

April 17, 2023

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Interagency Technical Working Group on
Race and Ethnicity Standards
1650 17th St. NW
Washington, DC 20500

Submitted via Regulations.gov

RE: Initial Proposals for Updating OMB’s Race and Ethnicity Statistical Standards, Docket No. OMB – 2023 – 0001

The AAMC (Association of American Medical Colleges) is a nonprofit association dedicated to improving the health of people everywhere through medical education, health care, medical research, and community collaborations. Its members are all 157 U.S. medical schools accredited by the [Liaison Committee on Medical Education](#); 13 accredited Canadian medical schools; approximately 400 teaching hospitals and health systems, including Department of Veterans Affairs medical centers; and more than 70 academic societies. Through these institutions and organizations, the AAMC leads and serves America’s medical schools and teaching hospitals and the millions of individuals across academic medicine, including more than 193,000 full-time faculty members, 96,000 medical students, 153,000 resident physicians, and 60,000 graduate students and postdoctoral researchers in the biomedical sciences. Following a 2022 merger, the Alliance of Academic Health Centers and the Alliance of Academic Health Centers International broadened the AAMC’s U.S. membership and expanded its reach to international academic health centers. Learn more at aamc.org

The goal of the AAMC Center for Health Justice, founded in 2021, is for all communities to have an opportunity to thrive — a goal that reaches well beyond medical care. Achieving health equity means addressing the common roots of health, social, and economic injustices and implementing policies and practices that are explicitly oriented toward equal opportunity. The Center for Health Justice partners with public health and community-based organizations, government and health care entities, the private sector, community leaders, and community members to build a case for health justice through research, analysis, and expertise. For more information, visit aamchealthjustice.org.

I. General Comments

The AAMC and the Center for Health Justice (Center) appreciate the opportunity to comment on the Office of Management and Budget’s (OMB) initial proposals for revising the OMB’s 1997 Statistical Policy Directive No. 15., *Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity* (hereinafter referred to as SPD 15). Over the last few years, we have closely followed the OMB’s efforts to update SPD 15, offering recommendations in 2016 on the first proposed changes to the standards since 1997.¹ Notably, out of approximately 400 public comments, the AAMC and the American

¹ AAMC Comments, Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, Docket No. OMB 2016-23672, <https://www.aamc.org/media/11646/download?attachment>.

Anthropological Association were the only higher education organizations that submitted a response to this request.² Our interest in staying engaged in the OMB’s efforts to revise SPD 15 have continued since 2016 with our recent participation in an OMB virtual public listening session, joined by three experts from the Center’s health equity community (*Collaborative for Health Equity: Act, Research, Generate Evidence*, or “CHARGE”). We also solicited feedback on the proposed revisions from the CHARGE community to inform our comments to the OMB.³

The OMB has requested comment on three proposals from the Federal Interagency Technical Working Group on Race and Ethnicity Standards. As discussed in further detail below, among additional comments and considerations for the OMB as it works to revise its standards and considers the need for guidance, the AAMC and the Center make the following broad recommendations on each of the three fundamental proposals:

- **Information about race and ethnicity should be collected in a single question that asks individuals how they identify rather than asking about their race or ethnicity using those terms.**
- **“Middle Eastern or North African” should be added as a new minimum category.**
- **Detailed race and ethnicity categories should be used by federal agencies as a default and the OMB should provide additional criteria and guidance for making the decision that minimal categories may be used for a specific purpose.**

We appreciate the OMB’s recognition of the critical need to revise SPD 15 “to ensure that [it is] keeping pace with changes in the population and evolving needs and uses for data”⁴ and commend the OMB for taking steps to uphold the credibility, integrity, impartiality, and utility of demographic information collected for federal statistical purposes.

Importance of Race and Ethnicity Data

Since the initial development of the standards in 1977, SPD 15 was revised once in 1997 and since those revisions, there have been significant changes to the political, social, economic, and demographic landscape of the United States (U.S.). One noteworthy change is the increase in racial and ethnic diversity, including the number of individuals that identify with more than one race and ethnicity. Also contributing to population diversity is the large number of immigrants that continue to arrive each year. Since 2000-2001, for example, 18,680,319 immigrants have arrived (with 1,010,923 immigrants arriving in 2021-2022, the most recent year for which data are available).⁵

Race and ethnicity data are used throughout the Federal Government in decennial census surveys and household surveys, to inform resource allocation and benefit decisions, for policy development, as well as the enforcement of anti-discrimination and voting rights laws.⁶ We also recognize the potential impact the collection of valid race, ethnicity, and other sociodemographic data can have on achieving health equity by ensuring the valid identification of health inequities experienced by racial and ethnic minorities and other groups that have been economically and socially marginalized, including rural communities, elderly

² Inside Higher Education, Which Groups Are Counted, November 7, 2016, <https://www.insidehighered.com/news/2016/11/07/omb-considers-revising-standards-collecting-data-race-ethnicity> (Accessed March 8, 2023).

³The AAMC and Center for Health Justice participated in the December 15, 2022 OMB Public Listening Session on Federal Race and Ethnicity Standards Revision. For more information about the Center for Health Justice CHARGE community, *see*: <https://www.aamchealthjustice.org/get-involved/aamc-charge>.

⁴ Initial Proposals for Updating OMB’s Race and Ethnicity Statistical Standards, 88 Federal Register 5377 (Jan. 27, 2023).

⁵ Brookings Institute, New Census Estimates Show a Tepid Increase in U.S. Population Growth, Buoyed by Immigration, Jan. 4, 2023, <https://www.brookings.edu/research/new-census-estimates-show-a-tepid-rise-in-u-s-population-growth-buoyed-by-immigration/> (Accessed March 8, 2023).

⁶88 Fed. Reg. 5376.

populations, and LGBTQ+ individuals. For example, the COVID-19 pandemic magnified the inadequacies of federal data collection efforts:

“[a]t the federal level, 36% of COVID-19 deaths and 17% of COVID-19 cases [were] missing race/ethnicity and poor quality racial/ethnic classifications is differential by race/ethnicity – with Asian Americans, Hispanics and American Indian/Alaska Natives more likely to be misclassified in administrative data. Moreover, datasets routinely and indiscriminately aggregate individuals into arbitrary ‘race/ethnicity’ categories (e.g., no distinctions between Chinese, Filipino), limiting the ability to describe and/or intervene on specific concerns for different groups.”⁷

This example highlights the need for a national, standardized data collection system that accurately captures race and ethnicity data and related information (e.g., social, environmental) to ensure equitable pandemic preparation and response to future health threats.^{8 9}

Conceptualization of Race and Ethnicity as Social Constructs

We would be remiss if we did not acknowledge the evolving social perceptions of “race” and “ethnicity,” the corresponding impact on SPD 15, as well as the broader use of race and ethnicity data for statistical purposes. Race and ethnicity are inherently complex, dynamic, and fluid socio-political constructs and in the proposed changes to SPD 15, the OMB discusses the resulting confusion when the terms are used in the separate question format for self-reporting (*see* Fig. 1 1997 Two Question Format for Self-Reporting, *see also* Section II below). The OMB notes that “many respondents [...] instead understand race and ethnicity to be similar, or the same concepts [],” pointing to Hispanic or Latino respondents not reporting a race or selecting the “Some Other Race” option after responding to the ethnicity question on the decennial census and the American Community Survey.¹⁰

There are also growing concerns with how the terms “race” and “ethnicity” are used in research¹¹ with some scholars, such as the American Anthropological Association, recommending abandonment of the term “race” entirely.^{12 13} We share many of these concerns, especially given the historical underpinnings of race as a concept rooted in European colonialism, developed for the purpose of oppression, economic exploitation, and discrimination.¹⁴ Further, while we understand the interest in avoiding the use of race as a category in research, it is critical to measure the self-identification of race to redress systemic racism and persistent social inequities and disparities. It is also critical for federal agencies to continue to prioritize the

⁷ Yi SS, Doan et al., With No Data, There's No Equity: Addressing the Lack of Data on COVID-19 for Asian American Communities, October 23, 2021. *See also*, Race/Ethnicity: Current Data and Changes Over Time, <https://www.kff.org/coronavirus-covid-19/issue-brief/covid-19-cases-and-deaths-by-race-ethnicity-current-data-and-changes-over-time>, August 22, 2022 (Accessed March 8, 2023).

⁸ AAMC Press Release, AAMC Calls for Enhanced COVID-19 Data Collection on Health Disparities, April 10, 2020 <https://www.aamc.org/news-insights/press-releases/aamc-calls-enhanced-covid-19-data-collection-health-disparities> (Accessed March 8, 2023).

⁹ Alberti PM, Lantz PM, Wilkins CH (2020) “Equitable Pandemic Preparedness and Rapid Response: Lessons from COVID-19 for Pandemic Health Equity” *J Health Polit Policy Law* 8641469. <https://doi.org/10.1215/03616878-8641469>.

¹⁰ 88 Fed. Reg. 5379.

¹¹ Beyond the Boxes, Part 2: Defining Race and Ethnicity, <https://iaphs.org/beyond-the-boxes-part-2-defining-race-and-ethnicity/> (Accessed March 24, 2023).

¹² Umek W, Fischer B. We Should Abandon “Race” as a Biological Category in Biomedical Research. *Female Pelvic Med. Reconstr. Surg.* 2020 Dec 1; 26(12):719-720. doi: 10.1097/SPV.0000000000000979. PMID: 33136609; PMCID: PMC7682789.

¹³ American Anthropological Association, Statement on Race, <https://www.americananthro.org/ConnectWithAAA/Content.aspx?ItemNumber=2583> (Accessed March 24, 2023).

¹⁴ AAPA Statement on Race and Racism, June 14, 2019, <https://onlinelibrary.wiley.com/doi/full/10.1002/ajpa.23882> (Accessed March 24, 2023). *See also*, Flanagan A, Frey T, Christiansen SL, AMA Manual of Style Committee. Updated Guidance on the Reporting of Race and Ethnicity in Medical and Science Journals. *JAMA.* 2021;326(7):621–627. doi:10.1001/jama.2021.13304. Article highlights how terms commonly associated with race and ethnicity have changed, are dated, and evolving. *Id.*

widespread collection and analysis of both quantitative and qualitative race and ethnicity data. This will ensure the utilization of an evidence-based approach to the creation of any new racial and ethnic category in SPD 15 such as the proposed “Middle Eastern or North African” minimum reporting category.

We also appreciate the contemporaneous discussions taking place across the research community on the collection and use of race and ethnicity data and related definitional considerations. For example, in March 2023, the National Academies of Sciences Engineering & Medicine (Academies) released a new framework for using population descriptors in genomics research, recommending researchers “avoid[] typological thinking” in genetics and genomics research, and explaining that “[e]rroneous categorical assumptions can be scientifically and ethically detrimental, particularly when applied to studies of human history, identity, variation, and traits or diseases.”¹⁵

Specifically, in reference to the OMB’s revisions to SPD 15, the Academies cautions against the use of the OMB categories, emphasizing that researchers “only have to use these categories when reporting study participant demographics of those they recruited. That is, the need and rationale for reporting to funding agencies is distinct from how researchers design their study and analyze their data. In the latter cases, researchers should use the most appropriate population descriptors for the questions they are probing instead of using the OMB categories reflexively.”¹⁶

We recognize that the Academies’ report is specific to genomics research, and that race, ethnicity, and other population descriptors have very different uses in this context than SPD 15. In support of the concerns raised by the Academies, we encourage the OMB to reinforce the position that there are various uses and corresponding needs for race and ethnicity data depending on the *specific research context* (e.g., pharmacogenomics/precision medicine), citing the Academies report as one example.

II. Collection of Race and Ethnicity Information Using One Combined Question

Given the significant changes to the country’s demographic landscape since 2016, as well as changes to the public’s perception and understanding of the terms “race” and “ethnicity,” we support the OMB’s interest in gaining a better understanding of how a combined question impacts self-reporting, including an evaluation of whether the terms “race” and ethnicity” should be used in the question stem or whether an alternative phase is more appropriate to minimize respondent confusion and improve inclusivity.

For over a decade, the AAMC has asked the question “How do you self-identify? Please check all that apply.” Most medical school applicants have provided these data each year. For example, about 97% of all eligible applicants (i.e., U.S. citizens or permanent residents) provided self-identity data on race/ethnicity in the most recent American Medical College Application Service (AMCAS) cycle). Moreover, a review of the open-ended responses suggests little (if any) concern about this approach across the 170,661 applications in the past three medical school application cycles.

As further described below, given the ambiguities among race, ethnicity, culture, ancestry, geography, country, nationality, and other descriptors, a more inclusive question would allow individuals to conceptualize their identities however they think is best. **Therefore, we recommend the adoption of the question “how do you self-identify” instead of the proposed “what is your race or ethnicity.” We also suggest the development of guidance related to the interpretation and presentation of trend analysis**

¹⁵ National Academies of Sciences, Engineering, and Medicine. 2023. Using Population Descriptors in Genetics and Genomics Research: A New Framework for an Evolving Field. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26902>. See also, Callier SL. The Use of Racial Categories in Precision Medicine Research. *Ethn Dis*. 2019 Dec 12;29(Suppl 3):651-658. doi: 10.18865/ed.29.S3.651. PMID: 31889770; PMCID: PMC6919973.

¹⁶ *Id.*

since changes to the “Other” and “White” reporting category will be an artifact of survey methodology and not necessarily a result of a demographic shift.

Decline in “White Race Alone”

The 2010 U.S. Census, *Race and Hispanic Origin Alternative Questionnaire Experiment* and qualitative follow-up, revealed that a combined question facilitated self-identification for Hispanic/Latino respondents. Specifically, utilization of one race and ethnicity question resulted in significant decreases in the proportion of respondents choosing the “Other” or “White Race Alone” category, changes attributed to Hispanic respondents’ finding their identity in the combined question.¹⁷ Results from the 2020 Census provides an updated perspective that aligns with the 2010 Census findings: “[n]early all groups saw population gains this decade and the increase in the Two or More Races population (referred to throughout this story as the Multiracial population) was especially large (up 276%). The White alone population declined by 8.6% since 2010.”¹⁸

Consistent with the Census results, the AAMC also saw similar decreases in the “White Race Alone” reporting when it transitioned from a combined race and ethnicity question format for its surveys and administrative data collections in 2013.¹⁹ We agree with the Census Bureau’s assertion that the combined question for race and ethnicity, as well as improvements to data processing and coding have “...[yielded] an even more accurate portrait of how the U.S. population self-identifies, especially for people who self-identify as multiracial or multiethnic.”²⁰ As a result, the AAMC has continued to use a combined question and as recommended above, we encourage the OMB to adopt this change.

Administrative Burden

The OMB has expressed concerns about potential burden on agencies if a combined question is implemented, recommending flexibilities for agencies “dependent on aggregate data, data that are not self-reported, or data from non-Federal providers.”²¹ While we share these concerns, we note that the OMB does not provide best practices or specific examples of *what* flexibilities agencies could implement.

As an example, the OMB and the Office of the Chief Statistician released a comprehensive Memorandum in June 2022 on the current flexibilities and best practices for SPD 15, including a detailed FAQ to assist with decision-making.²² This guidance is a prime example of how agencies could implement the revised standards, especially agencies that require flexibility while still adhering to SPD 15’s overarching goals. To assist with implementation of SPD 15 and to help decrease administrative burden, we encourage the OMB to develop similar guidance informed by the feedback received from this comment process and other opportunities for public feedback.

¹⁷AAMC Comments to OMB, Supra Note 1. *See also*: Census Bureau Releases Results From the 2010 Census Race and Hispanic Origin Alternative Questionnaire Research, https://www.census.gov/newsroom/releases/archives/2010_census/cb12-146.html (Accessed March 8, 2023).

¹⁸ 2020 Census Illuminates Racial and Ethnic Composition of the Country, <https://www.census.gov/library/stories/2021/08/improved-race-ethnicity-measures-reveal-united-states-population-much-more-multiracial.html> (Accessed March 8, 2023).

¹⁹ AAMC Comments to OMB Supra Note 1.

²⁰ 2020 Census Illuminates Racial and Ethnic Composition of the Country, August 12, 2021, <https://www.census.gov/library/stories/2021/08/improved-race-ethnicity-measures-reveal-united-states-population-much-more-multiracial.html> (Accessed March 8, 2023). *See Also*: Research to Improve Data on Race and Ethnicity, US Census Bureau, <https://www.census.gov/about/our-research/race-ethnicity.html> (Accessed March 8, 2023).

²¹ 88 Fed. Reg. 5379.

²² Flexibilities and Best Practices for Implementing the Office of Management and Budget’s 1997 Standards for Maintaining, Collecting, And Presenting Federal Data on Race and Ethnicity (Statistical Policy Directive No. 15), July 2022, <https://www.whitehouse.gov/wp-content/uploads/2022/07/Flexibilities-and-Best-Practices-Under-SPD-15.pdf> (Accessed March 24, 2023).

III. New Minimum Category: Middle Eastern or North African

The proposed changes to SPD 15 also include the long-anticipated addition of a “Middle Eastern or North African” (MENA) minimum reporting category, as well as changes to the definition of the current White category to remove the MENA classification.

In its 2016 letter to the OMB the AAMC supported the proposed addition of MENA to the minimum reporting categories, and we continue to urge adoption of this new category.²³ For many years, the single largest proportion of write-in responses to the AAMC’s open-ended self-identity questions for matriculating students have reflected Middle Eastern or North African backgrounds. As a result, over the past two years, the AAMC has piloted an updated self-identity question on the Matriculating Student Questionnaire, whereby “Middle Eastern or North African” appears as a separate self-identity option. In the first year, 4.7% of respondents identified as MENA, and 5.4% of respondents identified as MENA in the second year. The pilot has encouraged the AAMC to make “Middle Eastern or North African” a standard self-identity across all AAMC data collections that collect self-identity information.

The addition of a MENA subcategory has been a focal point of discussion for almost three decades²⁴ with many members of the MENA community serving as vocal advocates for the inclusion of a MENA category in federal collections since they perceive their identity as distinct from White — arguing that aggregating them into the White category “renders them invisible in population counts.”²⁵ Lawmakers have also been supportive of this change. Last year the Committee on Oversight and Reform urged the director of the OMB and the U.S. Census Bureau to include a MENA category in the decennial census and the OMB standards, explaining that “[f]ederal demographic data does not reflect the realities of MENA individuals and community-based organizations, which makes it increasingly difficult for advocates, researchers, agency officials, and policymakers to communicate, understand, and address community needs. As a result, federal policymaking and program implementation rarely address the lived experiences of members of the MENA community.”²⁶

A consequence of the misidentification of MENA individuals as “White,” has also resulted in health and health care inequities for this community. As highlighted by the Committee on Oversight and Reform, the evidence base documenting these inequities is limited.²⁷ This is due to the lack of robust collection efforts and the inability for MENA individuals to “find themselves” in the OMB standards, preventing the selection of a racial and ethnic category that accurately reflects their self-identity.

Additional Research Considerations

Among other questions, the OMB has requested feedback on whether the term “Middle Eastern or North African” will likely be understood and accepted by those in the MENA community (e.g., whether the acronym “MENA” is appropriate and whether the proposed nationality and ethnic group examples adequately represent the MENA category). We appreciate the OMB’s consideration for how this new category would be *consistently* understood, especially given the diverse lived experiences within the MENA

²³ AAMC Comments to OMB, Supra Note 1.

²⁴ 88 Fed. Reg. 5379.

²⁵ Lobbying for a ‘MENA’ category on U.S. Census, August 13, 2014, <https://www.usatoday.com/story/news/nation/2014/08/13/stateline-census-mena-africa-mideast/13999239/> (Accessed March 24, 2023).

²⁶ Letter from the Committee on Oversight and Reform, June 14, 2022, <https://oversightdemocrats.house.gov/sites/democrats.oversight.house.gov/files/2022-06-14.CBM%20Tlaib%20et%20al.%20to%20Young-OMB%20and%20Santos-USCB%20re%20MENA%20Census%20FINAL.pdf> (Accessed March 24, 2023).

²⁷ *Id.*

community that impacts self-identity (e.g., born in the U.S., recently immigrated, immigrated but have lived in the U.S. for a period).

The questions the OMB has presented for comment require direct input and collaboration with MENA individuals and communities. We recommend following up with respondents that have provided meaningful data and information in response to this comment request. We also suggest collaboration with advocacy and community-based organizations such as the Arab American Institute Foundation and National Network for Arab American Communities, a growing network of independent Arab American community-based organizations that have been actively engaged on this issue.²⁸

We would also like to bring to the OMB’s attention an article published last year by the Proceedings of the National Academy of Sciences, *Middle Eastern and North African Americans May Not be Perceived, Nor Perceive Themselves, to be White*, describing issues with the classification of MENA Americans as White using data from an experiment on self-identity in the MENA community.²⁹ This article could provide a foundation for the OMB’s interest in better understanding the characteristics that would make the MENA definition more representative and how the definition could be “consistently understood” by MENA respondents.

Finally, as the OMB is likely aware, federal agencies and lawmakers are discussing this issue as the revisions to SPD 15 are taking place. In the spirit of alignment, it would benefit the OMB to collaborate with current federal and legislative efforts (*see*, Health Equity and Middle Eastern and North African Community Inclusion Act of 2022, established to “help ensure the experiences and needs of the MENA community are reflected in the federal government’s focus on public health.”³⁰ *See also*, Congressional letter to HHS Secretary Becerra urging the addition of MENA to federal data collections).³¹

IV. Detailed Race and Ethnicity Categories

In the Initial Proposal, the OMB set forth two levels of granularity with respect to race and ethnicity data: detailed categories and minimum categories. **The AAMC supports the OMB’s proposal to require federal agencies collect race and ethnicity at the detailed category level as a default. The minimum categories should be used only when an agency determines that the potential benefit of the detailed data does not justify the additional burden to the agency or the public or poses a risk to privacy or confidentiality. The OMB should include the criteria for determining when the minimum categories could be used in its revised standards, not only in guidance.**

We recognize that the use of minimum categories may provide an agency with more flexibility and in some cases collection of detailed information can increase the burden on the agency and on the public. However, the collection of information in detailed categories, especially when these categories can be effectively “rolled up” into the broader minimum categories, allows for a more comprehensive analysis, including identifying and addressing racial and ethnic inequities.

²⁸ National Network for Arab American Communities, <https://www.accesscommunity.org/about> (Accessed March 27, 2023).

²⁹ Middle Eastern and North African Americans may not be perceived, nor perceive themselves, to be White *Proc Natl Acad Sci U S A*. 2022 Feb 15; 119(7): e2117940119. Published online 2022 Feb 7. doi: [10.1073/pnas.2117940119](https://doi.org/10.1073/pnas.2117940119) PMID: PMC8851556, PMID: [35131945](https://pubmed.ncbi.nlm.nih.gov/35131945/) Social Sciences.

³⁰ Dingell, Tlaib, Eshoo, & Kelly Introduce Health Equity Bill for MENA Communities, <https://debbiedingell.house.gov/news/documentsingle.aspx?DocumentID=3420> (Accessed March 27, 2023).

³¹ Dingell, Tlaib Urge HHS to Add “Middle Eastern or North African” Self-Identification Category to Address Health Disparities, https://debbiedingell.house.gov/uploadedfiles/12.16.22_dingell_tlaib_letter_to_hhs_on_mena.pdf (Accessed March 27, 2023).

We also recommend that when minimum categories are used, respondents are provided with a list of each of the detailed categories that would be included in those minimum categories next to each checkbox selection to ensure that an individual can confidently choose the same or equivalent designation each time they identify themselves. We also suggest the addition of a checkbox for a category such as “Some Other Race or Ethnicity” (with an open-ended write-in option) for those individuals who do not identify with any of the enumerated categories. For nearly 20 years the AAMC has allowed individuals to select “some other race or ethnicity,” an option that has been helpful for better understanding the diversity of the biomedical community. In each of the past two years, 4.7% of medical school applicants identified as “some other race or ethnicity.”

The OMB should also consider the following to inform potential guidance:

- **Intergovernmental Working Group**—Establish an inter-governmental working group consisting of diverse technical experts to identify key issues that should be clarified in related guidance. This group should include representatives from the *White House Interagency Working Group on Equitable Data* and key contributors to the *2015 National Content Test*. In addition to federal partners, it should include state and local community advisors.
- **Use of SPD 15 by State and Local Entities**—Consider how state, local entities, and other interested parties (e.g., community-based organizations, research institutions) will use SPD 15 and related guidance.
- **Privacy and Confidentiality**—Identify how the collection and use of disaggregated data might impact respondent confidentiality, privacy, and potential re-identification (e.g., certain communities might have concerns about safety or surveillance, reinforcing the need for increased confidentiality and privacy protections).
- **Misclassification Issues**—Consider challenges related to the analysis and reporting of data for individuals who identify with more than one race and ethnicity subcategory (e.g., selecting Salvadoran and writing in Guatemalan).
- **Technology and Financial Resources**—Examine issues related to technological capacity and the financial resources necessary for the collection and reporting of granular data collection.
- **Proxy Considerations**—Consider measures for the “proxy collection” of race and ethnicity when self-identification is not feasible.
- **Incorporation of Community Wisdom**—Federal agencies should incorporate community wisdom into guidance and other decision-making policies and processes. Special consideration should be given to communities and relevant parties that might be disproportionately impacted by disaggregated data collection in addition to other topics (e.g., communication on the intended use of federal data, public communication and dissemination of results, survey development, development of training and educational materials).
- **Develop Public Trust**—The AAMC Center for Health Justice developed the *Principles of Trustworthiness* to guide organizations and government entities in efforts to equitably partner with communities and build trust among members of those communities. We would be happy to assist the OMB with its continued efforts to engage communities in the revisions to SPD 15 and beyond.³²

³² AAMC Center for Health Justice, <https://www.aamc.org/healthjustice>; See also, AAMC Principles of Trustworthiness, <https://www.aamc.org/trustworthiness>, Principles of Trustworthiness Toolkit, <https://www.aamc.org/trustworthiness#toolkit>. See also, From the National to the Local: Issues of Trust and a Model for Community-Academic-Engagement, <https://www.frontiersin.org/articles/10.3389/fpubh.2023.1068425/full>.

V. Terminology and Definitions

The OMB states that “recent research shows inconsistent understanding and use of the terms ‘majority’ and ‘minority’ and that the terms may be perceived by some as pejorative and not inclusive.”³³ **We support the OMB’s proposed removal of antiquated and polarizing terminology, especially terms that reinforce racial and ethnic hierarchy and white supremacy, especially in light of the growing multi-racial diversity in the U.S.**

As stated in the AAMC Center for Health Justice’s and American Medical Association’s, *Guide to Language Narrative and Concepts*, “[d]ominant narratives absolve people and institutions of responsibility for social injustice.” The use and impact of dominant narratives in social culture is also discussed:

“[Dominant narratives] exist in the public consciousness and cultural memory, reinforced in stories, images, symbols, myths, practices, customs, art, mass media, textbooks, fiction and more. Often resistant to change, they become normalized and unquestioned, like stories about the founding of the United States, a slave-holding society where only propertied white men could vote. Dominant narratives protect and advance the interests of privileged social groups, often dividing populations with common concerns, and obscuring alternative visions of what is possible.”³⁴

Evidence-Based Updates to Definitions and Terminology

To facilitate transparency and increase the public’s understanding of the OMB’s rationale for adopting changes to certain terminology and definitions and not others (e.g., “Negro,” removal of “Far East” from the Asian definition, “multi-racial/multi-ethnic,” “transnational”), we encourage the inclusion of an evidence-based rationale in support of any changes to SPD 15’s terms and/or definitions. This might include reference to current research, including any qualitative and/or quantitative feedback received from this comment process, the OMB town halls, community forums, or other avenues for community input. In addition, we support the OMB’s interest in receiving additional feedback on the “previously tested definitions of minimum categories” and whether those definitions should be updated.

The AAMC recognizes that the OMB has referenced literature and research on the proposed subcategories (such as how the subcategories are listed in order of prevalence based on Census research). It would be helpful for the OMB to provide additional supporting information addressing the rationale for including the proposed subcategories. For example, the OMB could provide information in related guidance on the proposed inclusion of subcategories under “white.” The AAMC acknowledges the various opinions about the inclusion of white subcategories on data collections and encourages the OMB to be transparent regarding the rationale to include these subcategories. This additional supporting information would also assist agencies and other entities with the development of internal and external communications when planning for updates to data collections and data reports in response to the proposed changes to SPD 15.

Proposed Removal of the Term “Negro”

We appreciate the OMB’s interest in examining whether the term “Negro” should be removed from the Black or African American definition within the minimum categories. The term was initially added to SPD 15 in 1997, the last time the standards underwent revision. Since this point, there have been robust discussions across the community on the removal of the term from federal forms and the culturally

³³ 88 Fed. Reg. 5383.

³⁴ Association of American Medical Colleges, American Medical Association, *Advancing Health Equity: A Guide to Language, Narrative and Concepts* (2021), <https://www.ama-assn.org/system/files/ama-aamc-equity-guide.pdf>.

appropriate use of the term itself.³⁵ In 2013, the U.S. Census Bureau made the decision to remove “Negro” from its census forms³⁶ and in 2014, the U.S. Army issued a formal apology for referring to Black or African American service members as “Negro” within Army regulations 600-20 (“Army Command Policy”).³⁷ In 2016 President Barack Obama signed H.R. 4238, amending two federal acts defining “minorities” by terms that are outdated (“Negro,” “Oriental”).³⁸ Civil rights advocacy groups, such as the National Urban League, have also vocalized opposition to the use of the term. In a written statement to NPR, the president and CEO of the National Urban League stated: there is “very clear consensus that the obsolete term 'Negro' should be eliminated.” Urging “the administration to proceed immediately, keeping the fairness and accuracy of the census at the forefront of concern.”³⁹

We commend the OMB for taking steps to evaluate whether outdated or culturally inappropriate terms should be removed from SPD 15 and support the OMB’s proposed removal of “Negro” from SPD 15. To ensure transparency and uphold public trust in the OMB’s decision-making, we also strongly encourage any final decision on the removal or updates to certain terminology or definitions be supported by clear qualitative *and* quantitative data rooted in robust community feedback.

American Decedents of Slavery and Other Ancestry Considerations

The OMB has also requested input on how federal forms or surveys can collect data related to “descent from enslaved peoples originally from the African continent,” and whether this should be collected within the “Black or African American” minimum category, through a separate question approach, or another approach. The AAMC attended the OMB’s March Town Hall meetings and noted the many commenters asking for federal forms and surveys to capture ancestry data and related information, including data related to descendants from enslaved peoples from the African continent (e.g., “American Descendants of Slavery,” “American Freedmen”).

We respect the historical importance of this designation and appreciate the current efforts on the state, local, and congressional level to address historical and current injustice and socioeconomic disparities through reparations (also referred to as “restorative justice”).⁴⁰ While we acknowledge the potential benefits related to the collection of ancestry data we believe that it is premature to implement a specific standard without more research and input. We recommend the OMB create an opportunity for robust public feedback through a Request for Information separate from the current proposed revisions to SPD 15. We also support additional opportunities for community convenings or other forums to discuss other ancestry issues of importance (e.g., how to best describe indigenous identity). **Should this information be collected, we urge that it be collected through an entirely separate question since it falls outside of the scope of SPD 15’s racial and ethnic categorizations.**

³⁵ Ebony Magazine, White House to Decide if Negro Will Remain on Federal Forms, <https://www.ebony.com/white-house-negro-federal-forms/> (Accessed April 3, 2023).

³⁶ National Public Radio, No More ‘Negro’ For Census Bureau Forms And Surveys, February 25, 2013, <https://www.npr.org/2017/12/13/568317026/negro-not-allowed-on-federal-forms-white-house-to-decide> (Accessed April 3, 2023).

³⁷ CNN, Army Apologizes for Policy Approving use of Word ‘Negro,’ <https://www.cnn.com/2014/11/07/politics/army-apology-for-regulation-negro-word/index.html> (Accessed April 3, 2023).

³⁸ CNN, U.S. Government to Stop Using These Words to Refer to Minorities, May 22, 2016, <https://www.cnn.com/2016/05/22/politics/obama-federal-law-minorities-references/index.html>, See Also, H.R.4238 - To amend the Department of Energy Organization Act and the Local Public Works Capital Development and Investment Act of 1976 to modernize terms relating to minorities (Public Law No: 114-157, May 20, 2016).

³⁹ Supra Note 36.

⁴⁰ E.g., H.R.40 - Commission to Study and Develop Reparation Proposals for African Americans Act, 117th Congress (2021-2022).

VI. Implementation Considerations

In closing, the OMB has requested input on other ways SPD 15 could be improved, including additional topics for future research. In consideration of this request, we recommend the following:

- **Ongoing Evaluation of SPD 15**

We applaud the OMB for revising these much-anticipated revisions to SPD 15 and urge implementation of robust prospective and retrospective evaluation mechanisms in coordination with federal agencies, state/local entities, and non-governmental collaborators. For example, the AAMC takes seriously the review of our race and ethnicity collection standards by evaluating the open-ended feedback to race and ethnicity questions (e.g., by experimenting with new question formats and by having a written policy whereby the race and ethnicity data collection standards need to be reviewed *every three years*). Similarly, we encourage the OMB to implement an evaluation timeframe that ensures the analysis of time trends and other evaluation efforts to improve data collection processes and data quality. This would ensure a timely assessment of changes in racial and ethnic health care gaps, utilization of the most up to date and culturally appropriate definitions and terms, optimization of education and training materials, among other considerations.

- **Intergovernmental Collaboration and Advancing Equity across the Government**

Notably, the OMB is revising SPD 15 during a time when the Administration is simultaneously implementing Executive Order (EO) 13985, *Advancing Racial Equity and Support for Underserved Communities Through Federal Government*, which the AAMC Center for Health Justice commented on in 2021.⁴¹ In a recent announcement on the progress of this initiative, the White House indicated that the Office of Science and Technology Policy will coordinate the implementation of the recommendations of the previously established *Interagency Working Group on Equitable Data*. In 2022 this working group released a report that includes several recommendations applicable to SPD 15, including the recommendation to “make disaggregated data the norm while protecting privacy.”⁴² In the spirit of advancing collaboration and alignment with related federal activities, we also encourage coordination (to the extent practicable) with other agency efforts to advance equity across the Government (e.g., HHS Healthy People 2030,⁴³ FDA’s efforts to increase enrollment of underrepresented racial and ethnic populations in clinical trials⁴⁴).

- **Publication of SPD 15 and Related Guidance**

The OMB has proposed that SPD 15 and related documents are published online in a central location. We agree but respectfully remind the OMB that not all individuals and communities have equitable access to web-based technology and/or web access. It is crucial that the revised proposals, related

⁴¹ See AAMC Center for Health Justice Comments to OMB on Advancing Racial Equity across the Federal Government, July 2, 2021, <https://www.aamc.org/media/55326/download?attachment>.

⁴² Recommendations from the Equitable Data Working Group, <https://www.whitehouse.gov/wp-content/uploads/2022/04/eo13985-vision-for-equitable-data.pdf> (Accessed March 27, 2023). As noted in the report: “[s]ample sizes in many national statistical surveys would need to be increased to generate estimates for smaller populations – such as individual LGBTQI+ communities and smaller racial and ethnic groups – without jeopardizing the confidentiality of survey respondents. Additionally, because increases in sample size are not a cost-effective way to study the smallest population subgroups, the Working Group recommends support for other alternative avenues as well. For instance, statistical agencies should explore creating multi-year datasets for national surveys that will allow publishing estimates for small populations.” *Id.*

⁴³ Centers for Disease Control and Prevention, National Center for Health Statistics, https://www.cdc.gov/nchs/healthy_people/hp2030/hp2030-data-sources.htm (Accessed March 28, 2023). See also, AAMC Center for Health Justice Response to Healthy People 2030, <https://www.aamc.org/media/64101/download?attachment> (December 2, 2022).

⁴⁴ The DEPICT Act, Public Law 117-164, <https://aboutblaw.com/6o0>, See also, AAMC Comments to FDA, June 13, 2022, Diversity Plans to Improve Enrollment of Participants From Underrepresented Racial and Ethnic Populations in Clinical Trials; [Docket No. FDA – 2021 – D – 0789], <https://www.aamc.org/media/61296/download?attachment>.

guidance, and announcements for ongoing public comment reach *all* impacted and interested communities, especially those who might be unaware of notices proffered in the Federal Register or through an OMB or White House press release. To ensure this takes place, the OMB should solicit feedback on best practices for efficient communication and collaboration with interested parties to ensure this goal is met.

▪ **Additional Research Areas**

As the OMB contemplates the comments received from this request and identifies additional areas for research, we suggest the following:

- **LGBTQ+ Data:** Collection of other demographic data for groups that are not currently represented in SPD 15 such as LGBTQ+ populations. Standardizing federal data collection efforts for sexual orientation and gender identity data would accelerate our nation’s ability to address health and health care inequities facing LGBTQ+ and other sexual and gender diverse communities (See *Executive Order on Advancing Equity for LGBTQI Individuals*).⁴⁵ Updates in this area should also include inquiry into appropriate nomenclature for sex, gender, sexual orientation.
- **Other Data:** Data collection on other key areas that intersect with people’s identities⁴⁶ (e.g., religion, country of origin, primary language, disability status, social determinants of health).
- **Reorganization of Minimum Categories:** The order in which the minimum categories are displayed on federal data collections should be reconsidered. For example, the Census Bureau has indicated that it lists the white category first (2020 Census) due to population size.⁴⁷ Alternatively, JAMA’s guidance on the *Reporting of Race and Ethnicity in Medical and Science Journals* recommends that racial and ethnic categories should be listed in alphabetical order instead of order of majority.⁴⁸ For many years, the AAMC has taken the approach of alphabetizing the race and ethnicity categories and subcategories. As a result, we believe the order of the current minimum categories should be reevaluated, especially considering the OMB’s current interest in adopting equitable terminology (e.g., proposed removal of “minority/majority”).
- **Multi-Sector Convening:** Convene a multi-sector group to evaluate additional changes and potential research areas not implemented as part of the current revisions to SPD 15. For example, the National Academies Committee on National Statistics published the 2022 Interim Report, *Understanding the Quality of the 2020 Census*, and plans to release a final report with recommendations to help the Bureau plan for the 2030 Census. Importantly, the Panel noted “interactions with census stakeholders have indicated an erosion of trust and confidence, in the wake of exceptionally difficult circumstances surrounding 2020,” urging the Bureau to work toward transparency and improvements for 2030.⁴⁹ As expressed throughout this letter, we encourage similar efforts to convene diverse experts and community members to identify additional

⁴⁵ Executive Order on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals, June 15, 2022, <https://www.whitehouse.gov/briefing-room/presidential-actions/2022/06/15/executive-order-on-advancing-equality-for-lesbian-gay-bisexual-transgender-queer-and-intersex-individuals/>.

⁴⁶ Lorena Garcia, et. al., Taking Action to Advance the Study of Race and Ethnicity: The Women’s Health Initiative, January 4, 2022.

<https://womensmidlifehealthjournal.biomedcentral.com/articles/10.1186/s40695-021-00071-6>

⁴⁷ 2020 Census Frequently Asked Questions, <https://www.census.gov/programs-surveys/decennial-census/decade/2020/planning-management/release/faqs-race-ethnicity.html> (Accessed March 27, 2023).

⁴⁸ Supra Note 13.

⁴⁹ National Academies of Sciences, Engineering, and Medicine. 2022. *Understanding the Quality of the 2020 Census: Interim Report*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26529>.

opportunities for research and data collection. We recommend the OMB work with the Academies on this project if not already involved.

The AAMC and AAMC Center for Health Justice appreciate the opportunity to offer comments on this important undertaking and would be more than happy to provide additional information on any of the recommendations offered in these comments or on the AAMC's data collection projects on race and ethnicity. We look forward to the issuance of the final revisions to SPD 15 and encourage ongoing opportunities to engage the community in furtherance of this work.

For questions, please contact me or my colleagues, Daria Grayer, Director, Regulation and Policy (dgrayer@aamc.org) or Hershel Alexander, Senior Director, Data Operations and Services (halexander@aamc.org).

Sincerely,

Handwritten signature of Ross McKinney, Jr. MD in blue ink.

Ross McKinney, Jr, MD.
Chief Scientific Officer

Handwritten signature of Philip M. Alberti, PhD in blue ink.

Philip M. Alberti, PhD
Founding Director, AAMC Center for Health Justice
Senior Director, Health Equity Research and Policy

cc: David J. Skorton, MD, President and Chief Executive Officer