ponapean (Pohnpelan), Polynesian, Solomon Islander, Tahitian, Tarawa Islander, Tokelauan, Tongan, Trukese (Chuukese), and Yapese.

The "Asian" category will be defined as "A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam."

The Native Hawaiians presented compelling arguments that the standards must facilitate the production of data to describe their social and economic situation and to monitor discrimination against Native Hawaiians in housing, education, employment, and other areas. Under the current standards for data on race and ethnicity, Native Hawaiians comprise about three percent of the Asian and Pacific Islander population. By creating separate categories, the data on the Native Hawaiians and other Pacific Islander groups will no longer be overwhelmed by the aggregate data of the much larger Asian groups. Native Hawaiians will comprise about 60 percent of the new category.

The Asian, Native Hawaiian, and Pacific Islander population groups are well defined; moreover, there has been experience with reporting in separate categories for the Native Hawaiian and Pacific Islander population groups. The 1990 census included "Hawaiian," "Samoan," and "Guamanian" as response categories to the race question. In addition, two of the major tests conducted as part of the current review (the NCS and the RAETT) used "Hawaiian" and/or "Native Hawaiian," "Samoan," "Guamanian," and "Guamanian or Chamorro" as response options to the race question. These factors facilitate breaking apart the current category.

Terminology for Hispanics.--OMB does not accept the recommendation to retain the single term "Hispanic." Instead, OMB has decided that the term should be "Hispanic or Latino." Because regional usage of the terms differs--Hispanic is commonly used in the eastern portion of the United States, whereas Latino is commonly used in the western portion--this change may contribute to improved response rates.

The OMB decisions on the Interagency Committee's specific recommendations are presented below:

(1) OMB accepts the following recommendations concerning reporting more than one race:

When self-identification is used, a method for reporting more than one race should be adopted.

The method for respondents to report more than one race should take the form of multiple responses to a single question and not a "multiracial" category.

When a list of races is provided to respondents, the list should not contain a "multiracial" category.

Based on research conducted so far, two recommended forms for the instruction accompanying the multiple response question are "Mark one or more \* \* \*" and "Select one or more \* \* \*"

If the criteria for data quality and confidentiality are met, provision should be made to report, at a minimum, the number of individuals identifying with more than one race. Data producers are encouraged to provide greater detail about the distribution of multiple responses.

The new standards will be used in the decennial census, and other data producers should conform as soon as possible, but not later than January 1, 2003.

(2) OMB accepts the following recommendations concerning a combined race and Hispanic ethnicity question:

When self-identification is used, the two question format should be used, with the race question allowing the reporting of more than one race.

When self-identification is not feasible or appropriate, a combined question can be used and should include a separate Hispanic category co-equal with the other categories.

When the combined question is used, an attempt should be made, when appropriate, to record ethnicity and race or multiple races, but the option to indicate only one category is acceptable.

(3) OMB accepts the following recommendations concerning the retention of both reporting formats:

The two question format should be used in all cases involving self-identification.

The current combined question format should be changed and replaced with a new format which includes a co-equal Hispanic category for use, if necessary, in observer identification.

(4) OMB accepts the following recommendation concerning the ordering of the Hispanic origin and race questions:

When the two question format is used, the Hispanic origin question should precede the race question.

(5) OMB accepts the following recommendation concerning adding Cape Verdean as an ethnic category:

A Cape Verdean ethnic category should not be added to the minimum data collection standards.

(6) OMB accepts the following recommendation concerning the addition of an Arab or Middle Eastern ethnic category:

An Arab or Middle Eastern ethnic category should not be added to the minimum data standards.

(7) OMB interprets the recommendation not to add any other categories to mean the expansion of the minimum set to include new population groups. The OMB decision to break apart the "Asian or Pacific Islander" category does not create a category for a new population group.

(8) OMB accepts the following recommendation concerning changing the term "American Indian" to "Native American":

The term American Indian should not be changed to Native American.

(9) OMB accepts the following recommendation concerning changing the term "Hawaiian" to "Native Hawaiian":

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The term "Hawaiian" should be changed to "Native Hawaiian."

(10) OMB does not accept the recommendation concerning the continued classification of Native Hawaiians in the Asian or Pacific Islander category.

OMB has decided to break apart the Asian or Pacific Islander category into two categories--one called "Asian" and the other called "Native Hawaiian or Other Pacific Islander." As a result, there are five categories in the minimum set for data on race.

The "Native Hawaiian or Other Pacific Islander" category is defined as "A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands."

The "Asian" category is defined as "A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam."

(11) OMB accepts the following recommendations concerning the use of "Alaska Native" instead of "Eskimo" and "Aleut": "Alaska Native" should replace the term "Alaskan Native."

Alaska Native should be used instead of Eskimo and Aleut.

The Alaska Native response option should be accompanied by a request for tribal affiliation when possible.

(12) OMB accepts the following recommendations concerning the classification of Central and South American Indians:

Central and South American Indians should be classified as American Indian.

The definition of the "American Indian or Alaska Native" category should be modified to include the original peoples from Central and South America.

In addition, OMB has decided to make the definition for the American Indian or Alaska Native category more consistent with the definitions of the other categories.

(13) OMB accepts the following recommendations concerning the term or terms to be used for the name of the Black category:

The name of the Black category should be changed to "Black or African American."

The category definition should remain unchanged.

Additional terms, such as Haitian or Negro, can be used if desired.

(14) OMB decided to modify the recommendations concerning the term or terms to be used for Hispanic:

The term used should be "Hispanic or Latino."

The definition of the category should remain unchanged.

In addition, the term "Spanish Origin," can be used if desired.

Accordingly, the Office of Management and Budget adopts and issues the revised minimum standards for Federal data on race and ethnicity for major population groups in the United States which are set forth at the end of this Notice.

## Topics for Further Research

There are two areas where OMB accepts the Interagency Committee's recommendations but believes that further research is needed: (1) multiple responses to the Hispanic origin question and (2) an ethnic category for Arabs/Middle Easterners.

**Multiple Responses to the Hispanic Origin Question.**--The Interagency Committee recommended that respondents to Federal data collections should be permitted to report more than one race. During the most recent public comment process, a few comments suggested that the concept of "marking more than one box" should be extended to the Hispanic origin question. Respondents are now asked to indicate if they are "of Hispanic origin" or "not of Hispanic origin." Allowing individuals to select more than one response to the ethnicity question would provide the opportunity to indicate ethnic heritage that is both Hispanic and non-Hispanic.

The term "Hispanic" refers to persons who trace their origin or descent to Mexico, Puerto Rico, Cuba, Central and South America, and other Spanish cultures. While there has been considerable public concern about the need to review Directive No. 15 with respect to classifying individuals of mixed racial heritage, there has been little comment on reporting both an Hispanic and a non-Hispanic origin. On many Federal forms, Hispanics can also express a racial identity on a separate race question. In the decennial census, individuals who consider themselves part Hispanic can also indicate additional heritages in the ancestry question.

On one hand, it can be argued that allowing individuals to mark both categories in the Hispanic origin question would parallel the instruction "to mark (or select) one or more" racial categories. Individuals would not have to choose between their parents' ethnic heritages, and movement toward an increasingly diverse society would be recognized.

On the other hand, because the matter of multiple responses to the Hispanic ethnicity question was not raised in the early phases of the public comment process, no explicit provisions were made for testing this approach in the research conducted to inform the review of Directive No. 15. While a considerable amount of research was focused on how to improve the response rate to the Hispanic origin question, it is unclear whether and to what extent explicitly permitting multiple responses to the Hispanic origin question would affect nonresponse to the race question or hamper obtaining more detailed data on Hispanic population groups.

Information on the possible impact of any changes on the quality of the data has been an essential element of the review. While the effects of changes in the Hispanic origin question are unknown, they could conceivably be substantial. Thus, OMB has decided not to include a provision in the standards that would explicitly permit respondents to select both "Hispanic origin" and "Not of Hispanic Origin" options. OMB believes that this is an item for future research. In the meantime, the ancestry question on the decennial census long form does provide respondents who consider themselves part Hispanic to write in additional heritages.

Research on an Arab/Middle Easterner category.--During the public comment process, OMB received a number of requests to add an ethnic category for Arabs/Middle Easterners so that data could be obtained that could be useful in monitoring discrimination. The public comment process indicated, however, that there was no agreement on a definition for this category. The combined race, Hispanic origin, and ancestry question in the RAETT, which was designed to address requests that were received from groups for establishing separate categories, did not provide a solution.

While OMB accepted the Interagency's Committee recommendation not to create a new category for this population group, OMB believes that further research should be done to determine the best way to improve data on this population group. Meanwhile, the write-ins to the ancestry question on the decennial census long form will continue to provide information on the number of individuals who identify their heritage as Arab or Middle Easterner.

#### E. Tabulation Issues

The revised standards retain the concept of a minimum set of categories for Federal data on race and ethnicity and make possible at the same time the collection of data to reflect the diversity of our Nation's population. Since the

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Interagency Committee's recommendation concerning the reporting of more than one race was made available for public comment, the focus of attention has been largely on how the data would be tabulated. Because of the concerns expressed about tabulation methods and our own view of the importance of this issue, OMB committed to accelerate the work on tabulation issues when it testified in July 1997 on the Interagency Committee's recommendations.

A group of statistical and policy analysts drawn from the Federal agencies that generate or use these data has spent the past few months considering the tabulation issues. Although this work is still in its early stages, some preliminary guidance can be shared at this time. In general, OMB believes that, consistent with criteria for confidentiality and data quality, the tabulation procedures used by the agencies should result in the production of as much detailed information on race and ethnicity as possible.

Guidelines for tabulation ultimately must meet the needs of at least two groups within the Federal Government, with the overriding objective of providing the most accurate and informative body of data. The first group is composed of those government officials charged with carrying out constitutional and legislative mandates, such as redistricting legislatures, enforcing civil rights laws, and monitoring progress in anti-discrimination programs. (The legislative redistricting file produced by the Bureau of the Census, also known as the Public Law 94-171 file, is an example of a file meeting such legislative needs.) The second group consists of the staff of

statistical agencies producing and analyzing data that are used to monitor economic and social conditions and trends.

Many of the needs of the first group can be met with an initial tabulation that provides, consistent with standards for data quality and confidentiality, the full detail of racial reporting; that is, the number of people reporting in each single race category and the number reporting each of the possible combinations of races, which would add to the total population. Depending on the judgment of users, the combinations of multiple responses could be collapsed. One method would be to provide separate totals for those reporting in the most common multiple race combinations and to collapse the data for other less frequently reported combinations. The specifics of the collapsed distributions must await the results of particular data collections. A second method would be to report the total selecting each particular race, whether alone or in combination with other races. These totals would represent upper bounds on the size of the populations who identified with each of the racial categories. In some cases, this latter method could be used for comparing data collected under the old standards with data collected under the new standards. It is important that users with the same or closely related responsibilities adopt the same tabulation method. Regardless of the method chosen for collapsing multiple race responses, the total number reporting more than one race must be made available, if confidentiality and data quality requirements can be met, in order to ensure that any changes in response patterns resulting from the new standards can be monitored over time.

Meeting the needs of the second group (those producing and analyzing statistical data to monitor economic and social conditions and trends), as well as some additional needs of the first group, may require different tabulation procedures. More research must be completed before guidelines that will meet the requirements of these users can be developed. A group of statistical and policy experts will review a number of alternative procedures and provide recommendations to OMB concerning these tabulation requirements by Spring 1998. Four of the areas in which further exploration is needed are outlined below.

Equal employment opportunity and other anti-discrimination programs have traditionally provided the numbers of people in the population by selected characteristics, including racial categories, for business, academic, and government organizations to use in evaluating conformance with program objectives. Because of the potentially large number of categories that may result from application of the new standards, many with very small numbers, it is not clear how this need for data will be best satisfied in the future.

The numbers of people in distinct groups based on decennial census results are used in developing sample designs and survey controls for major demographic surveys. For example, the National Health Interview Survey uses census data to increase samples for certain population groups, adjust for survey non-response, and provide weights for estimating health outcomes at the national level. The impact of having data for many small population groups with

multiple racial heritages must be explored.

Vital statistics data include birth and death rates for various population groups. Typically the numerator (number of births or deaths) is derived from administrative records, while the denominator comes from intercensal population estimates. Birth certificate data on race are likely to have been self reported by the mother. Over time, these data may become comparable to data collected under the new standards. Death certificate data, however, frequently are filled out by an observer, such as a mortician, physician, or funeral director. These data, particularly for the population with multiple racial heritages, are likely to be quite different from the information obtained when respondents report about themselves. Research to define comparable categories to be used in both numerators and denominators is needed to assure that vital statistics are as accurate and useful as possible.

More generally, statistical indicators are often used to measure change over time. Procedures that will permit meaningful comparisons of data collected under the previous standards with those that will be collected under the new standards need to be developed.

The methodology for tabulating data on race and ethnicity must be carefully developed and coordinated among the statistical agencies and other Federal data users. Moreover, just as OMB's review and decision processes have benefited during the past four years from extensive public participation, we expect to discuss tabulation methods with data users within and outside the Federal Government. OMB expects to issue additional guidance with respect to tabulating data on race and ethnicity by Fall 1998.

Sally Katzen,  
Administrator, Office of Information and Regulatory Affairs.

#### Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity

This classification provides a minimum standard for maintaining, collecting, and presenting data on race and ethnicity for all Federal reporting purposes. The categories in this classification are social-political constructs and should not be interpreted as being scientific or anthropological in nature. They are not to be used as determinants of eligibility for participation in any Federal program. The standards have been developed to provide a common language for uniformity and comparability in the collection and use of data on race and ethnicity by Federal agencies.

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The standards have five categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. There are two categories for data on ethnicity: "Hispanic or Latino," and "Not Hispanic or Latino."

## 1. Categories and Definitions

The minimum categories for data on race and ethnicity for Federal statistics, program administrative reporting, and civil rights compliance reporting are defined as follows:

**American Indian or Alaska Native.** A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

**Asian.** A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

**Black or African American.** A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."

**Hispanic or Latino.** A person of Cuban, Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino."

**Native Hawaiian or Other Pacific Islander.** A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

**White.** A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Respondents shall be offered the option of selecting one or more racial designations. Recommended forms for the instruction accompanying the multiple response question are "Mark one or more" and "Select one or more."

## 2. Data Formats

The standards provide two formats that may be used for data on race and ethnicity. Self-reporting or self-identification using two separate questions is the preferred method for collecting data on race and ethnicity. In situations where self-reporting is not practicable or feasible, the combined format may be used.

In no case shall the provisions of the standards be construed to limit the collection of data to the categories described above. The collection of greater detail is encouraged; however, any collection that uses more detail shall be organized in such a way that the additional categories can be aggregated into these minimum categories for data on race and ethnicity.

With respect to tabulation, the procedures used by Federal agencies shall result in the production of as much detailed information on race and ethnicity as possible. However, Federal agencies shall not present data on detailed categories if doing so would compromise data quality

or confidentiality standards.

a. Two-Question Format

To provide flexibility and ensure data quality, separate questions shall be used wherever feasible for reporting race and ethnicity. When race and ethnicity are collected separately, ethnicity shall be collected first. If race and ethnicity are collected separately, the minimum designations are:

Race:

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

Ethnicity:

- Hispanic or Latino
- Not Hispanic or Latino

When data on race and ethnicity are collected separately, provision shall be made to report the number of respondents in each racial category who are Hispanic or Latino.

When aggregate data are presented, data producers shall provide the number of respondents who marked (or selected) only one category, separately for each of the five racial categories. In addition to these numbers, data producers are strongly encouraged to provide the detailed distributions, including all possible combinations, of multiple responses to the race question. If data on multiple responses are collapsed, at a minimum the total number of respondents reporting “more than one race” shall be made available.

b. Combined Format

The combined format may be used, if necessary, for observer-collected data on race and ethnicity. Both race (including multiple responses) and ethnicity shall be collected when appropriate and feasible, although the selection of one category in the combined format is acceptable. If a combined format is used, there are six minimum categories:

- American Indian or Alaska Native
- Asian
- Black or African American
- Hispanic or Latino
- Native Hawaiian or Other Pacific Islander
- White

When aggregate data are presented, data producers shall provide the number of respondents who marked (or selected) only one category, separately for each of the six categories. In addition to these

numbers, data producers are strongly encouraged to provide the detailed distributions, including all possible combinations, of multiple responses. In cases where data on multiple responses are collapsed, the total number of respondents reporting “Hispanic or Latino and one or more races” and the total number of respondents reporting “more than one race” (regardless of ethnicity) shall be provided.

### 3. Use of the Standards for Record Keeping and Reporting

The minimum standard categories shall be used for reporting as follows:

#### a. Statistical Reporting

These standards shall be used at a minimum for all federally sponsored statistical data collections that include data on race and/or ethnicity, except when the collection involves a sample of such size that the data on the smaller categories would be unreliable, or when the collection effort focuses on a specific racial or ethnic group. Any other variation will have to be specifically authorized by the Office of Management and Budget (OMB) through the information collection clearance process. In those cases where the data collection is not subject to the information collection clearance process, a direct request for a variance shall be made to OMB.

#### b. General Program Administrative and Grant Reporting

These standards shall be used for all Federal administrative reporting or record keeping requirements that include data on race and ethnicity. Agencies that cannot follow these standards must request a variance from OMB. Variances will be considered if the agency can demonstrate that it is not reasonable for the primary reporter to determine racial or ethnic background in terms of the specified categories, that determination of racial or ethnic background is not critical to the administration of the program in question, or that the specific program is directed to only one or a limited number of racial or ethnic groups.

#### c. Civil Rights and Other Compliance Reporting

These standards shall be used by all Federal agencies in either the separate or combined format for civil rights and

[[Page 58790]]

other compliance reporting from the public and private sectors and all levels of government. Any variation requiring less detailed data or data which cannot be aggregated into the basic categories must be specifically approved by OMB for executive agencies. More detailed reporting which can be aggregated to the basic categories may be used at the agencies’ discretion.

### 4. Presentation of Data on Race and Ethnicity

Displays of statistical, administrative, and compliance data on race and ethnicity shall use the categories listed above. The term “nonwhite” is not acceptable for use in the presentation of Federal

Government data. It shall not be used in any publication or in the text of any report.

In cases where the standard categories are considered inappropriate for presentation of data on particular programs or for particular regional areas, the sponsoring agency may use:

a. The designations "Black or African American and Other Races" or "All Other Races" as collective descriptions of minority races when the most summary distinction between the majority and minority races is appropriate;

b. The designations "White," "Black or African American," and "All Other Races" when the distinction among the majority race, the principal minority race, and other races is appropriate; or

c. The designation of a particular minority race or races, and the inclusion of "Whites" with "All Other Races" when such a collective description is appropriate.

In displaying detailed information that represents a combination of race and ethnicity, the description of the data being displayed shall clearly indicate that both bases of classification are being used.

When the primary focus of a report is on two or more specific identifiable groups in the population, one or more of which is racial or ethnic, it is acceptable to display data for each of the particular groups separately and to describe data relating to the remainder of the population by an appropriate collective description.

## 5. Effective Date

The provisions of these standards are effective immediately for all new and revised record keeping or reporting requirements that include racial and/or ethnic information. All existing record keeping or reporting requirements shall be made consistent with these standards at the time they are submitted for extension, or not later than January 1, 2003.

[FR Doc. 97-28653 Filed 10-29-97; 8:45 am]

BILLING CODE 3110-01-P

April 27, 2023

Shalanda Young  
Director  
Office of Management and Budget  
1650 17th Street NW  
Washington, DC 20500

**Re: Submission of Group Sign-on Letter to Revise OMB's 1997 Statistical Policy Directive No. 15**

Dear Director Young,

The undersigned organizations appreciate the opportunity to comment on the initial proposals from the Federal Interagency Technical Working Group on Race and Ethnicity Standards (Working Group) for revising OMB's 1997 Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD 15).

We represent patient advocacy, health care and business leadership organizations and have come together to advance a stakeholder-informed data equity movement that includes engagement with federal agencies, employers, labor, health systems, clinicians and historically under-represented populations. The recommendations that follow stem from three invitational stakeholder convenings in 2022 in which we participated to discuss the issues that attend data collection standards and ethical use with regards to race, ethnicity and language (REL) data and sexual orientation and gender identity (SOGI) data. They are explained in greater detail in an issue brief released in March by the National Minority Quality Forum and the Blue Cross Blue Shield Association entitled, *“Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy.”*

Significant health inequities plague the U.S. health care system, impacting historically marginalized racial<sup>1</sup>, ethnic, socioeconomic<sup>2</sup> and LGBTQ+<sup>3</sup> communities.<sup>4</sup> There are many causes for these inequities, including, but not limited to, systemic racial, ethnic, language and LGBTQ+ biases and their intersectional relationship to concomitant sex, gender, age, disability, socioeconomic, cultural and geographic factors. Together, these forces have created, perpetuated and exacerbated inequalities in access to the benefits of the American health services research, delivery and financing system. The consequences of these biases manifest as disparate, but preventable and amenable morbidity and mortality every year.

The well-documented disparities in the availability of and access to high-quality health care in terms of diagnosis and treatment that could result in disparate outcomes are pervasive, multi-faceted and multi-

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<sup>1</sup> U.S. Department of Health and Human Services Task Force on Black and Minority Health, 1985-1986.

[https://collections.nlm.nih.gov/catalog/nlm:nlmuid-8602912-mvset?\\_gl=1\\*1kfz8hy\\*\\_ga\\*MTI0NDgzOTM2NS4xNjc3Njk2Mzg5\\*\\_ga\\_P1FPTH9PL4\\*MTY3NzY5NjUwMS4xLjAuMTY3NzY5NjUwMS4wLjAuMA.\\*\\_ga\\_7147EPK006\\*MTY3NzY5NjUwMS4xLjAuMTY3NzY5NjUwMS4wLjAuMA.](https://collections.nlm.nih.gov/catalog/nlm:nlmuid-8602912-mvset?_gl=1*1kfz8hy*_ga*MTI0NDgzOTM2NS4xNjc3Njk2Mzg5*_ga_P1FPTH9PL4*MTY3NzY5NjUwMS4xLjAuMTY3NzY5NjUwMS4wLjAuMA.*_ga_7147EPK006*MTY3NzY5NjUwMS4xLjAuMTY3NzY5NjUwMS4wLjAuMA.)

<sup>2</sup> Riley WJ. “Health disparities: gaps in access, quality and affordability of medical care.” *Trans Am Clin Climatol Assoc.* 2012. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3540621/>.

<sup>3</sup> Baptiste-Roberts K, Oranuba E, Werts N, Edwards LV. “Addressing Health Care Disparities Among Sexual Minorities.” *Obstet Gynecol Clin North Am.* March 2017. <https://pubmed.ncbi.nlm.nih.gov/28160894/>.

<sup>4</sup> Blue Cross Blue Shield Association. “The Ethical and Transparent Use of Data to Reduce Health Disparities,” page 2. [https://www.bcbs.com/sites/default/files/healthequity/REL/HE\\_REL\\_Data\\_Paper.pdf](https://www.bcbs.com/sites/default/files/healthequity/REL/HE_REL_Data_Paper.pdf).

sectorial. They are challenging, but not insurmountable. Failure to be proactive to redress these inequities compromises not only the health of families and communities, but also the financial health of employers and the bottom lines of businesses across all industry sectors.

The planned OMB update of Directive No. 15 can enable every sector of the health services research, delivery and financing system to advance the diversity, equity and inclusion plans that they have announced as priorities. Further, a case can be made that absent the Directive No. 15 update and other steps outlined below, collectively, these efforts will fail.

The value of comprehensive data on a full range of populations and population cohorts cannot be overstated. Standardized, precise data create opportunities for insurers, health care providers, employers and patient advocates to design and implement targeted solutions to better meet the needs of perpetually underserved groups. Through adoption of robust and comprehensive REL and SOGI data, health entities can better monitor health services access and utilization, design focused incentives for health providers to reduce inequities, track changes in health outcomes by population cohort and respond accordingly, and more accurately measure progress on reducing disparities. By incorporating a richer data set reflecting inclusive workforce composition, employers can make informed decisions on which health plan can best meet the needs of employees and their families.

Collecting and exchanging data with the right level of detail necessitates a multi-stakeholder effort. No single sector has sufficiently robust and precise data to redress systemic inequities in health care. The collaboration between health care leaders, social service agencies and community-based organizations supports working together to address data equity challenges. Because such inequities are universal, it is imperative the health care research, delivery and financing enterprise coalesce around adoption of national data collection and standards for health equity data sets. The Office of the National Coordinator for Health IT (ONC) noted that advancing the use of data standards and interoperability of health equity data is crucial to improving the health and well-being of all individuals and communities. Beyond adopting a common standard for health equity data, more work is needed across the ecosystem to solve this challenge.<sup>5</sup>

Industry adoption of updated Directive No. 15 standards is essential. During the Directive No. 15 updating process, the evolving nature of SOGI data must be accommodated. Equity in access to the data collection process, as well as assuring that all population cohorts are reflected in the data is at the crux of systemic equity.

In addition to technical standards, standards are needed to define how best to engage with individuals and their families. If trust is indeed a factor that affects the ability to collect reliable data, distrust must not be triggered during the data collection process. Uniformity in the data collection tools, lexicon and framing of questions is essential.

Accordingly, we support the following recommendations for inclusion in the OMB Directive No. 15 update that is scheduled for completion in 2024:

- Directive No. 15 should provide clear and consistent requirements for the collection, of REL and SOGI data that include a minimum standard for disaggregated R/E collection and are consistent with

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<sup>5</sup> Blue Cross Blue Shield Association. "The Ethical and Transparent Use of Data to Reduce Health Disparities," page 5. [https://www.bcbs.com/sites/default/files/healthequity/REL/HE\\_REL\\_Data\\_Paper.pdf](https://www.bcbs.com/sites/default/files/healthequity/REL/HE_REL_Data_Paper.pdf).

industry interoperability standards (e.g., Fast Healthcare Interoperability Resources (FHIR) standards).

- OMB should incorporate the current data standards promulgated by the DHHS Assistant Secretary for Planning and Evaluation/Office of Minority Health into Directive No. 15 and require that these be the minimum standard categories for collecting disaggregated REL data.
- OMB should intentionally and proactively elicit and accept additional input from diverse stakeholders regarding SOGI data collection and utilization into the Directive No. 15 update.
- OMB should enforce non-voluntary, uniform and universal adoption of the updated OMB Directive No. 15 standards upon release in 2024 for all government agencies, and all private sector health care stakeholders including payers and providers.

Thank you for your consideration of these recommendations. We stand ready to work with the Working Group and OMB to implement an inclusive updating process that will serve to improve the inputs and outcomes of health care, inform research and innovation, and assure that coverage and payment policies reflect and assign equitable value to the full diversity of the American general population.

Sincerely,

Advocates for Community Health

Alliance for Women's Health & Prevention

American Benefits Council

American Cancer Society Cancer Action Network

American College of Physicians

American Diabetes Association

American Heart Association

American Nurses Association

Association of Black Cardiologists

Association of Black Health-system Pharmacists

Black Women's Health Imperative

Blue Cross Blue Shield Association

Minority Health Institute, Inc

National Health Council

National Hispanic Medical Association

National LGBTQ Task Force

National Minority Quality Forum

National Rural Health Association

Satcher Health Leadership Institute, Morehouse School of Medicine

# Data Equity Coalition

## MISSION

*The mission of the Data Equity Coalition is to develop and recommend policy solutions that advocate for race, ethnicity, language representation and sexual orientation and gender identification standards in support of health outcomes.*

## Background

Starting in August 2022, the National Minority Quality Forum and Blue Cross Blue Shield Association jointly led four Data Equity Community Convenings collectively attended by over 25 organizations representing patients, consumers, payers, providers, businesses, and social change constituencies. Together, these leaders discussed gaps in data specificity that support efforts to address health equity, specifically the variability in the types of data collected, and how data is analyzed and applied. Discussants also emphasized the importance of understanding the manner in which data is collected, noting that the highest quality data is self-reported.

NMQF and BCBSA took the learnings from these convenings and applied them in an issue brief, [“Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy.”](#) The brief describes policy challenges and recommended solutions to advance a stakeholder-informed data equity movement that includes engagement with federal agencies, employers, labor, health systems, clinicians and historically under-represented populations. Specifically, the brief makes four recommendations to the Office of Management and Budget for an update to Statistical Policy Directive No. 15 (SPD 15) by summer 2024, the federal government’s minimum standard for collecting race and ethnicity data.

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**Purpose** Influence the content of OMB’s updated SPD 15 standards. Educate policymakers on the importance of data in advancing health equity and the need for more granular data collection standards.

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**Meeting Frequency** Bi-monthly for one hour, virtual only or hybrid in format

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**Membership** Organizations representing patients, consumers, payers, providers, businesses, and social change constituencies.

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**Structure/ Responsibilities** The coalition will be convened by NMQF and BCBSA. All other members will be responsible for attending meetings, sharing their perspectives on the topics under discussion, reviewing documents and opting-in to public-facing collective activities.

## Collective Advocacy and Education

The Data Equity Coalition's initial efforts will focus on collective advocacy to advance the consensus-based policy recommendations in the issue brief that, when implemented, will strengthen the data foundation and accrue to the benefit of all corporate and consumer stakeholders. Specifically, the coalition will engage with the Office of Management and Budget through public comment opportunities and private meetings to socialize and refine recommendations for improving SPD 15 by further disaggregating the minimum standard collection categories and requiring non-voluntary, uniform and universal adoption of the new SPD 15 by all government and private sector stakeholders. In addition to working to improve SPD 15, the coalition members will brainstorm additional opportunities for collective engagement to further advance data equity.

The Coalition will also seek to educate government and private sector stakeholders on the meaning of data equity, and the importance of data equity as a pillar of health equity through meetings and written communications. The value of comprehensive data on a full range of populations and population cohorts cannot be overstated. Standardized, precise data create opportunities for the healthcare ecosystem to design and implement targeted solutions that meet the needs of historically underrepresented communities.

High-quality, reliable data are key to measuring, monitoring and reporting changes in the care provided, in the outcomes of the care, and in the disparities associated with those outcomes. Health care and health policy professionals recognize that data collection and analysis should reflect the extraordinary diversity of the American population if genuine progress is to be achieved. Together, we will brainstorm and execute on projects to spread this message and advance our goal of creating a health care system that is informed by diverse voices to equally serve all our country's diverse populations with dignity and respect.

## Opportunities for Stakeholder Engagement

OMB has given a timeline of Summer 2024 to release the revisions to SPD 15.

- We are expecting at least one more formal comment opportunity when OMB releases their proposal, likely in Fall 2023 (based on Technical Working Group proposal + public comments).
- NMQF is seeking a meeting with OMB to explore the feasibility of our recommendations.
- Potential additional sign on and meeting opportunities for coalition members for meeting with OMB, other entities under the HHS umbrella, including (Office of the CMS Administrator, Office of Minority, Health, CMII, etc).
  - There may be opportunities to further refine collection categories to meet the needs of coalition members.
- Education around socialization of the issue brief recommendations with the Hill/ Tri-Caucus and other policymakers are being explored for the coming year.



# News Release

**For Immediate Release:**

April 29, 2024

**Contact:**

[Press@bcbsa.com](mailto:Press@bcbsa.com)

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**Health Equity Cannot Be Achieved Without Data Equity**

*New issue briefs from the Data Equity Coalition give recommendations to standardize data collection methods to improve health outcomes in historically underserved communities*

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**CHICAGO** – To reduce inequities in the U.S. health system, the Data Equity Coalition is calling for standardized data collection methods around race, ethnicity, language (REL), sexual orientation, gender identity (SOGI) and disability status through a new series of [issue briefs](#).

“Data standardization is crucial to advancing health equity and creating a better system of health—one centered on trust,” said Blue Cross Blue Shield Association President and CEO, Kim Keck. “Data is more than just numbers—data represents real people. When every part of the health care system collects the same inclusive information, we can work together to ensure people get the care that they need.”

[Significant inequities](#) plague the U.S. health care system and disproportionately impact historically marginalized racial, ethnic, socioeconomic and LGBTQ+ communities. As a result, these underserved and under-represented communities experience birth complications at [higher rates](#), face [greater barriers](#) to accessing mental health care and are [more likely](#) to die from treatable and preventable conditions. Without clear data standards, these equity gaps will persist.

“NMQF’s mission is to reduce patient risk by assuring optimal care for all,” said National Minority Quality Forum President and CEO, Gary Puckrein, Ph.D. “Our vision is an American health services research, delivery, and financing system whose operating principle is to reduce patient risk for amenable morbidity and mortality while improving quality of life. Within that context, partnering with BCBSA and other engaged organizations on data equity has been, and continues to be logical and essential.”

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For the first time since 1997, the Office of Management and Budget published revised federal standards for maintaining, collecting and presenting federal data on race and ethnicity, but more progress is needed to better reflect the changing demographics of the U.S. population.

Among other recommendations to advance true data equity, the Data Equity Coalition calls for:

- Ensuring gender identity measures allow non-cisgender people to properly reflect their identities in responses
- Disaggregating race and ethnicity data to the maximum extent possible
- Ensuring REL and SOGI indicators are captured and routinely monitored for maternal health outcomes
- The implementation of robust cybersecurity standards to ensure the data collected is safe from technological breaches and hacks

Leaders from the organizations authoring the white papers said the following:

**Eduardo Sanchez, M.D., M.P.H., FAAFP., Chief Medical Officer for Prevention, American Heart Association**

“If we can see it, we can address it. Data disaggregation allows us to detect differences, if they exist, between and within populations, and to design policies and programs that can help eliminate health disparities and achieve health equity.”

**Linda Goler Blount, M.P.H., President, Black Women’s Health Imperative**

“Working within a data equity approach means that we must not only collect data but use data to learn how to make the necessary changes in health systems to keep Black women healthy in maternal care.”

**Indivar Dutta-Gupta, President & Executive Director, The Center for Law and Social Policy (CLASP)**

“As an organization focused on eliminating poverty, CLASP knows that policymakers need robust data to address economic insecurity and advance health equity. Yet data far too often neglects the very communities with the most distinct needs and who are ill-served by our current systems.”

**Schroeder Stribling, President & CEO, Mental Health America**

“We must ensure that our data collection standards reflect the country’s changing demographics. More equitable data is key to addressing the health care system’s persistent inequities—especially as it relates to mental health care access for members of underserved communities.”

**Kierra Johnson, Executive Director, National LGBTQ Task Force**

“The National LGBTQ Task Force urges the expansion and improvement of sexual orientation, gender identity and sex characteristics data collection to improve health equity. We implore the administration, Congress, and government agencies to allocate resources that meet the needs of LGBTQ individuals.”

For more information, please find the complete set of issue briefs [here](#).

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**Blue Cross Blue Shield Association**

*The Blue Cross and Blue Shield Association is a national federation of independent, community-based and locally*

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operated Blue Cross and Blue Shield companies that collectively provide health care coverage for one in three Americans.

**About the National Minority Quality Forum**

Founded in 1998, National Minority Quality Forum (NMQF) is a United States-based, health care research, education and advocacy organization whose mission is to reduce patient risk and advance health equity. NMQF utilizes data and research to support and mobilize healthcare organizations, leaders, policymakers, and patients in advocating for optimal care for every individual, especially those in minoritized communities. For more information, please visit <http://www.nmqf.org>.

**American Heart Association**

The American Heart Association is a relentless force for a world of longer, healthier lives. We are dedicated to ensuring equitable health in all communities. Through collaboration with numerous organizations, and powered by millions of volunteers, we fund innovative research, advocate for the public's health and share lifesaving resources. The Dallas-based organization has been a leading source of health information for a century. During 2024 - our Centennial year - we celebrate our rich 100-year history and accomplishments. As we forge ahead into our second century of bold discovery and impact our vision is to advance health and hope for everyone, everywhere. Connect with us on [heart.org](http://heart.org), Facebook, X or by calling 1-800-AHA-USA1.

**Black Women's Health Imperative**

The Black Women's Health Imperative is a national non-profit organization dedicated to advancing the health and well-being of Black women and girls. With a 40-year history of groundbreaking advocacy and research, BWHI remains committed to addressing the unique health challenges faced by Black women and ensuring their voices are heard in healthcare policy and practice.

**Center for Law and Social Policy**

The Center for Law and Social Policy (CLASP) is a national, nonpartisan, anti-poverty organization advancing policy solutions for people with low incomes, with a focus on addressing systemic racism as the primary cause of poverty for communities of color.

**Mental Health America**

Mental Health America is the nation's leading community-driven nonprofit dedicated to promoting mental health and well-being, resilience, recovery, and closing the mental health equity gap. Mental Health America's work is driven by its commitment to promote mental health as a critical part of whole person health, including prevention services for all; early identification and intervention for those at risk; and integrated care, services and supports for those who need them. Learn more at [MHAnational.org](http://MHAnational.org).

**National LGBTQ Task Force**

The National LGBTQ Task Force advances full freedom, justice, and equality for LGBTQ people. We are building a future where everyone can be free to be their entire selves in every aspect of their lives. Today, despite all the progress we have made to end discrimination, millions of LGBTQ people face barriers in every aspect of their lives: in housing, employment, healthcare, retirement, and basic human rights. Those barriers must go.



# Data Equity Coalition

**TUESDAY, APRIL 8, 2025**

**RESOURCE GUIDE**

# DEC Feedback: Number One Priority to Sustain Equitable Data Standards + Number One Concern

Protecting funding for NIH, NCI, and CDC and President's EO to eliminate DEI.

Making sure Tribal Epidemiology Centers and Tribes have access to the data they need to understand and advance the health and well-being of American Indians and Alaska Natives.

Maintaining race ethnicity data collection standards that continue to document the health disparities occurring in BIPOC communities and particularly Black women, and to advocate and watch closely impact of stories in the way that data and research are being stripped from government websites thus impact health equity

Health Equity/ ending racial health disparities and the President's EO eliminating DEI.

Maintain data quality standards across federal and research data systems to include accurate collection and reporting of racial/ethnic data and SOGI data; reclamation of DEI efforts and the threats to all equity-related work.

The dismantling of federal agencies that provide oversight; and possible changes to FDA and equity in clinical trials, including changes to CMS, OIG offices; reduction in funding.

Preserve funding for health agencies (NIH, CDC, and others) and support states in collecting detailed data, and our main concern is the impact of EOs, including suppression and removal of federal data on race/ethnicity, sexual orientation, and gender identity.

Addressing women and lung cancer and President's Executive Order that impacts DEI work priorities and Research Impact on our communities.

Maintain the collection of racial and ethnic data within HHS and advocate for the continuation of the Offices of Minority Health.

# What Inspires Hope in Light of Adversity?

Seeing people stepping into spaces they have not stepped into before

Unity in advocacy so no one feels alone in the fight against adversities.

Hope comes from working in coalition with allies.

Purpose, connection, and resilience inspire hope for me.

Seeing communities come together, leveraging new skills and resources

The goodness of many/most people.

Prioritizing visibility in light of efforts to make invisible.

Action and active, supportive leadership.

Coalescing in community.

Standing with others unafraid, unapologetic champions of equity.

# Standardizing Data to Advance Health

## OUR MISSION:

Develop and recommend policy solutions that advocate for race, ethnicity, language, sexual orientation and gender identification standards in support of advancing equity in care and health outcomes.

## OUR GOALS:



OUR PLATFORMS:  <https://dataequitycoalition.com>

# Overview of OMB SPD 15 2024 Revision

In March 2024, the Office of Management and Budget published a set of revisions to **Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity**.

- Collecting data using a single combined race and ethnicity question, allowing multiple responses.
- Adding Middle Eastern or North African (MENA) as a minimum reporting category.
- Updating terminology in SPD 15, removing the use of “majority” and “minority.”
- The deadline for compliance with the revised SPD 15 is March 28, 2029.
- Requiring agency Action Plans on Race and Ethnicity Data by September 2025.
- Establishing an Interagency Committee on Race and Ethnicity Statistical Standards

Data is foundational to understanding disparities and measuring our progress in eliminating them. These revisions will enhance the ability to compare information and data across federal agencies and understand how well federal programs serve a diverse America.

**What is your race and/or ethnicity?**  
*Select all that apply and enter additional details in the spaces below.*

**American Indian or Alaska Native** – Enter, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc.

**Asian** – Provide details below.

Chinese       Asian Indian       Filipino  
 Vietnamese       Korean       Japanese  
Enter, for example, Pakistani, Hmong, Afghan, etc.

**Black or African American** – Provide details below.

African American       Jamaican       Haitian  
 Nigerian       Ethiopian       Somali  
Enter, for example, Trinidadian and Tobagonian, Ghanaian, Congolese, etc.

**Hispanic or Latino** – Provide details below.

Mexican       Puerto Rican       Salvadoran  
 Cuban       Dominican       Guatemalan  
Enter, for example, Colombian, Honduran, Spaniard, etc.

**Middle Eastern or North African** – Provide details below.

Lebanese       Iranian       Egyptian  
 Syrian       Iraqi       Israeli  
Enter, for example, Moroccan, Yemeni, Kurdish, etc.

**Native Hawaiian or Pacific Islander** – Provide details below.

Native Hawaiian       Samoan       Chamorro  
 Tongan       Fijian       Marshallese  
Enter, for example, Chuukese, Palauan, Tahitian, etc.

**White** – Provide details below.

English       German       Irish  
 Italian       Polish       Scottish  
Enter, for example, French, Swedish, Norwegian, etc.

# Trump Executive Orders Impacting Data Equity

## 1. Ending Radical and Wasteful Government DEI Programs And Preferencing

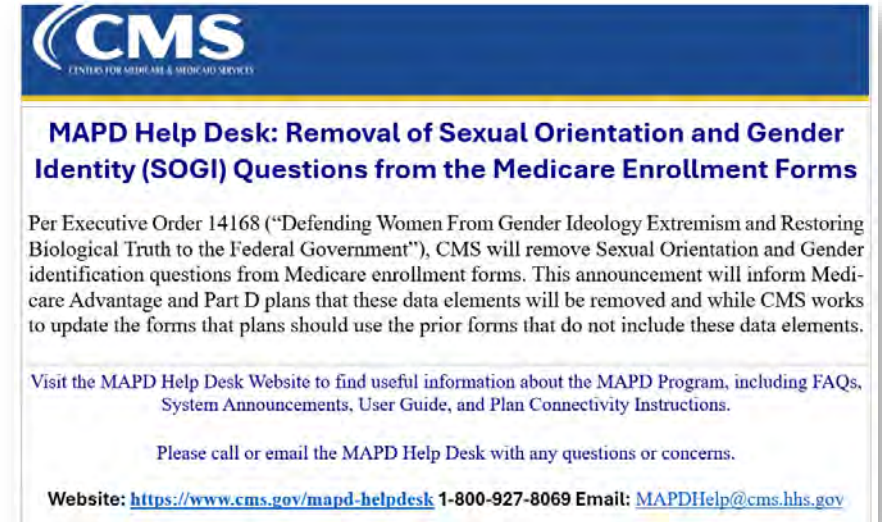
- The Center for Medicare and Medicaid Innovation will no longer collect data from its payment model participants on race, ethnicity, and preferred language (REL) and sexual orientation, gender identity (SOGI).

## 2. Defending Women from Gender Ideology Extremism and Restoring Biological Truth to the Federal Government

- The Centers for Medicare and Medicaid Services will be removing the voluntary SOGI questions from Medicare enrollment forms.

## 3. Initial Rescissions of Harmful Executive Orders and Actions

- Advancing Racial Equity
- Asian American, Native Hawaiian, and Pacific Islander Community
- Black American/African Diaspora Community
- Latino and Hispanic Community
- LGBTQIA+ Community
- Native American Community



**CMS**  
CENTERS FOR MEDICARE & MEDICAID SERVICES

**MAPD Help Desk: Removal of Sexual Orientation and Gender Identity (SOGI) Questions from the Medicare Enrollment Forms**

Per Executive Order 14168 (“Defending Women From Gender Ideology Extremism and Restoring Biological Truth to the Federal Government”), CMS will remove Sexual Orientation and Gender identification questions from Medicare enrollment forms. This announcement will inform Medicare Advantage and Part D plans that these data elements will be removed and while CMS works to update the forms that plans should use the prior forms that do not include these data elements.

Visit the MAPD Help Desk Website to find useful information about the MAPD Program, including FAQs, System Announcements, User Guide, and Plan Connectivity Instructions.

Please call or email the MAPD Help Desk with any questions or concerns.

Website: <https://www.cms.gov/mapd-helpdesk> 1-800-927-8069 Email: [MAPDHelp@cms.hhs.gov](mailto:MAPDHelp@cms.hhs.gov)



The WHITE HOUSE

45 47

PRESIDENTIAL ACTIONS

**ADDITIONAL RESCISSIONS OF HARMFUL EXECUTIVE ORDERS AND ACTIONS**

The White House | March 14, 2025

# Medicare SOGI Inquiry

The HPMS memo is titled "Online Enrollment Center (OEC) and the Removal of Sexual Orientation and Gender Identity (SOGI) Questions from Medicare Enrollment Forms."

Here is the memo from the Biden administration that established the inclusion of the questions:

### HPMS Memo CY 2025 Enrollment Guidance Changes



Here is an article about the removal of the questions:

### Biden's Sexual Orientation and Gender Identity (SOGI) Questions Removed from Medicare Forms



# Data Leadership is a Key Component of the BCBS Health Strategy

## BCBS HEALTH STRATEGY



# Concerns for SPD15

In January, the Cato Institute released a blog post recommending that OMB rescind SPD15 and issue another SPD15 that prohibits the collection of race and ethnicity **except in instances mandated by statute**. OMB is expected to do this, but the timeline is uncertain.

Here is the post: [How the Trump Administration Can Obstruct Future Government Attempts to Reestablish Affirmative Action and DEI Policies | Cato at Liberty Blog.](#)

We have not been informed that federal agencies have stopped working on their required SPD15 Action Plans.



## Reducing the Office of Minority Health (OMH)

*The Office of Minority Health has reduced staff, though the reductions technically comply with the statute. OMH is not expected to undertake any initiatives beyond that granted by statutory authority.*

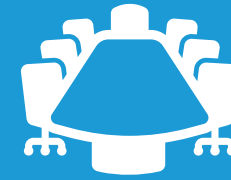
# Action Steps Requested



Hill visits, but we also need more community touchpoints right now, or at least getting this information distributed on more trusted news spaces (i.e., Urban Views, Ad Council, etc.)



State partnerships to elevate data visibility



Private sector support



*In Memoriam*

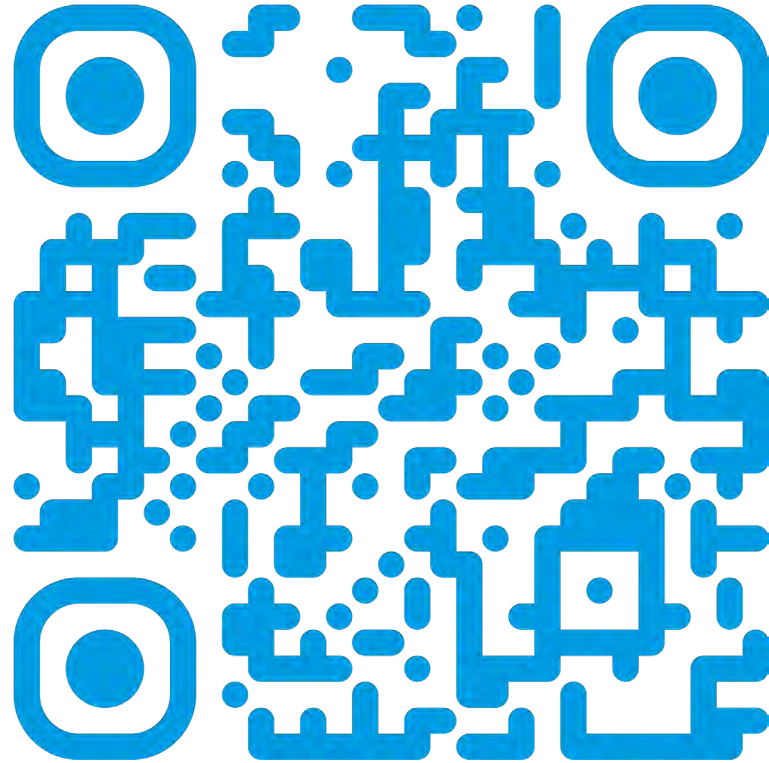
KEYSHA BROOKS-COLEY

# Honoring the Legacy of Keysha Brooks-Coley





# DATA EQUITY COALITION





# Welcome!

## Data Equity Coalition

*Convened by BCBCSA and NMQF*

**APRIL 9, 2024 | 1:00 PM – 2:00 PM ET**



**DATA EQUITY**  
COALITION

# Standardizing Data to Advance the Health Equity Movement

## OUR MISSION:

Develop and recommend policy solutions that advocate for race, ethnicity, language, sexual orientation and gender identification standards in support of advancing equity in care and health outcomes.

## OUR GOALS:



OUR PLATFORMS:  <https://dataequitycoalition.com>

# Coalition Members

## Stakeholders that have joined the Data Equity Coalition:

- Advocates for Community Health
- Alliance for Women's Health and Prevention
- American Benefits Council
- American Cancer Society Cancer Action Network
- American Diabetes Association®
- American Heart Association
- Asian & Pacific Islander American Health Forum
- AAMC Center for Health Justice
- Association of Black Cardiologists
- Association of Black Health-system Pharmacists
- Black Women's Health Imperative
- Blue Cross Blue Shield Association
- Families USA
- Go2 for Lung Cancer
- Leukemia & Lymphoma Society
- Mental Health America
- Minority Health Institute, Inc.
- National Hispanic Medical Association
- National LGBTQ Task Force
- National Minority Quality Forum
- National Rural Health Association
- Urban Institute



***Supporters still have a seat at the virtual table!***

# OMB SPD 15



# **Congratulations Data Equity Advocates!**

**YOUR ADVOCACY HAS MADE A DIFFERENCE!**

**UPDATING DIRECTIVE NO.15 AFTER NEARLY 30 YEARS!**

# Press Release



## News Release

Blue Cross Blue Shield Association  
750 8th St. NW, Suite 900  
Washington, D.C. 20001  
[www.bcbs.com](http://www.bcbs.com)

For Immediate Release:

March 29, 2024

Contact:

[press@bcbsa.com](mailto:press@bcbsa.com)

Adjoa Kyerematen

[Akyerematen@nmqf.org](mailto:Akyerematen@nmqf.org)

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### New Data Standard Will Lead to Equitable Health

*BCBSA and NMQF applaud the move toward data standardization regarding race and ethnicity but say more progress is needed*

---

WASHINGTON – For the first time since 1997, the Office of Management and Budget (OMB) published revised federal standards for maintaining, collecting and presenting Federal data on race and ethnicity.

In September 2023, The Blue Cross Blue Shield Association (BCBSA) and the National Minority Quality Forum (NMQF) founded the [Data Equity Coalition](#) aimed at improving health outcomes through more accurate and representative data.

Top priorities for the coalition include clear requirements for race, ethnicity, language and sexual orientation and gender identity data, disaggregated race/ethnicity collection as well as non-voluntary, uniform adoption of the updated OMB standard for all government agencies and private sector health care stakeholders.

Following today's OMB announcement, BCBSA President and CEO Kim Keck and NMQF President and CEO Gary Puckrein released the respective statements:

Blue Cross Blue Shield Association is an association of independent Blue Cross and Blue Shield companies.

**Kim Keck, BCBSA President and CEO:**

"Behind data are real people, and for the first time in nearly 30 years, we're closer to the forms people fill out in the doctor's office looking more like the diverse country we live in. It is a step that will help people feel seen, a critical factor to build much needed trust in health care."

"We applaud OMB for making this critical change—and are proud of the work we've done with the National Minority Quality Forum—through the Data Equity Coalition—to get to this point."

"We hope this is the first of many actions that the federal government will take to create a better system of health."

**Dr. Gary Puckrein, NMQF President and CEO:**

"The National Minority Quality Forum welcomes this long-awaited update to OMB Statistical Policy Directive 15."

"The OMB update represents a movement toward the establishment and standardization of a comprehensive data collection infrastructure that is the essential foundation of an American health services research, delivery, and financing enterprise that supports the diversity and intersectionality that is the American general population of the 21<sup>st</sup> Century and beyond."

"NMQF's mission is to reduce patient risk by assuring optimal care for all. Our vision is an American health services research, delivery, and financing system whose operating principle is to reduce patient risk for amenable morbidity and mortality while improving quality of life."

"Within that context, partnering with BCBSA and other engaged organizations on data equity has been, and continues to be, logical and essential."

**About the National Minority Quality Forum**

The National Minority Quality Forum (NMQF) is a 501(c)(3) not-for-profit research and advocacy organization based in Washington, DC. The mission of NMQF is to reduce patient risk by assuring optimal care for all. NMQF's vision is an American health services research, delivery and financing system whose operating principle is to reduce patient risk for amenable morbidity and mortality while improving quality of life. For more information, please visit [www.nmqf.org](http://www.nmqf.org).

**About Blue Cross Blue Shield Association**

The Blue Cross and Blue Shield Association is a national federation of independent, community-based and locally operated Blue Cross and Blue Shield companies that collectively provide health care coverage for one in three Americans.



THE WHITE HOUSE  
WASHINGTON

MARCH 28, 2024

**OMB Publishes Revisions to  
Statistical Policy Directive No. 15:  
Standards for Maintaining,  
Collecting, and Presenting Federal  
Data on Race and Ethnicity**

# OMB Decisions

Recommendation	OMB Decision	Notes
<p>Directive No.15 should provide clear and consistent requirements for collecting REL (race, ethnicity, language) and SOGI (sexual orientation and gender identification) data that include a minimum standard for disaggregated R/E (race and ethnicity) collection and are compatible with industry interoperability standards (e.g., <a href="#">Fast Healthcare Interoperability Resources (FHIR) standards</a>).</p>	<p><b>Partially Affirmed.</b> OMB accepts the recommendation to combine the separate questions on race and ethnicity into a single combined race and ethnicity question &amp; <u>OMB requires the collection of more detailed data as a default</u>; agencies are required to collect the detailed categories described, the detailed categories were selected to represent the largest population groups within the minimum categories, according to the results of the 2020 Census.</p>	<p><b>Not Addressed:</b></p> <ul style="list-style-type: none"><li>▪ Language</li><li>▪ SOGI (sexual orientation and gender identification) data</li><li>▪ Industry interoperability standards (e.g., Fast Healthcare Interoperability Resources (FHIR) standards)</li></ul>

# OMB Decisions

Recommendation	OMB Decision	Notes
<p>Incorporate the current data standards promulgated by the DHHS Assistant Secretary for Planning and Evaluation/Office of Minority Health into Directive No.15 and requires that these be the minimum standard categories for collecting disaggregated REL data.</p>	<p><b>Affirmed</b></p> <ul style="list-style-type: none"><li>▪ American Indian or Alaska Native</li><li>▪ Asian</li><li>▪ Black or African American</li><li>▪ Hispanic or Latino</li><li>▪ <b>Middle Eastern or North African</b></li><li>▪ Native Hawaiian or Pacific Islander</li><li>▪ White</li></ul> <p>Agencies are required to collect the detailed categories as a default. These detailed categories were selected to represent the largest population groups within the minimum categories.</p>	<p>Adding Middle Eastern or North African as a new minimum category</p>

# OMB Decisions

Recommendation	OMB Decision	Notes
<p>OMB should intentionally and proactively elicit and accept additional input from diverse stakeholders regarding SOGI data collection and utilization in the Directive No. 15 update.</p>	<p><b>Partially Affirmed.</b></p> <ul style="list-style-type: none"><li>▪ Over <u>20,000 comments</u> provided in response to a <u>January 2023 Federal Register Notice</u> proposing revisions to the Directive,</li><li>▪ <u>94 listening sessions</u> hosted by the Working Group,</li><li>▪ <u>3 public virtual townhalls</u>, and a Tribal consultation.</li><li>▪ The Interagency Technical Working Group, consisting of federal government career staff representing 35 agencies.</li></ul>	<p><b>Not Addressed:</b></p> <ul style="list-style-type: none"><li>▪ SOGI and Language were omitted from Directive 15. OMB's jurisdictional authority is Race and Ethnicity. Both SOGI and Language were however acknowledged via public comment and through OMB listening sessions.</li></ul>

# OMB Decisions

Recommendation	OMB Decision	Notes
<p>OMB should enforce non-voluntary, uniform and universal adoption of the updated OMB Directive No. 15 standards upon release in 2024 for all government agencies, and all private sector health care stakeholders including payers and providers.</p>	<p><b>Partially Affirmed.</b></p> <ul style="list-style-type: none"><li>▪ Non-voluntary, uniform and universal adoption of the updated OMB Directive No. 15 standards upon release in 2024 for all government agencies</li><li>▪ Phased approach to implementation</li></ul>	<ul style="list-style-type: none"><li>▪ The Standard is silent on private sector healthcare stakeholders including payers and providers.</li></ul>

# SPD 15 Implementation and Enforcement

**Mar '24** →

Surveys and Administrative Forms are requested for expedited updates

**18 Months** →

Federal Agencies have 18-months to comply via the implementation of required Agency Action Plans

**March 28, 2029** →

Due date for federal compliance is 5 years for updating standards

**Every 10 Years**

SPD 15 reviews will take place over a 10-year cycle and will include opportunity for public input and comment

# Minimum Categories

Figure 1. Race and Ethnicity Question with Minimum Categories, Multiple Detailed Checkboxes, and Write-In Response Areas with Example Groups

**What is your race and/or ethnicity?**  
*Select all that apply and enter additional details in the spaces below.*

**American Indian or Alaska Native** – Enter, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc.

**Asian** – Provide details below.

Chinese       Asian Indian       Filipino  
 Vietnamese       Korean       Japanese

Enter, for example, Pakistani, Hmong, Afghan, etc.

**Black or African American** – Provide details below.

African American       Jamaican       Haitian  
 Nigerian       Ethiopian       Somali

Enter, for example, Trinidadian and Tobagonian, Ghanaian, Congolese, etc.

**Hispanic or Latino** – Provide details below.

Mexican       Puerto Rican       Salvadoran  
 Cuban       Dominican       Guatemalan

Enter, for example, Colombian, Honduran, Spaniard, etc.

**Middle Eastern or North African** – Provide details below.

Lebanese       Iranian       Egyptian  
 Syrian       Iraqi       Israeli

Enter, for example, Moroccan, Yemeni, Kurdish, etc.

**Native Hawaiian or Pacific Islander** – Provide details below.

Native Hawaiian       Samoan       Chamorro  
 Tongan       Fijian       Marshallese

Enter, for example, Chuukese, Palauan, Tahitian, etc.

**White** – Provide details below.

English       German       Irish  
 Italian       Polish       Scottish

Enter, for example, French, Swedish, Norwegian, etc.



**DATA EQUITY**  
COALITION

# Next Steps: Acceleration of Advocacy Efforts


Agency meetings are not just to meet the minimum ~ advocate for more:



**SOGI**



**EO 14075**



**Language**



**Private Sector**



**Payers and Providers**



**Disability**



**Healthcare Ecosystem**

# Intersectionality and Inclusivity

**Data is increasingly diverse.**



Intersectionality in the approach to data equity is essential for inclusivity to mitigate marginalizing individual identity and perpetuating disadvantage and discrimination.



Intersectional approaches to data examine the multi-dimensionality of identity and its impacts.



Therefore, data is an essential resource that can enable inclusivity.

# DEC Coalition Letter to HHS



January 26, 2024

The Honorable Xavier Becerra  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, DC 20201

Re: Data Equity and Expansion of Language and SOGI to Statistical Policy Directive No. 15

Dear Secretary Becerra,

The National Minority Quality Forum and the Blue Cross Blue Shield Association submit this letter on behalf of the Data Equity Coalition, including patient advocacy, health care, and business leadership organizations collaborating to advance a stakeholder-informed data equity movement. We appreciate sharing our recommendations from the public comment opportunity to OMB for inclusion in the updated Statistical Policy Directive No. 15, due for release in Summer 2024:

- Directive No. 15 should provide clear and consistent requirements for collecting REL (race, ethnicity, language) and SOGI (sexual orientation and gender identification) data that include a minimum standard for disaggregated race and ethnicity collection that are compatible with industry interoperability standards (e.g., Fast Healthcare Interoperability Resources (FHIR) standards).
- OMB should incorporate the current data standards promulgated by the Department of Health and Human Services (DHHS) Assistant Secretary for Planning and Evaluation/Office of Minority Health into Directive No. 15, outlining a framework of two separate questions for race and ethnicity with seven categories and six subcategories, including the addition of a Middle Eastern or North African (MENA) ethnicity category, and require that these be the minimum standard categories for collecting disaggregated REL data.
- OMB should intentionally and proactively elicit and accept additional input from diverse stakeholders regarding SOGI data collection and utilization in the Directive No. 15 update.
- OMB should enforce non-voluntary, uniform, and universal adoption of the updated OMB Directive No. 15 standards upon release in 2024 for all government agencies and all private sector healthcare stakeholders, including payers and providers.

The process that resulted in these recommendations and a more detailed discussion of the attendant issues is included in the issue brief, "[Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy](#),"<sup>1</sup> which was released in March by the National Minority Quality Forum and the Blue Cross Blue Shield Association.

<sup>1</sup> Blue Cross Blue Shield Association and National Minority Quality Forum, March 28, 2023, "Standardizing Data to Advance the Health Equity Movement: A Multi-sectorial Strategy," [https://dataequitycoalition.com/wp-content/uploads/2023/07/NMQF\\_Brief\\_Paper.pdf](https://dataequitycoalition.com/wp-content/uploads/2023/07/NMQF_Brief_Paper.pdf).

# Recommendations

HHS is critically important to advancing data equity. We respectfully request prioritizing the following recommendations:

**1.** Upon release of the updated SPD 15 by OMB, HHS should act as efficiently and effectively as possible to adopt the standards as the minimum requirement for all HHS programs, existing and new, that collect data in the covered domains of race and ethnicity.

**2.** HHS should require private-sector program participants to use the new minimum SPD 15 standards and provide technical assistance to help implementation.

**3.** HHS should build on SPD 15 by creating minimum standards for collecting language and SOGI data promulgated by Executive Order 14075 and 2022 NASEM Report, and intentionally and proactively elicit and adopt input from diverse community stakeholders within and external to the federal government.

# NMQF Summit

eventbrite



## WE HAVE THE DATA, NOW WHAT?

A LOOK BACK AT OVER 25 YEARS

// APRIL 29 - 30TH //  
THE WATERGATE HOTEL  
WASHINGTON D.C.

REGISTER NOW!

Monday, April 29



### 2024 NMQF Leadership Summit Registration

Welcome to the registration site for the 2024 National Minority Quality Forum Leadership Summit on Health Disparities and Health Braintrust!



By National Minority Quality Forum • 240 followers

3.7k attendees hosted

Follow

# NMQF Session ~ Advancing Data Equity: Highlighting Statistical Policy Directive 15

Through a series of mini briefs, participating stakeholders will overview their perspective on next steps to accelerate data equity solutions, reducing disparities, REL and SOGI imperatives and the importance of SPD 15 update as a critical opportunity to accelerate the broader goal of achieving equity in health care.

The mini briefs released will include:





**DATA EQUITY**  
COALITION

# Officially Join the Coalition



## Permission Sign-On: Data Equity Coalition

[Sign in to Google](#) to save your progress. [Learn more](#)

\* Indicates required question

What is the name of your organization? \*

Your answer

What is your name? \*

Your answer

Are you authorized to join the Data Equity Coalition on behalf of your organization? \*

Yes

No



# Thank You!

## Data Equity Coalition

*Convened by BCBCSA and NMQF*

**APRIL 9, 2024 | 1:00 PM – 2:00 PM ET**



— NATIONAL —  
MINORITY QUALITY  
— FORUM —



An association of independent Blue Cross and Blue Shield companies

# Welcome!

# Data Equity Convening

**JUNE 13, 2023 | 10:00 AM – 11:00 AM EST**

# Agenda

---

**10:00 am** Welcome and Introductions

---

**10:10 am** Thank you from NMQF and BCBSA

---

**10:20 am** Update on Next Steps with OMB

---

**10:25 am** Coalition Formation and Next Steps

---

**10:35 am** Responding to Questions

---

**10:55 pm** Final Thoughts + Conclusion

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# Welcome and Introductions





# STANDARDIZING DATA TO ADVANCE THE HEALTH EQUITY MOVEMENT: A MULTI-SECTORIAL STRATEGY

March 28, 2023

Summary of a cross-sector dialogue sponsored by:  
Blue Cross Blue Shield Association  
and National Minority Quality Forum



The Blue Cross Blue Shield Association is an association of independent, locally operated Blue Cross and Blue Shield companies.

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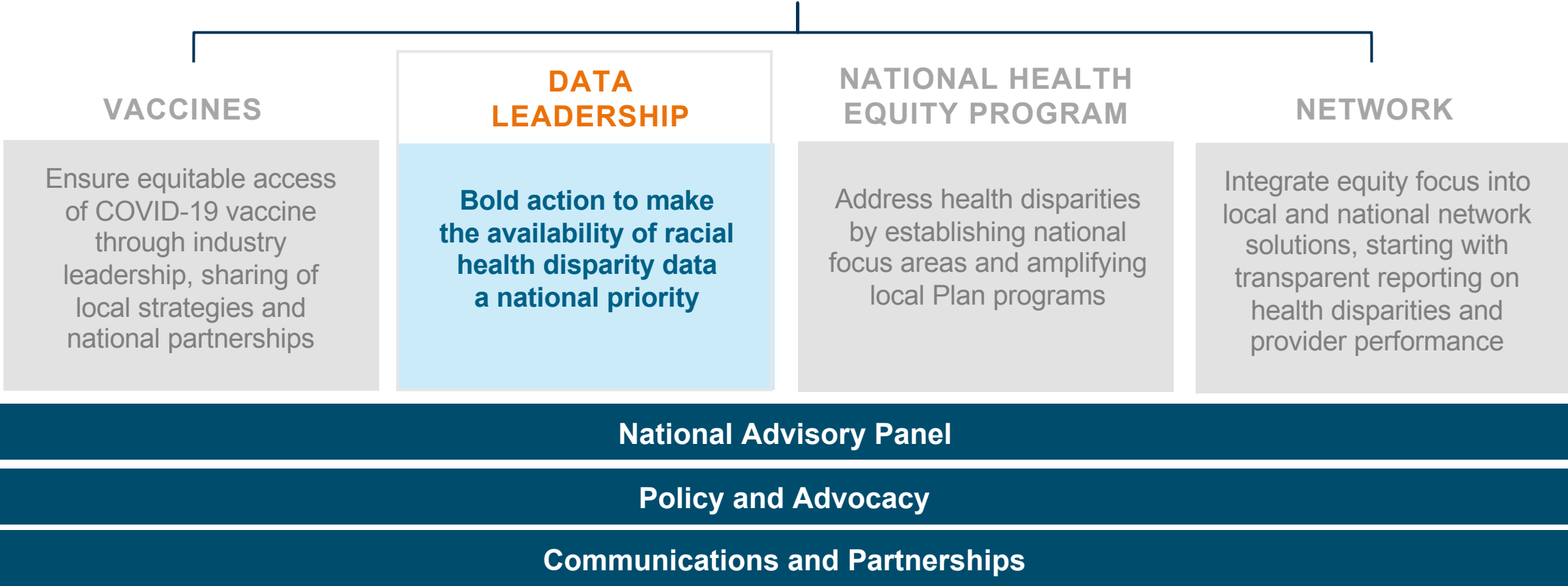
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An association of independent Blue Cross and Blue Shield companies

# Data Leadership is a key component of the BCBS Health Equity Strategy

## BCBS HEALTH EQUITY STRATEGY



# Recommendations

**NMQF and BCBSA support the following recommendations for inclusion in the OMB Directive No. 15 update that is scheduled for completion in 2024:**

1

Directive No. 15 should provide clear and consistent requirements for the collection, of REL and SOGI data that include a minimum standard for disaggregated R/E collection and are consistent with industry interoperability standards (e.g., Fast Healthcare Interoperability Resources (FHIR) standards).

2

OMB should incorporate the current data standards promulgated by the DHHS Assistant Secretary for Planning and Evaluation/Office of Minority Health into Directive No. 15 and require that these be the minimum standard categories for collecting disaggregated REL data.

3

OMB should intentionally and proactively elicit and accept additional input from diverse stakeholders regarding SOGI data collection and utilization into the Directive No. 15 update.

4

OMB should enforce non-voluntary, uniform and universal adoption of the updated OMB Directive No. 15 standards upon release in 2024 for all government agencies, and all private sector health care stakeholders including payers and providers.

# Public Comment Opportunity



## FEDERAL REGISTER

The Daily Journal of the United States Government



Notice

### Initial Proposals For Updating OMB's Race and Ethnicity Statistical Standards

A Notice by the Management and Budget Office on 01/27/2023

Comments on this document are being accepted at [Regulations.gov](https://www.regulations.gov).

[SUBMIT A FORMAL COMMENT](#)

10506 comments received. [View posted comments](#)

---

**PUBLISHED DOCUMENT**

**AGENCY:**  
Office of Information and Regulatory Affairs, Office of Management and Budget, Executive Office of the President.

**ACTION:**  
Notice and request for comments.

**SUMMARY:**  
The Office of Management and Budget (OMB) requests comments on the initial proposals from the Federal Interagency Technical Working Group on Race and Ethnicity Standards (Working Group) for revising OMB's 1997 Statistical Policy

**DOCUMENT DETAILS**

**Printed version:**  
PDF

**Publication Date:**  
01/27/2023

**Agency:**  
Office of Management and Budget

**Dates:**  
Comments must be provided in writing to OMB no later than 75 days from the publication of this notice to ensure consideration.

[Site Feedback](#)

Document Type:

Federal Register / Vol. 88, No. 18 / Friday, January 27, 2023 / Notices 5375

is planned to continue through 2036, with regular updating of these statistics planned thereafter.

**FOR FURTHER INFORMATION CONTACT:** For additional information, contact: Andrew Stawasz, email: [NaturalCapitalAccounting@omb.eop.gov](mailto:NaturalCapitalAccounting@omb.eop.gov), telephone: (202) 681-7051.

**SUPPLEMENTARY INFORMATION:** On August 22, 2022, OMB, on behalf of the Working Group, issued "Request for Information To Support the Development of a Strategic Plan on Statistics for Environmental-Economic Decisions." (75 FR 31450). The Working Group is co-chaired by OMB, the Office of Science and Technology Policy, and the Department of Commerce. The Request for Information announced the availability of a draft document entitled "National Strategy to Develop Statistics for Environmental-Economic Decisions: A U.S. System of Natural Capital Accounting and Associated Environmental-Economic Statistics" (Strategic Plan) and initiated a 60-day public comment period. Public comments received are available via [www.regulations.gov](https://www.regulations.gov) under docket number OMB-2022-0008. The Working Group revised the Strategic Plan in response to comments and other information received and is now announcing the availability of the final Strategic Plan, available at <https://www.whitehouse.gov/wp-content/uploads/2023/01/Natural-Capital-Accounting-Strategy-final.pdf>.

Following the Administration's commitment to initiate natural capital accounts and environmental-economic statistics in April 2022, Statistics for Environmental-Economic Decisions makes five recommendations to Federal departments and agencies for how to develop and use natural capital accounts and environmental-economic statistics.

1. The natural capital accounts and environmental-economic statistics should be pragmatic and provide information to:

- Guide sustainable development and macroeconomic decision making;
- Support Federal decision making in programmatic, policy, and regulatory settings;
- Provide structure and data that promote the competitiveness of U.S. businesses;
- Support resilient state, territorial, Indigenous, Tribal, and local communities; and
- Facilitate conservation and environmental policy.

2. The natural capital accounts and associated environmental-economic statistics should provide domestic comparability through time and advance international comparisons and harmonization in order to enable the United States to lead with respect to the development of global standards and implementation of those standards.

3. The natural capital accounts and associated environmental-economic statistics should be embedded in the broader U.S. economic statistical system, and guide the process of standard development with three sub-recommendations. Federal departments and agencies should:

- Incorporate the internationally-agreed standards of the U.N. System of Environmental Economic Accounting to guide development of U.S. natural capital accounts, where those standards are relevant to the United States and robustly developed. This includes following the standard supply-use framework that structures national economic accounts;
- Adhere to more than one, but a small number of, specific asset boundaries, connected to economic activities, in order to accommodate different applications and contexts and be inclusive of different uses and perspectives; and
- Use rigorous and the best available economic science for monetizing the value of natural assets.

4. Federal departments and agencies should use a 15-year phased approach to transition from research grade environmental-economic statistics and natural capital accounts to comparable statistical products, and produce a single headline summary statistic, along with supporting products, tables and reports that provide information in physical and monetary units.

5. The phased approach is designed to enable now information to be available early in the process, facilitate the first pilot accounts appearing in 2023, while over the long term meeting high statistical standards and producing a durable and more comprehensive set of statistics to expand the national economic accounts.

6. The Strategic Plan recommends that natural capital accounts produce a new forward-looking headline measure focused on the change in wealth held in nature: Change in Natural Asset Wealth. Integrating this new measure with changes in GDP would provide a more complete and more useful view of U.S. economic progress. Pairing Change in Natural Asset Wealth with GDP would help society tell if today's consumption is being accomplished without compromising the future opportunities that nature provides.

7. The Strategic Plan also recommends the use of dashboards for biological and physical measures.

8. The Federal Government should apply existing expertise and make use of the substantial authorities within Federal departments and agencies, by coordinating across agencies, to develop and update the system of natural capital accounts and environmental-economic statistics in an efficient manner.

**Richard L. Revesz,**  
Administrator, Office of Information and Regulatory Affairs  
EFR Doc: 2023-01068 Filed 1-26-23; 845 and BILLING CODE 3110-01-P

**OFFICE OF MANAGEMENT AND BUDGET**

**Initial Proposals For Updating OMB's Race and Ethnicity Statistical Standards**

**AGENCY:** Office of Information and Regulatory Affairs, Office of Management and Budget, Executive Office of the President.

**ACTION:** Notice and request for comments.

**SUMMARY:** The Office of Management and Budget (OMB) requests comments on the initial proposals from the Federal Interagency Technical Working Group on Race and Ethnicity Standards (Working Group) for revising OMB's 1997 Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD 15). Responses to this Notice will be shared with the Working Group and will help the Working Group develop their final recommendations to OMB and will also help OMB determine how to revise SPD 15 to improve the quality and usefulness of Federal race and ethnicity data.

**DATES:** Comments must be provided in writing to OMB no later than 75 days from the publication of this notice to ensure consideration during the final decision-making process.

**ADDRESSES:** Please submit comments via <https://www.regulations.gov>, a Federal website that allows the public to find, review, and submit comments on documents that agencies have published in the *Federal Register* and that are open for comment. Simply type "OMB-2023-0001" in the Comment or Submission search box, click Go, and

142 FR 58723 (Oct. 20, 1987), available at <https://www.ecfr.gov/current/title-49/chapter-I/subchapter-B/part-100/section-100.10-10/pdf/97-29857.pdf>.

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# Key Dates

**August 8, 2023**  
**1 PM (bi-monthly) on the**  
**second Tuesday**

Coalition meeting 1 PM

**September 21, 2023**  
**12 PM EST**

OMB Listening Session

# Opportunities for Stakeholder Engagement

OMB has given a timeline of Summer 2024 to release the revisions to SPD 15.

- We are expecting at least one more formal comment opportunity when OMB releases their proposal, likely in Fall 2023 (based on Technical Working Group proposal + public comments).
- Potential additional sign on and meeting opportunities for coalition members for meeting with OMB, other entities under the HHS umbrella, including (Office of the CMS Administrator, Office of Minority, Health, CMII, etc.).
- There may be opportunities to further refinement of collection categories to meet the needs of coalition members.
- Education around socialization of the issue brief recommendations with the Hill, Tri-Caucus, and other policy makers are being explored forth coming year.
- Hosting a listening session with OMB in the fall is a priority activity - **\*Sept 21, 2023 @ 12 PM.**

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- 4 Education around socialization of the issue brief recommendations with the Hill/ Tri-Caucus and other policy makers are being explored forth coming year.
- 5 Hosting a listening session with OMB in the fall is key to our efforts as well.

# Data Equity Coalition Draft Website

*COPY IS CURRENTLY IN DRAFT. FEEDBACK IS  
ALWAYS APPRECIATED!*





**DATA EQUITY**  
COALITION

## Standardizing Data to Advance the Health Equity Movement

### OUR MISSION:

Develop and recommend policy solutions that advocate for race, ethnicity, language and sexual orientation and gender identification standards in support of advancing equity in care and health outcomes.

### OUR GOALS:



Advance policy recommendations through collective advocacy to ensure equity in data representation.



Engage with lawmakers and regulatory entities to prioritize data standards supporting the update to Statistical Policy Directive No. 15.



Educate stakeholders on the importance of data equity as essential to the broader health equity movement and the improvement of health outcomes.

### OUR PLATFORMS:



[DataEquityCoalition.org](https://DataEquityCoalition.org)



[@DataEquityCo](https://www.facebook.com/DataEquityCo)



[@DataEquityCo](https://www.twitter.com/DataEquityCo)

## WEBSITE PREVIEW:

### *Homepage*



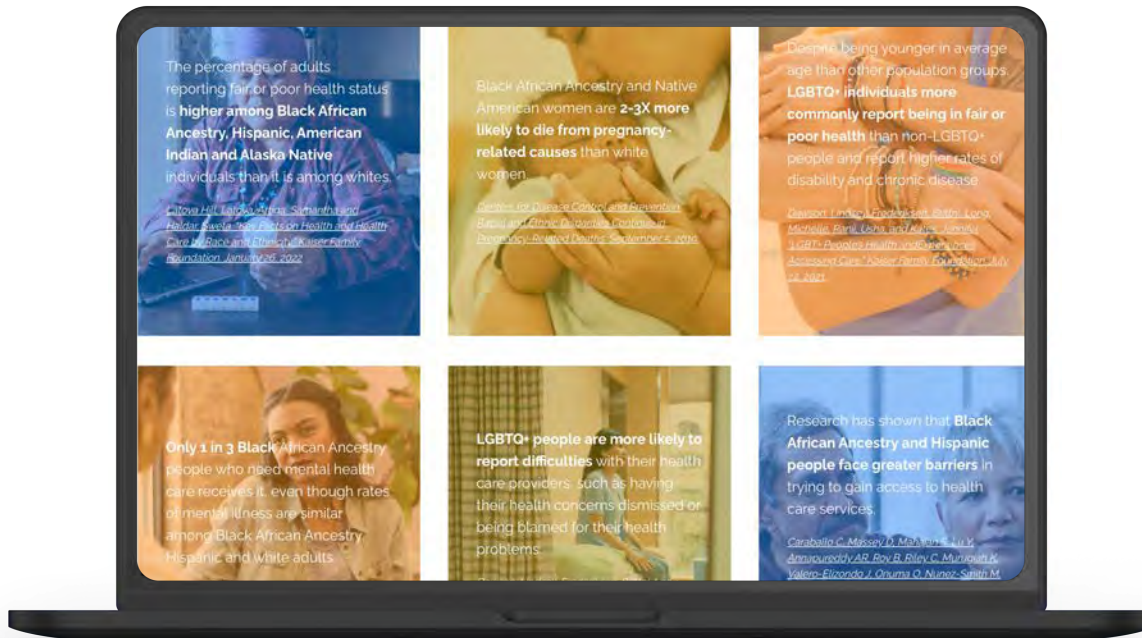
### *About page*



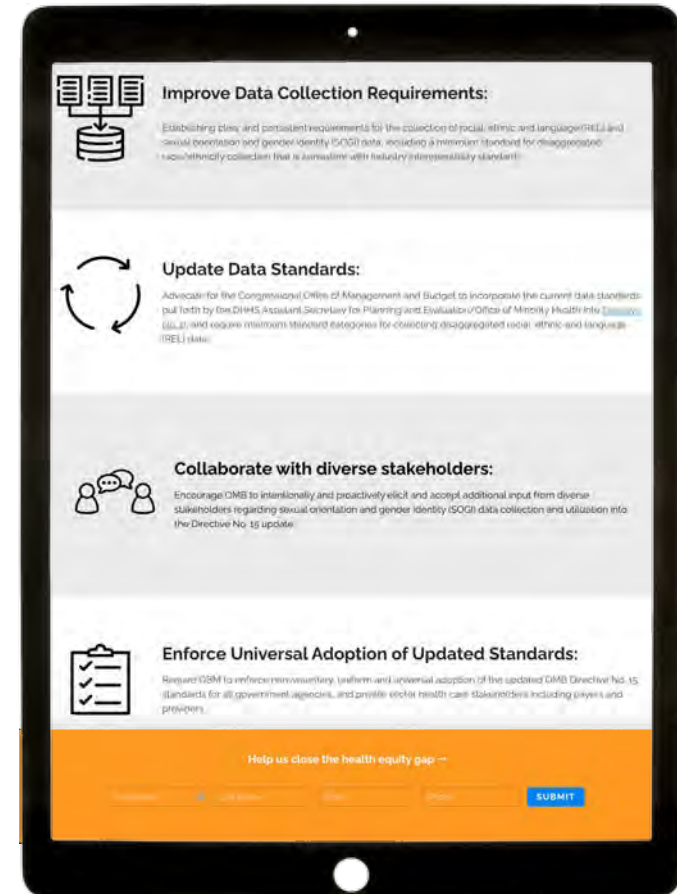
As we commit to embracing diversity, culture and heritage as a nation, our methods of collecting and reporting accurate patient data are critical to providing the best health care options - especially for historically underrepresented communities.

## WEBSITE PREVIEW:

### Issues page



### Solutions page





— NATIONAL —  
MINORITY QUALITY  
— FORUM —



An association of independent Blue Cross and Blue Shield companies

# Thank You!

## Data Equity Convening

JUNE 13, 2023 | 10:00 AM – 11:00 AM EST