

April 27, 2023

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725 17th Street, NW  
Washington, DC 20503

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725 17th Street, NW  
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Office of Management and Budget  
1650 17th Street, NW  
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Re: Docket No. OMB-2023-0001; Initial Proposals for Updating OMB's Race and Ethnicity Statistical Standards

Dear Director Young, Dr. Orvis, and Mr. Sivinski:

Trust for America's Health (TFAH) is grateful for the opportunity to comment on the initial proposals from the Federal Interagency Technical Working Group on Race and Ethnicity Standards (Working Group) for revising the Office of Management and Budget's (OMB) 1997 Statistical Policy Directive No. 15 Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD 15). TFAH is a non-profit, non-partisan public health policy, research, and advocacy organization committed to promoting optimal health for every person and community and making health equity foundational to policymaking at all levels. TFAH focuses on the antecedents of poor health and on prevention. TFAH advances evidence-based policy recommendations to strengthen the nation's public health system.

Data are fundamental to advancing health equity. In our own work, TFAH collects data from several federal agencies on a variety of public health issues, including obesity, substance use, mental health, and emergency preparedness. Ensuring that accurate data are collected by the federal and state entities from whom we derive our data is fundamental to our policy and advocacy efforts, including racial and ethnic data. These data allow us to characterize public health issues, identify subgroups that may be disproportionately impacted by those health challenges, and advocate for solutions that are equitable and effective. Despite the rapidly changing landscape of race and ethnicity in the United States, the SPD 15 has only been updated once since its inception 46 years ago, with the last update more than two decades ago. As a

result, TFAH applauds OMB for recognizing the need for improved, accurate, actionable data collection of race and ethnicity. TFAH also applauds the Working Group’s governing principles, specifically, the Working Group’s acknowledgment that race and ethnicity are socio-political constructs that are independent of biological and genetic ancestry,<sup>1</sup> and its commitment to respecting individual dignity in the revision of SPD 15.

Over the years, the makeup of the United States has become more racially and ethnically diverse. According to the 2020 Census, the non-Hispanic white population is still the most prevalent racial or ethnic group at 57.8%, but decreased from 63.7% in 2010.<sup>2</sup> The Diversity Index of the United States increased as well, from 54.9% in 2010 to 61.1% in 2020.<sup>3</sup> While race is a sociopolitical construct, there is a link between race and health outcomes because of structural racism, discrimination, and oppression.<sup>4</sup> For example, as a result of the legacy of policies rooted in structural racism, such as redlining and the subsequent underinvestment in communities, people of color experience higher rates of many chronic diseases, such as diabetes, hypertension, obesity, asthma, and heart disease than white people.<sup>5</sup> Health outcomes are particularly impacted among Black Americans, whose life expectancy is 4 years lower than white Americans.<sup>6</sup>

The accuracy and precision of race and ethnicity data are critical in identifying the needs of different populations and understanding the disproportionate distribution of resources. Numerous health crises have been brought to light as a result of accurate data collection, including identifying the maternal health crisis among Black women, understanding the disproportionate impact of COVID-19 on people of color and guiding the equitable distribution of tests and vaccines, understanding the disparate impacts of Hurricane Katrina on different New Orleans zip codes, and unveiling the systemic racism at the root of the Flint water crisis. While these health crises have been identified, we still need accurate data to understand the disaggregated impact of these events on specific population subgroups, the recovery and resiliency of certain subgroups, subgroup outcomes, and understand and ensure the equitable application of policies and programs.

Further, varying immigration and migration patterns highlight the need to update our outdated racial and ethnic categories to support more accurate and useful data that allows the unmasking of different health needs of different groups. For example, accurate data can help identify and

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<sup>1</sup> Mersha TB, Beck AF. The social, economic, political, and genetic value of race and ethnicity in 2020. *Human Genomics*. 2020;14(37). <https://doi.org/10.1186/s40246-020-00284-2>.

<sup>2</sup> Jensen E, Jones N, Rabe M, Pratt B, Medina L, Orozco K, Spell L (August 12, 2021). The chance that two people chosen at random are of different race or ethnicity groups has increased since 2010. United States Census Bureau. Retrieved from <https://www.census.gov/library/stories/2021/08/2020-united-states-population-more-racially-ethnically-diverse-than-2010.html>.

<sup>3</sup> The Diversity Index calculation indicates the percent chance that two people chosen at random will be from different racial or ethnic groups. Ibid.

<sup>4</sup> Centers for Disease Control and Prevention. Racism and health. Retrieved from <https://www.cdc.gov/minorityhealth/racism-disparities/index.html>. Accessed March 21, 2023.

<sup>5</sup> Centers for Disease Control and Prevention (April 8, 2021). Impact of racism on our nation’s health. Retrieved from <https://www.cdc.gov/minorityhealth/racism-disparities/impact-of-racism.html>.

<sup>6</sup> Ibid.

address additional public health challenges, like subgroup obesity trends (e.g., are certain subgroups experiencing a greater challenge with access to nutrient dense foods?), and subgroup differences related to mental health conditions and substance use disorder.

For all of these reasons, it is imperative to update SPD 15 to reflect the current landscape of the United States. TFAH’s recommendations in response to specific proposals are detailed below.

### **Working Group Proposal #1: Collect race and ethnicity data using one combined question.**

TFAH supports the Working Group’s proposal to collect race and ethnicity data using one combined question.

#### **1a. Please provide links or references to relevant studies that examine or test any impacts of collecting race and ethnicity information using separate questions compared to a combined question.**

In previous Census results, many Americans did not select a race category: In the 2010 Census, about 6.2% respondents selected only “some other race.”<sup>7</sup> Since then, the Census Bureau has embarked on years-long research to improve the accuracy and reliability of its race and ethnicity data. This includes the 2010 Alternative Question Experiment (AQE) and the 2015 National Content Test (NCT) to understand how people self-identify their race and ethnicity, and which Census question format best supports respondents’ identities.

The Census Bureau designed the 2015 National Content Test (NCT) to compare different questionnaire design strategies for race and ethnicity. The test compared responses between the original separate race and ethnicity question, a combined question with write-in response areas, and a combined question with detailed checkboxes. The analysis report found the following<sup>8</sup>:

- Higher percentages of respondents reported as “Hispanic” using the combined question versus the separate question format
- A significantly lower percentage of respondents reported as “some other race” (SOR) when using a combined question (1%) versus the separate question (10%) format
- There were no significant differences in the reporting of Asian, Black, or Native Hawaiians and Pacific Islander (NHPI) individuals when comparing the separate question to the combined question format
- A significantly lower percentage of respondents reported as “Middle Eastern and North African (MENA)” using the separate question versus the combined question *with detailed checkboxes* format

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<sup>7</sup> Pew Research Center. (2014, March 14). U.S. Census looking at big changes in how it asks about race and ethnicity. Fact Tank. Retrieved from <https://www.pewresearch.org/fact-tank/2014/03/14/u-s-census-looking-at-big-changes-in-how-it-asks-about-race-and-ethnicity/>.

<sup>8</sup> U.S. Census Bureau. (2015). Final Analysis Report of the 2015 National Content Test Race and Ethnicity Study. Retrieved from <https://www2.census.gov/programs-surveys/decennial/2020/program-management/final-analysis-reports/2015nct-race-ethnicity-analysis.pdf>.

By combining the race and Hispanic origin questions into one question on race/ethnicity, Census research shows that Hispanic populations can better identify themselves within the race and ethnicity categories. The NCT analysis report found the following<sup>9</sup>:

- In the separate question format, Hispanic respondents reported other race categories (White, SOR, etc.) at significantly higher rates than those who received either combined question format
- Nonresponse to the combined question was lower than nonresponse to the separate race question

Overall, Census research shows that using the combined question with detailed checkboxes design supported research objectives of increasing reporting within the current standard OMB categories, decreasing nonresponse rates, improving accuracy and reliability, and achieving similar or higher levels of detailed reporting for all major racial and ethnic groups.

### **1b. To what extent would a combined race and ethnicity question that allows for the selection of one or more categories impact people's ability to self-report all aspects of their identity?**

Research on previous Census results shows that the separated race and ethnicity question format hinders respondents' ability to accurately self-report their identity. One major challenge with the separated question format is that many Americans do not separate their race from their ethnic origin in the same way that researchers often do.<sup>10</sup> This is particularly true among Hispanic populations. In the 2010 Census, Hispanic populations accounted for more than 18.5 million of the 19 million people who checked "some other race" to describe themselves.<sup>11</sup> Furthermore, a 2015 survey found that 67% of Hispanic adults consider being Hispanic part of their racial background or both their racial and ethnic backgrounds.<sup>12</sup> This challenge persisted after the recent 2020 Census, where only half of Americans (49%) said the race and ethnicity questions reflect their self-identity of race and origin "very well."<sup>13</sup> In addition, Hispanic respondents were more likely than white or Black respondents to say the questions describe their self-identity "not too well" or "not well at all."

Previously, the Census Bureau conducted the 2010 Alternative Question Experiment (AQE) research to better understand how people identify themselves in various contexts. The AQE

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<sup>9</sup> Ibid.

<sup>10</sup> Pew Research Center. (2015, June 18). Census considers new approach to asking about race by not using the term at all. Fact Tank. Retrieved from <https://www.pewresearch.org/fact-tank/2015/06/18/census-considers-new-approach-to-asking-about-race-by-not-using-the-term-at-all/>.

<sup>11</sup> Pew Research Center. (2014, March 14). U.S. Census looking at big changes in how it asks about race and ethnicity. Fact Tank. Retrieved from <https://www.pewresearch.org/fact-tank/2014/03/14/u-s-census-looking-at-big-changes-in-how-it-asks-about-race-and-ethnicity/>.

<sup>12</sup> Pew Research Center. (2015). Chapter 7: The Many Dimensions of Hispanic Racial Identity. In R. Fry & M. Cohn (Eds.), *Multiracial in America* (pp. 86-101). Retrieved from <https://www.pewresearch.org/social-trends/2015/06/11/chapter-7-the-many-dimensions-of-hispanic-racial-identity/>.

<sup>13</sup> Parker, K., Minkin, R., & Menasce Horowitz, J. (2021, May 14). Only about half of Americans say census questions reflect their identity very well. Pew Research Center. Retrieved from <https://www.pewresearch.org/social-trends/2021/05/14/only-about-half-of-americans-say-census-questions-reflect-their-identity-very-well/>.

examined alternative question design strategies for improving the collection of data on race and ethnicity. Such strategies include a combined question with a detailed checkboxes and a write-in line. An analysis of the 2010 AQE found the following<sup>14</sup>:

- The combined question yielded higher response rates than separate question formats
- The combined question increased reporting of *detailed* responses for most groups but decreased reporting for others
- The combined question format more accurately reflected self-identity

The effectiveness of a combined race and ethnicity question format is also reflected in states' Medicaid application race, ethnicity, and language (REL) data. All state Medicaid agencies collect self-reported REL data from applicants during the eligibility and enrollment process. However, the type and granularity of information collected varies considerably. Six states' (Arizona, Colorado, Massachusetts, New York, Oregon, and Washington) paper applications asked some version of a combined race/ethnicity question. Five states' (Alaska, Maine, Nevada, New Jersey, and South Carolina) online applications asked a combined race/ethnicity question. Below are considerations for Federal agencies when using a combined race and ethnicity question based on states' efforts to collect accurate REL data<sup>15</sup>:

- Individuals may be more likely to complete the question if they recognize options that correspond to their racial and ethnic identities. A state currently using broad racial and ethnic categories may consider further breaking out those categories to represent locally relevant populations.

From the Census 2010 ACE, 2015 NCT, Medicaid REL data, and Pew Research survey data on the 2020 Census, including checkboxes within the combined question format is optimal for race/ethnicity data accuracy and self-identity reporting.

**Working Group Proposal #2: Add “Middle Eastern or North African” (MENA) as a new minimum category.**

**2a. Given the particular context of answering questionnaires in the U.S. (e.g., decennial census, Federal surveys, public benefit forms), is the term “Middle Eastern or North African (MENA)” likely to continue to be understood and accepted by those in this community? Further, would the term be consistently understood and acceptable among those with different experiences, i.e., those born in the U.S., those who immigrated but have lived for an extensive period of time in the U.S., and those who have more recently immigrated to the U.S.?**

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<sup>14</sup> U.S. Census Bureau. (2010). 2010 Census Coverage Measurement Memorandum Series #211: The 2010 Census Coverage Measurement Mailout/Mailback Survey (MOMS) and In-Person Follow-up (CQA). Retrieved from <https://www2.census.gov/programs-surveys/decennial/2010/program-management/5-review/cpex/2010-cpex-211.pdf>.

<sup>15</sup> Centers for Disease Control and Prevention. ICD-10-CM – ICD-10-CM Diagnosis and Procedure Codes – International Classification of Diseases – 10<sup>th</sup> Revision – Clinical Modification. Retrieved from <https://phinivads.cdc.gov/vads/ViewCodeSystem.action?id=2.16.840.1.113883.6.238>. Accessed March 21, 2023.

TFAH supports the Working Group’s proposal to add “Middle Eastern or North African” (MENA) as a new minimum category. While there may be individual differences in whether MENA Americans identify as white,<sup>16</sup> stakeholder groups representing the MENA community and other community advocates, including the Arab American Institute, the Arab American Civic Council in Anaheim, California, and the Center for Iranian Diaspora Studies at San Francisco State University, overwhelmingly support the change.<sup>17,18,19</sup> Importantly, MENA Americans, specifically younger generations, cite their experiences with discrimination as making them feel “othered” and excluded from whiteness.<sup>20,21</sup> Further, research indicates that by aggregating MENA Americans with white Americans, the health disparities and health inequities they face remain hidden.<sup>22</sup> TFAH believes that collecting this data is imperative to understanding health disparities that may exist in the MENA population, and will allow the government and other stakeholders to adequately implement equitable solutions.

**2b. Do these proposed nationality and ethnic group examples adequately represent the MENA category? If not, what characteristics or group examples would make the definition more representative?**

While “Middle Eastern or North African” has been supported by the community, the terminology is not without its challenges. For example, “Middle East” is a Eurocentric exonym that was coined by the British and is thus rooted in colonialism.<sup>23,24</sup> Additionally, “Middle East” is not consistently defined: while some definitions include the entire Arabian Peninsula and all or part of Egypt, others include the entirety of North Africa, extend north to Turkey, or include countries as far east as Pakistan.<sup>25</sup> As a result, the term “Middle East” may be confusing and exclusive.

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<sup>16</sup> Ajrouch, KJ, Jamal A. Assimilating to a white identity: The case of Arab Americans. *The International Migration Review*. 2007;41(4): 860-879. <https://www.jstor.org/stable/27645705>.

<sup>17</sup> Korte G (September 30, 2016). White House wants to add new racial category for Middle Eastern people. USA Today. Retrieved from <https://www.usatoday.com/story/news/politics/2016/09/30/white-house-wants-add-new-racial-category-middle-eastern-people/91322064/>.

<sup>18</sup> Parvini S, Simani E (March 28, 2019). Are Arabs and Iranians white? Census says yes, but many disagree. LA Times. Retrieved from <https://www.latimes.com/projects/la-me-census-middle-east-north-africa-race/>.

<sup>19</sup> Wang, HL (February 17, 2022). The U.S. census sees Middle Eastern and North African people as white. Many don’t. NPR. Retrieved from <https://www.npr.org/2022/02/17/1079181478/us-census-middle-eastern-white-north-african-mena>.

<sup>20</sup> Awad GH, Hashem H, Nguyen H. Identity and ethnic/racial self-labeling among Americans of Arab or Middle Eastern and North African descent. *Identity*. 2021;21(2):115-130. <https://doi.org/10.1080/15283488.2021.1883277>.

<sup>21</sup> Parvini S, Simani E (March 28, 2019). Are Arabs and Iranians white? Census says yes, but many disagree. LA Times. Retrieved from <https://www.latimes.com/projects/la-me-census-middle-east-north-africa-race/>.

<sup>22</sup> Awad GH, Hashem H, Nguyen H. Identity and ethnic/racial self-labeling among Americans of Arab or Middle Eastern and North African descent. *Identity*. 2021;21(2):115-130. <https://doi.org/10.1080/15283488.2021.1883277>.

<sup>23</sup> Scharnweber G (September 30, 2015). What and where is the Middle East? Middle East Policy Council. Retrieved from [https://csme.indiana.edu/documents/cirricula/MEPolicyCouncil\\_What-WhereMiddleEast.pdf](https://csme.indiana.edu/documents/cirricula/MEPolicyCouncil_What-WhereMiddleEast.pdf).

<sup>24</sup> Payind A, McClimans M. Defining the term “Middle East.” Keys to Understanding the Middle East. Retrieved from <https://ohiostate.pressbooks.pub/key2mideast/chapter/defining-the-term-middle-east/>. Accessed March 21, 2023.

<sup>25</sup> Scharnweber G (September 30, 2015). What and where is the Middle East? Middle East Policy Council. Retrieved from [https://csme.indiana.edu/documents/cirricula/MEPolicyCouncil\\_What-WhereMiddleEast.pdf](https://csme.indiana.edu/documents/cirricula/MEPolicyCouncil_What-WhereMiddleEast.pdf).

### **Working Group Proposal #3: Require the collection of detailed race and ethnicity categories by default.**

TFAH supports with the Working Group’s proposal to require the collection of more detailed race and ethnicity data than the minimum categories by default. The SPD 15 provides a minimum set of categories federal agencies need to collect information on race and ethnicity and to facilitate comparing data generated from different sources with different mechanisms at varying levels of detail.<sup>26</sup>

Research shows that there are differences in outcomes for different groups within the same minimum race and ethnicity groups.<sup>27</sup> Disaggregating racial and ethnic categories beyond the minimum categories provided in SPD15 is important for identifying needs among small population groups and heterogeneity of experiences between and within racial and ethnic groups.

#### **3a. Is the example design seen in Figure 2 inclusive such that all individuals are represented?**

At an overall category level, the groupings in *Figure 2* seem sufficiently inclusive such that all individuals are represented; however, at a granular level, these categories can be confusing depending on how people identify themselves. For some individuals, their identity is connected to their country of origin and tribal nation, which may not be represented on the proposed design in *Figure 2*. The questions “What is your race or ethnicity?” or “How do you identify?” provides challenges for these groups, such as peoples from the Caribbean and tribal nations.

The Caribbean is a unified region that has a common sense of citizenship and community.<sup>28</sup> Many individuals from this region identify themselves as Caribbean persons, claiming a unique identify that has characteristics that distinguish them from others.<sup>29</sup> While many Caribbean people identify with their country of birth, their country of birth does not define their racial or ethnic background.

Similar to the United States, the Caribbean nations, such as Jamaica and Guyana, are made up of people from diverse groups of people not only from African and East Indian, but also from Asian and European descent.

In *Figure 2*, Jamaica and Haiti are explicitly listed under the “Black or African American” category and Asian Indian is listed under the “Asian” category. For some people from countries, such as Jamaica, the design could be confusing because it implies that all people who identify as

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<sup>26</sup> The White House. “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).” <https://www.whitehouse.gov/wp-content/uploads/2022/07/Flexibilities-and-Best-Practices-Under-SPD-15.pdf>. Accessed March 17, 2023.

<sup>27</sup> Ibid.

<sup>28</sup> Premdas, Ralph. “Ethnicity and Identity in the Caribbean: Decentering a Myth.” [https://kellogg.nd.edu/sites/default/files/old\\_files/documents/234.pdf](https://kellogg.nd.edu/sites/default/files/old_files/documents/234.pdf). Accessed March 20, 2023.

<sup>29</sup> Ibid.

Jamaican are “Black or African American.” Similarly, South Asians from Guyana face a similar problem because the majority of the population are of South Asian descent,<sup>30</sup> but there is not a clear mechanism for this group to identify themselves in the proposed design. Due to these groups not clearly being identified within the proposed design in Figure 2, it can lead to varying responses from people in these groups on how they identify racially and ethnically, which in return can decrease the validity of the data.

Figure 2. Proposed Example for Self-Response Data Collections: Combined Question with Minimum and Detailed Categories

What is your race or ethnicity?  
 Select all that apply AND enter additional details in the spaces below.  
 Note, you may report more than one group.

**WHITE** – Provide details below.

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

**HISPANIC OR LATINO** – Provide details below.

Mexican or Mexican American       Puerto Rican       Cuban  
 Salvadoran       Dominican       Colombian  
 Enter, for example, Guatemalan, Spaniard, Ecuadorean, etc.

**BLACK OR AFRICAN AMERICAN** – Provide details below.

African American       Jamaican       Haitian  
 Nigerian       Ethiopian       Somali  
 Enter, for example, Ghanaian, South African, Barbadian, etc.

**ASIAN** – Provide details below.

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

**AMERICAN INDIAN OR ALASKA NATIVE** – Enter, for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Tribal Government, Tlingit, etc.

**MIDDLE EASTERN OR NORTH AFRICAN** – Provide details below.

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

**NATIVE HAWAIIAN OR PACIFIC ISLANDER** – Provide details below.

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

**3b. The example design seen in Figure 2 collects additional detail primarily by country of origin. What other potential types of detail would create useful data or help respondents to identify themselves?**

Other potential types of detail that would create useful data or help respondents to identify themselves include:

- **Provide multi-select checkboxes or open-ended questions.** Identity is complex, so the most inclusive approach for data collection is to avoid making respondents feel they are “boxed in” with only one possible answer. Giving respondents the freedom to express the

<sup>30</sup> Hu-DeHart, Evelyn, Kathleen Lopez. “Asian Diasporas in Latin America and the Caribbean: An Historical Overview.” <https://www.jstor.org/stable/23055220>. Accessed March 20, 2023.



diversity of their identity for a given trait will allow them to select multiple answers or self-identify.<sup>31</sup>

- **Assess the order of response choices.** The order of response choices can reinforce implicit biases—like putting “United States” as the first response to a question asking about country of origin, or “white” as the first response to race and ethnicity questions. Randomizing response choices, ordering them alphabetically or manually arranging the choices to support an inclusive survey experience are options that avoid implicit bias in the response order.<sup>32</sup>
- **Give respondents the option to opt-out.** Identity is personal, and if respondents are required to answer demographic questions, they might not complete the survey or form. Instead, include “Prefer Not to Answer” options to track how often respondents select that response choice and explore why individuals may be opting out of responding. In addition, we suggest replacing “Other” options with “Prefer to Describe” or “Prefer to Self-Describe” to avoid alienating respondents that do not see their identity represented.<sup>33</sup>

### **3c. Some Federal information collections are able to use open-ended write-in fields to collect detailed racial and ethnic responses, while some collections must use a residual closed-ended category (e.g., “Another Asian Group”). What are the impacts of using a closed-ended category without collecting further detail through open-ended written responses?**

Closed-ended questions have traditionally been used to collect race and Hispanic ethnicity data.<sup>34</sup> While there are benefits of closed-ended category questions, such as generally yielding higher responses than open-ended questions,<sup>35</sup> open-ended questions have greater advantages to entities collecting more granular ethnicity data. Though this method is not easy to conduct with large groups of people due to time intensive data entry and coding it requires, it allows respondents to identify themselves at a granular level in their own terms; furthermore, increasing the validity of their racial and ethnic identity.<sup>36</sup>

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<sup>31</sup> Kaplowitz, Rella, and Jasmine Johnson. “5 Best Practices for Equitable and Inclusive Data Collection”. <https://www.schusterman.org/article/5-best-practices-for-equitable-and-inclusive-data-collection>. Accessed March 20, 2023.

<sup>32</sup> Ibid.

<sup>33</sup> Ibid.

<sup>34</sup> Agency for Healthcare Research and Quality. “Chapter 3: Defining Categorization Needs for Race and Ethnicity Data.” <https://www.ahrq.gov/research/findings/final-reports/iomracereport/reldata3a.html>. Accessed March 21, 2023.

<sup>35</sup> Reja, Urša, Katja Lozar Manfreda, Valentina Hlebec, et al. “Open-ended vs. Close-ended Questions in Web Questionnaires.” *Developments in Applied Statistics*, 19: 159-174, 2003. [https://begrijpelijkeformulieren.org/sites/begrijpelijkeformulieren/files/Reja\\_e.a.\\_Open-ended\\_vs.\\_Close-ended\\_Questions\\_in\\_Web.pdf](https://begrijpelijkeformulieren.org/sites/begrijpelijkeformulieren/files/Reja_e.a._Open-ended_vs._Close-ended_Questions_in_Web.pdf).

<sup>36</sup> Eisenhower, Abbey, Karen Suyemoto, Fernanda Lucchese, et al. ““Which Box Should I Check?”: Examining Standard Check Box Approaches to Measuring Race and Ethnicity.”

An impact of using a closed-ended category without further detail through open-ended questions is that the data is not granular enough to capture the diversity of lived experiences within specific subgroups within the category and the potential implications of these experiences.<sup>37</sup>

Although collecting further detail through open-ended written responses is suggested, there are mechanisms for improving closed-ended, multiple choice measures. Ensuring the following options are encompassed in the data collection will aid in both accessing more granular data while reducing the redundancy with other options:<sup>38</sup>

- Adding a Hispanic/Latina(o) race category.<sup>39</sup>
- Designing an ethnicity variable that captures greater variability in responses, beyond the Hispanic/Latina(o) versus non-Hispanic/Latina(o) dichotomy, such as offering various, fine-grained ethnicity options that are tailored to the community of interest or an extensive menu of options organized by geographical region.<sup>40</sup>

### **3d. What should agencies consider when weighing the benefits and burdens of collecting or providing more granular data than the minimum categories?**

Granular data is crucial to knowledge about health disparities because diverse racial and ethnic groups may have different health outcomes among their subgroups.<sup>41</sup> While the current OMB standards include only two ethnicity categories (Hispanic and non-Hispanic), there are other ethnicities that exist.<sup>42</sup> Assessing and reducing disparities and illuminating health inequities requires ethnicity data that is more granular than is mandated by current OMB standards.<sup>43</sup>

Utilizing a measure that gives a more detailed, granular measure for race and ethnicity, and provides respondents with flexibility in identifying themselves could decrease missing data and misclassification, further increasing validity.<sup>44</sup> Additionally, collecting more granular data aids in more accurate analysis and allows for targeted interventions.<sup>45</sup> Granular data can also unmask disparities and inequities in small populations. The ability to conduct analyses on smaller populations is often limited by inconsistent collection of more granular race and ethnicity

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<sup>37</sup> Ibid.

<sup>38</sup> Eisenhower, Abbey, Karen Suyemoto, Fernanda Lucchese, et al. ““Which Box Should I Check?”: Examining Standard Check Box Approaches to Measuring Race and Ethnicity.”

<sup>39</sup> Ibid.

<sup>40</sup> Ibid.

<sup>41</sup> Office of Inspector General. “Data Brief: Inaccuracies in Medicare’s Race and Ethnicity Data Hinder the Ability to Assess Health Disparities.” <https://oig.hhs.gov/oei/reports/OEI-02-21-00100.pdf>. Accessed March 21, 2023.

<sup>42</sup> Agency for Healthcare Research and Quality. “Chapter 3: Defining Categorization Needs for Race and Ethnicity Data.” <https://www.ahrq.gov/research/findings/final-reports/iomracereport/reldata3a.html>. Accessed March 21, 2023.

<sup>43</sup> Ibid.

<sup>44</sup> Eisenhower, Abbey, Karen Suyemoto, Fernanda Lucchese, et al. ““Which Box Should I Check?”: Examining Standard Check Box Approaches to Measuring Race and Ethnicity.”

<sup>45</sup> Office of Inspector General. “Data Brief: Inaccuracies in Medicare’s Race and Ethnicity Data Hinder the Ability to Assess Health Disparities.” <https://oig.hhs.gov/oei/reports/OEI-02-21-00100.pdf>. Accessed March 21, 2023.

categories across federal data collection efforts.<sup>46</sup> By collecting more granular data, researchers and stakeholders can potentially increase the sample size for small populations, further allowing analysis that produces significant findings.

Although there are various benefits to collecting granular data, there are some potential burdens. One burden can be seen when analyzing open-ended/write-in race and ethnicity responses. Self-reported data are considered the best method for collecting information that reflects an individual's identity but can lead to varied responses from respondents and make it difficult for researchers to aggregate the responses into the minimum categories. Similarly, employing an open-ended response approach requires time consuming coding that can be an impractical method for conducting large-scale public health research.<sup>47</sup>

### **3e. Is it appropriate for agencies to collect detailed data even though those data may not be published or may require combining multiple years of data due to small sample sizes?**

Agencies should collect detailed data even though the data may not be published or may require combining multiple years of data due to small sample size. When deciding to collect detailed data, it is important to consider the number of expected responses for each population.<sup>48</sup> Having a low response rate can cause the data to yield insignificant findings, causing the data not to be represented.<sup>49</sup> Small population groups are often not represented in health inequality data due to small sample sizes, which can have negative consequences for these communities. Gaps in race and ethnicity data quality should not prevent their use or efforts to address disparities and inequities; however, without high-quality, self-reported data across all states, researchers and other stakeholders are limited in their ability to measure and monitor disparities, and address disparities in care, use of services, and health outcomes to evaluate the effectiveness in advancing health equity.

Studies have shown there are differing disparities in health conditions and behaviors among ethnic groups.<sup>50</sup> Collecting comparable data on multiple dimensions is essential to ensure that small populations are accounted for when measure disparities in access to care and health outcomes. Having more complete data will allow for assessments of the disparities at the intersection of multiple groups, such as measure health outcomes and access to care for disabilities by race and ethnicity. Incomplete data for small populations, such as American Indian and Alaska Native populations, may produce insufficient sample sizes needed for

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<sup>46</sup> Medicaid and CHIP Payment and Access Commission. "Medicaid Race and Ethnicity Data Collection and Reporting: Recommendations for Improvement." <https://www.macpac.gov/wp-content/uploads/2023/03/Chapter-1-Medicaid-Race-and-Ethnicity-Data-Collection-and-Reporting-Recommendations.pdf>. Accessed March 20, 2023.

<sup>47</sup> Eisenhower, Abbey, Karen Suyemoto, Fernanda Lucchese, et al. "Which Box Should I Check?": Examining Standard Check Box Approaches to Measuring Race and Ethnicity."

<sup>48</sup> The White House. "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)." <https://www.whitehouse.gov/wp-content/uploads/2022/07/Flexibilities-and-Best-Practices-Under-SPD-15.pdf>. Accessed March 17, 2023.

<sup>49</sup> Ibid.

<sup>50</sup> Chen, Sixia, Alexander Stubblefield, and Julie A Stoner. "Oversampling of Minority Populations Through Dual-Frame Surveys." *Journal of survey statistics and methodology*, 9(3):626–649, June 2021. <https://doi.org/10.1093/jssam/smz054>. Accessed March 21, 2023.

statistical analysis, which often lead to these groups not being reported in health inequality research.<sup>51</sup> While the ability to conduct analyses on smaller populations is limited because of inconsistent collection of more granular data on race and ethnicity across federal data collection efforts, aggregating data across a longer time frame will create a larger sample size and assist in overcoming the challenge of small population analysis.<sup>52</sup>

Oversampling is another common method used to overcome issues with analyzing data for small populations. It is an intentional sampling process that is designed to incorporate more members of a certain community into the sample for creating a larger sample size and to adjust the population distribution of the dataset.<sup>53</sup> While oversampling does require a longer period of time to collect data, having a racial and ethnic equity perspective means providing more resources and using more time for oversampling when necessary.<sup>54</sup> Systematically identifying patient populations, addressing needs of these populations, and monitoring improvements over time is an essential step towards equitable care.<sup>55</sup> This process is largely dependent on granular demographic data, like race and ethnicity, that stratifies the quality measures at a level of detail that can identify variations in health and health care among populations disproportionately impacted by poor health outcomes.<sup>56</sup>

**3f. What guidance should be included in SPD 15 or elsewhere to help agencies identify different collection and tabulation options for more disaggregated data than the minimum categories? Should the standards establish a preferred approach to collecting additional detail within the minimum categories, or encourage agencies to collect additional information while granting flexibility as to the kind of information and level of detail?**

The revised SPD 15 standards should include a preferred approach to collecting more detailed data on race and ethnicity data that extends beyond the minimum categories and that are able to be aggregated into the minimum standard categories.<sup>57</sup> Some guidance that should be included in SPD 15 or elsewhere to help agencies identify different collection options for more disaggregated data than the minimum categories are:

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<sup>51</sup> Medicaid and CHIP Payment and Access Commission. “Medicaid Race and Ethnicity Data Collection and Reporting: Recommendations for Improvement.” <https://www.macpac.gov/wp-content/uploads/2023/03/Chapter-1-Medicaid-Race-and-Ethnicity-Data-Collection-and-Reporting-Recommendations.pdf>. Accessed March 20, 2023.

<sup>52</sup> Urban Indian Health Institute. “Best Practices for American Indian and Alaska Native Data Collection.” <https://aiapi.asu.edu/sites/default/files/best-practices-for-american-indian-and-alaska-native-data-collection.pdf>. Accessed March 20, 2023.

<sup>53</sup> Ibid.

<sup>54</sup> Andrews, Kristine, Jenita Parekh, Shantai Peckoo. “A guide to incorporating a racial and ethnic equity perspective throughout the research process.” <https://www.childtrends.org/publications/a-guide-to-incorporating-a-racial-and-ethnic-equity-perspective-throughout-the-research-process>. Accessed March 20, 2023.

<sup>55</sup> Vega Perez, Ruben D., Lyndia Hayden, Jefri Mesa, et al. “Improving Patient Race and Ethnicity Data Capture to Address Health Disparities: A Case Study from a Large Urban Health System.” <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8815799/>. Accessed March 20, 2023.

<sup>56</sup> Ibid.

<sup>57</sup> The White House. “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).” <https://www.whitehouse.gov/wp-content/uploads/2022/07/Flexibilities-and-Best-Practices-Under-SPD-15.pdf>. Accessed March 17, 2023.

- The Office of Management and Budget (OMB) and the U.S. Census Bureau should develop protocols for using data disaggregation consistently throughout the collection, analysis, and reporting of racial and ethnic subgroup data. The protocols will encourage thorough execution of the federal data standards on race and ethnicity for maximized comparability and knowledge. Additionally, the protocols can address cross sector challenges, such as how to enumerate free text responses, how to analyze “only Hispanic” and “Hispanic multiracial” subgroups apart from ethnic categories, and how to report a “roll up” of racial and ethnic subgroups when adequate data are unavailable to report more detailed information.<sup>58</sup>
- OMB should develop educational resources on the importance of collecting self-reported race and ethnicity data, why the information is important, and examples on how the information can be used.<sup>59</sup>

The standards should establish a preferred approach to collecting additional detail within the minimum categories and encourage agencies to collect additional information while granting some flexibility. Some stakeholders have expressed frustration about the inconsistent requirements for race and ethnicity data across federal programs and the limited flexibility for more granular categories.<sup>60</sup> For example, the Uniform Data System (UDS) includes data from community health centers and asks respondents to give race data for their patients using one of the following categories: 1.) Asian, 2.) Native Hawaiian, 3.) Other Pacific Islander, 4.) Black/ African American, 5.) American Indian/Alaska Native, 6.) White, 7.) More than one race, or 8.) Unreported/ Refused to report race.<sup>61</sup> Meanwhile, the Transformed Medicaid Statistical Information System (T-MSIS) has a more detailed category for Native Hawaiian and Other Pacific Islander that is consistent with HHS standards and the Women, Infants, and Children (WIC) programs has Native Hawaiian and Pacific Islander as one race population, which is consistent with the OMB 1997 Directive.<sup>62</sup> These differences among federal agencies make it difficult for analyzing data across the agencies and clearly is needed from the federal government to ensure that all agencies are using the same approach.

**3g. Is the current “default” structure of the recommendation appropriate? Should SPD-15 pursue a more voluntary approach to the collection of disaggregated data, as opposed to having a default of collecting such data unless certain conditions are met?**

TFAH supports the current “default” structure of the recommendation as the appropriate method of collecting race and ethnicity data. The SPD-15 should default to collecting disaggregated data. Disaggregation of data about health into racial and ethnic subgroups provides a window to a

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<sup>58</sup> PolicyLink. “Counting a Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health.” [https://www.policylink.org/sites/default/files/Counting\\_a\\_Diverse\\_Nation\\_08\\_15\\_18.pdf](https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf). Accessed April 3, 2023.

<sup>59</sup> National Committee for Quality Assurance. “Improving Data on Race and Ethnicity: A Roadmap to Measure and Advance Health Equity.” <https://www.ncqa.org/wp-content/uploads/2022/01/GIH-Commonwealth-Fund-federal-data-report-part-2-1.pdf>. Accessed March 20, 2023.

<sup>60</sup> National Committee for Quality Assurance. “Improving Data on Race and Ethnicity: A Roadmap to Measure and Advance Health Equity.” <https://www.ncqa.org/wp-content/uploads/2022/01/GIH-Commonwealth-Fund-federal-data-report-part-2-1.pdf>. Accessed March 20, 2023.

<sup>61</sup> Ibid.

<sup>62</sup> Ibid.

broad range of important questions about the meaning of culture and identity in America.<sup>63</sup> Disaggregating data allows researchers to examine important information by different race and ethnicity subgroups, such as individuals in American Indian/Alaska Native tribes, allows them to examine the distribution of the information for the population.<sup>64</sup> Additionally, racial and ethnic health disparities can only be eliminated through having high-quality information available to track immediate problems underlying social determinants.<sup>65</sup>

Information on disaggregated data provides a guide to design and apply culturally and linguistically appropriate approaches to medicine and public health.<sup>66</sup> Health outcomes are often disaggregated by broad racial and ethnic categories, such as Black, Hispanic, Asian, white, or Native American.<sup>67</sup> However, diversity in the American population causes people's experiences to be masked within the broad groups when we do not disaggregate further within the broad categories.<sup>68</sup> This can be seen when comparing the factors that determine health and well-being for example of a fifth generation Chinese American with a Hmong refugee from Laos. While both are within the Asian category, their health behaviors and outcomes are different. Without granular ethnic data, practitioners, researchers, and other interventionists are less likely to design and target effective public health strategies, programs, and policies to impacted subgroups.<sup>69</sup> Therefore, it is appropriate to keep the current default structure.

### **3h. What techniques are recommended for collecting or providing detailed race and ethnicity data for categories with smaller population sizes within the U.S.?**

Techniques recommended for collecting/providing detailed race and ethnicity data for categories with smaller population sizes within the U.S. include:

- Disaggregating by subgroups, nativity, country of origin, etc., when possible, to determine the heterogeneity of experiences between and within racial and ethnic groups.<sup>70</sup>
- Oversample small populations when disaggregating data by race and ethnicity to produce meaningful results for small population groups, such as American Indian/Alaska Native and Asian American/Pacific Islander groups, which may be grouped into a single “other”

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<sup>63</sup> PolicyLink. “Counting a Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health.” [https://www.policylink.org/sites/default/files/Counting\\_a\\_Diverse\\_Nation\\_08\\_15\\_18.pdf](https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf). Accessed April 3, 2023

<sup>64</sup> Andrews, Kristine, Jenita Parekh, Shantai Peckoo. “A guide to incorporating a racial and ethnic equity perspective throughout the research process.” <https://www.childtrends.org/publications/a-guide-to-incorporating-a-racial-and-ethnic-equity-perspective-throughout-the-research-process>. Accessed March 20, 2023.

<sup>65</sup> PolicyLink. “Counting a Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health.” [https://www.policylink.org/sites/default/files/Counting\\_a\\_Diverse\\_Nation\\_08\\_15\\_18.pdf](https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf). Accessed April 3, 2023

<sup>66</sup> Ibid.

<sup>67</sup> Ibid.

<sup>68</sup> Ibid.

<sup>69</sup> Ibid.

<sup>70</sup> Andrews, Kristine, Jenita Parekh, Shantai Peckoo. “A guide to incorporating a racial and ethnic equity perspective throughout the research process.” <https://www.childtrends.org/publications/a-guide-to-incorporating-a-racial-and-ethnic-equity-perspective-throughout-the-research-process>. Accessed March 20, 2023.

category.<sup>71</sup> Having a racial and ethnic equity perspective means providing more resources for oversampling when necessary.<sup>72</sup>

- When a granular ethnicity group is too small for analysis and needs to be aggregated with other groups for meaningful analysis, ensure all granular data is mapped to broad race and ethnic categories and only report at the race or broad ethnicity level.<sup>73</sup>

#### **Working Group Proposal #4: Update terminology in SPD 15.**

##### **Recommendation: Update Terminology in SPD 15.**

TFAH supports the Working Group proposal to update terminology in SPD 15 to remove the outdated terms “Negro” from the Black or African American definition and “Far East” from the Asian definition, replacing the latter with “East Asian.” We also support removing “Other” from the “Native Hawaiian and Other Pacific Islander” definition, since the group label “other” for identifying race and ethnicity is uninformative and might be considered pejorative.<sup>74</sup> While “other” is sometimes used for comparison data,<sup>75</sup> methods such as oversampling small populations can be used for meaningful analysis.

We also support ending use of the terms “majority” and “minority.” The term “minority” is overly vague and implies hierarchy among groups.<sup>76</sup> Other terms such as “underserved populations” (e.g., when referring to health disparities among groups) or “underrepresented populations” (e.g., when referring to a disproportionately low number of individuals in a program) may be used as an alternative.<sup>77</sup>

#### **Working Group Proposal #5: Guidance is necessary to implement SPD 15 revisions on Federal information collections.**

**5b. With the proposals to use a combined race and ethnicity question and to add MENA as a minimum category, what specific bridging concerns do Federal data users have? Please submit any research on bridging techniques that may be helpful to the Working Group.**

The National Center for Health Statistics releases bridged-race population estimates of the resident population of the United States for use in calculating vital rates. These estimates result from bridging the 31 race categories used in Census 2000 and Census 2010, as specified in the 1997 Office of Management and Budget (OMB) standards for the collection of data on race and

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<sup>71</sup> Ibid.

<sup>72</sup> Ibid.

<sup>73</sup> Agency for Healthcare Research and Quality. “F. Granular Ethnicities with No Determinate OMB Race Classification.” <https://www.ahrq.gov/research/findings/final-reports/iomracereport/reldata3a.html>. Accessed March 21, 2023.

<sup>74</sup> Ibid.

<sup>75</sup> Ibid.

<sup>76</sup> Flanagan, A., Tracey Frey, Stacey L. Christiansen, et al. “Updated Guidance on the Reporting of Race and Ethnicity in Medical and Science Journals.” *JAMA*, 326(7):621–627, August 2021. <https://doi.org/10.1001/jama.2021.13304>.

<sup>77</sup> Ibid.

ethnicity, to the four race categories specified in the 1977 OMB standards.<sup>78</sup> One key takeaway on data bridging from the report is that “The number of possibilities is more limited when bridging is from multiple-race groups to single-race categories than vice versa, making the bridging simpler. For example, a multiple-race response of ‘Black and White’ implies two single-race possibilities: Black or White. On the other hand, a single-race response of ‘White’ implies a multitude of multiple-race possibilities, including any multiple-race group for which White is a component.” Therefore, a combined race and ethnicity question and additional minimum category (MENA), will disaggregate the white racial category. This can lead to the following challenges in data bridging:

- Undercounting Hispanic population data: The current separate ethnicity question asks whether respondents identify as Hispanic or Latino. However, using a combined question raises concerns about bridging Census data on ethnicity with Census data on race *and* ethnicity.<sup>79</sup>
- Underestimating MENA population data: The 2020 Census definition of “white”<sup>80</sup> includes MENA populations as subsumed in the white racial category. Therefore, data bridging MENA as a separate category versus under the “white” category will be challenging. Some researchers argue that data bridging these categories can lead to the underestimation of health disparities within MENA populations.<sup>81</sup>

### **5e. What guidance should be provided for the collection and reporting of race and ethnicity data in situations where self-identification is unavailable?**

Using observation or imputed data for race, ethnicity, and language data should be minimally used and done only in the absence of other self-identification methods. If someone has declined to answer, there should not be any collection of or reporting of race and ethnicity. Specific guidance for the collection and reporting of race and ethnicity data in situations where self-identification is unavailable are:

- Use clear and consistent criteria for identification: When collecting race and ethnicity data by proxy or observation, clear and consistent criteria should be used to identify the individual’s race and ethnicity.

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<sup>78</sup> National Center for Health Statistics, “United States Census 2000 Population with Bridged Race Categories” (2003). Available at [https://www.cdc.gov/nchs/data/series/sr\\_02/sr02\\_135.pdf](https://www.cdc.gov/nchs/data/series/sr_02/sr02_135.pdf).

<sup>79</sup> Piché DM, Sayeed S. Combining race and ethnicity in the census: implications for the Hispanic/Latino population. *J Immigr Minor Health*. 2001 Apr;3(2):87-96. doi: 10.1023/a:1011394710788. PMID: 120-11891.

<sup>80</sup> U.S. Census Bureau. QuickFacts: United States. Population estimates, July 1, 2022, (V2022) and Race, Hispanic or Latino, and Age: United States, U.S. Census Bureau QuickFacts. Available from: <https://www.census.gov/quickfacts/fact/note/US/RHI625221#:~:text=of%20Hispanic%20origin,-.White.,Italian%2C%20Lebanese%2C%20and%20Egyptian.>

<sup>81</sup> Schulz, A. J., Israel, B. A., Mentz, G., Bernal, C., Caver, D., DeMajo, R., ... & Yen, I. H. (2019). A Critical Assessment of the 2020 Census White Population Definition: Implications for Research on Health Disparities. *American Journal of Public Health*, 109(S1), S37-S43. doi: 10.2105/AJPH.2018.304881



- Document the methodology used: When collecting race and ethnicity data by proxy or observation, it is important to document the methodology used to ensure that the data is accurate and can be replicated.
- Ensure privacy and confidentiality: When collecting race and ethnicity data by proxy or observation, it is important to ensure that the individual's privacy and confidentiality are protected.<sup>82, 83, 84</sup>

The changes made to the National Survey on Drug Use and Health (NSDUH) by the National Institute on Drug Abuse (NIDA) can provide valuable insights and guidance for implementing revisions to SPD 15. Specifically,<sup>85, 86</sup>:

- Provide clear guidance on definitions: NIDA revised the NSDUH to provide clear definitions of the terms used to collect race and ethnicity data, including “Hispanic or Latino” and “White.” Similarly, OMB revising their data collection procedures should provide clear and consistent guidance on how to collect and report race and ethnicity data.
- Consider respondent burden: NIDA revised the NSDUH to reduce respondent burden by combining questions on race and ethnicity into a single question. Similarly, stakeholders revising their data collection procedures should consider the burden on respondents and seek to minimize it to the extent possible.
- Develop and test data collection instruments: NIDA developed and tested the revised NSDUH data collection instruments to ensure that they were effective in collecting accurate and reliable data. Similarly, stakeholders revising their data collection procedures should develop and test their instruments to ensure that they are effective in collecting accurate and reliable race and ethnicity data.
- Provide training to data collectors: NIDA provided training to data collectors to ensure that they understood the revised data collection procedures and could accurately and consistently collect race and ethnicity data. Similarly, stakeholders revising their data collection procedures should provide training to data collectors to ensure that they understand the revised procedures and can accurately and consistently collect race and ethnicity data.

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<sup>82</sup> U.S. Department of Health and Human Services. (2011). HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. Retrieved from <https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0>.

<sup>83</sup> Centers for Disease Control and Prevention. (2011). Background and Purpose: CDC Race and Ethnicity Code Set Version 1.0. Retrieved from <https://www.cdc.gov/phln/resources/vocabulary/documents/CDC-Race-Ethnicity-Background-and-Purpose.pdf>.

<sup>84</sup> National Academies of Sciences, Engineering, and Medicine. (2017). Once, Only Once, and in the Right Place: Residence Rules in the Decennial Census. National Academies Press. Retrieved from <https://nap.nationalacademies.org/catalog/11727/once-only-once-and-in-the-right-place-residence-rules>.

<sup>85</sup> Substance Abuse and Mental Health Services Administration. (n.d.). NSDUH: National Survey on Drug Use and Health. Retrieved from <https://www.samhsa.gov/data/data-we-collect/nsduh-national-survey-drug-use-and-health>.

<sup>86</sup> Substance Abuse and Mental Health Services Administration. (2019). Methodological Summary and Definitions. Retrieved from <https://www.samhsa.gov/data/report/2019-methodological-summary-and-definitions>.

## **Comments on Additional Topics and Future Research**

**6a. SPD 15 does not dictate the order in which the minimum categories should be displayed on Federal information collections. Agencies generally order alphabetically or by population size; however, both approaches have received criticism. What order, alphabetical or by population size, do you prefer and why? Or what alternative approach would you recommend?**

TFAH recommends that OMB orders the minimum categories alphabetically to avoid the perception of preference for or bias towards any race or ethnicity. Sorting alphabetically is more practical than sorting by population size, which might also reduce the appearance of bias, but would require having accurate, updated data and more frequent interval updates to systems and paper forms. To avoid potential data collection or reporting errors, TFAH recommends that OMB sort the categories alphabetically.

**6b. The current minimum categories are termed:**

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

**Do you have suggestions for different terms for any of these categories?**

Aside from adding a “Middle Eastern or North African” (MENA) category and removing “Other” from “Native Hawaiian or Other Pacific Islander” as described previously in this letter, TFAH does not suggest using different terms to describe any of the minimum categories listed in the proposal.

**TFAH has further identified several other areas that the Working Group should consider:**

- OMB should examine its use of the word “origin” in SPD 15. While the term “national origin” has a specific definition in American law,<sup>87</sup> this definition may not be universally understood or agreed to. OMB could consider defining the term, or using more specific language in SPD 15.
- OMB should consider potential differences between perceived identity (i.e., the way society views a person) and personal identity (i.e., the way a person views themselves). In addition to the previous discussion about personal identity among Middle Eastern or North African individuals, personal identity is extremely significant for many Black

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<sup>87</sup> Race, national origin, and ethnicity: What’s the difference? (March 25, 2021). Watkins & Letofsky. Retrieved from <https://www.wl-llp.com/blog/2021/03/race-national-origin-and-ethnicity-whats-the-difference/>.

Americans and impacts their connections with one another.<sup>88</sup> Research also suggests that perceived race and ethnicity is correlated, but not interchangeable, with self-identified race and ethnicity.<sup>89</sup> Adding a question to SPD 15 that differentiates between perceived and personal identity could unearth interesting data and trends around discrimination, racial discordance, and other topics that the federal government should explore.

- OMB should eliminate the use of the term “Far East” to identify people from East Asia. The term is vague, has colonialist roots, homogenizes a wide range of diverse cultures, and contributes to the alienation of East Asian countries and people.<sup>90</sup> TFAH supports the Working Group’s proposal to replace with the geographically defined term “East Asian.”
- OMB should continue to actively seek input from individuals representing the populations of interest about what demographic data will be most helpful, relevant and inclusive. Soliciting and incorporating feedback from respondents about how they choose to express or define their identities is a good practice to integrate.<sup>91</sup>
- It is important note that adequate funding and technical assistance to build their data capacity will be critical for all federal agencies and data collectors reporting to the federal government. These investments should be directed toward administrative and professional training, updating information technology systems for full compliance with data disaggregation requirements and updates, and training on how to collect data based on the updated standards.<sup>92</sup>

### **Closing Remarks**

Data collection is an imperative tool that allows for the implementation of effective and equitable solutions to the most important public health problems. TFAH is encouraged that OMB is proposing to update SDP 15 to collect more robust and updated race and ethnicity data that can help further these efforts and improve public health and promote health equity.

Sincerely,

J. Nadine Gracia, MD, MSCE  
President and CEO  
Trust for America’s Health

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<sup>88</sup> Cox K, Tamir C (April 14, 2022). Race is central to identity for black Americans and affects how they connect with each other. Pew Research Center. <https://www.pewresearch.org/race-ethnicity/2022/04/14/race-is-central-to-identity-for-black-americans-and-affects-how-they-connect-with-each-other/>.

<sup>89</sup> Stepanikova I, Oates GR. Dimensions of racial identity and perceived discrimination in health care. *Ethnicity & Disease*. 2016;26(4): 501-512. doi: 10.18865/ed.26.4.501.

<sup>90</sup> Hill C. What’s the matter with saying ‘The Orient’? Japan Society. Retrieved from [https://aboutjapan.japansociety.org/content.cfm/whats\\_the\\_matter\\_with\\_saying\\_the\\_orient#sthash.HbBcTLid.AksnIuIa.dpbs](https://aboutjapan.japansociety.org/content.cfm/whats_the_matter_with_saying_the_orient#sthash.HbBcTLid.AksnIuIa.dpbs). Accessed March 21, 2023.

<sup>91</sup> Kaplowitz, Rella, and Jasmine Johnson. “5 Best Practices for Equitable and Inclusive Data Collection“. <https://www.schusterman.org/article/5-best-practices-for-equitable-and-inclusive-data-collection>. Accessed March 20, 2023.

<sup>92</sup> Ibid.