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April 27, 2023

Submitted via E-mail to [Statistical\\_Directives@omb.eop.gov](mailto:Statistical_Directives@omb.eop.gov)

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Office of Information and Regulatory Affairs  
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1650 17<sup>th</sup> Street NW  
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**RE: Initial Proposals for Updating OMB's Race and Ethnicity Statistical Standards**

The National Health Law Program (NHeLP), founded in 1969, protects and advances health justice for low-income and underserved individuals and families by advocating, educating, and litigating at the federal and state levels. NHeLP works to advance health equity and quality health care for all without bias or barriers. As such, NHeLP has long advocated for collection of demographic data in federal programs to improve understanding of diverse populations, address disparities, protect civil rights, and facilitate the provision of culturally, clinically, and linguistically appropriate health care.

OMB's Notice of Initial Proposals to update Directive 15 will have a profound effect on the way policymakers, researchers, advocates, and the public understand health care access, outcomes, experiences, quality, and more among underserved communities.<sup>1</sup> NHeLP supports the proposed changes to Directive 15 that would combine data collection on race, ethnicity, and tribal affiliation into one question, add a response option for Middle Eastern and North African (MENA) populations, update terminology, and collect more detailed

information as a default. Our comments also provide specific suggestions about ways that OMB can support federal, state, and local agencies and programs in collecting race, ethnicity, tribal affiliation, and other demographic information.<sup>2</sup> NHeLP strongly encourages OMB to finalize the updated Directive 15 without delay but no later than the target of early 2024 to enable their use on the upcoming 2030 Census. NHeLP also encourages OMB to set standards for the collection and use of demographic information beyond race, ethnicity, and tribal affiliation—including sexual orientation, gender identity, and intersex status; disability and functional status; and written and spoken language—to improve the overall quality and usability of demographic data nationwide.<sup>3</sup>

OMB should clarify in the text of Directive 15 that the standards apply to any entity that collects demographic information on behalf of the federal government or as part of a federally-funded program or activity. State and local programs and private entities rely on the federal government’s standards for demographic data collection as a baseline, and this revision will have a profound impact on the way race, ethnicity, and tribal affiliation data is collected and used across the nation.

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<sup>1</sup> 88 Fed. Reg. 5375 (Jan. 27, 2023), <https://www.govinfo.gov/content/pkg/FR-2023-01-27/pdf/2023-01635.pdf>.

<sup>2</sup> Throughout our comments, we discuss the application of the proposed updates in the Notice to the programs and activities of federal agencies. However, we also encourage OMB to consider the ways in which the proposed updates will impact state and local agencies as well as private entities who are subject to the standards found in Directive 15. State, local, and private entities that carry out activities funded by the federal government play a critical role in demographic data collection, as they are often the entities that engage with individuals. OMB should include specific recommendations and resources in its guidance to assist these partners in building demographic data collection capacity. OMB should also clarify in the text of Directive 15 that the standards apply to any entity that collects demographic information on behalf of the federal government or as part of a federally-funded program or activity.

<sup>3</sup> See Charly Gilfoil, Nat’l Health L. Prog., *The White House Takes Big Steps Toward Data Equity—But More Is Needed* (Feb. 21, 2023), <https://healthlaw.org/the-white-house-takes-big-steps-toward-data-equity-but-more-is-needed/>.



## I. Collecting Race and Ethnicity Using One Combined Question Reduces “Other” Responses; Yields Better Data

Extensive research based on nationally representative data demonstrates that the combined question format proposed in the Notice will produce more useful demographic information than the data collection methods presently used. The Census Bureau has conducted extensive testing of race and ethnicity data collection on the decennial Census and produced in-depth analysis of the way people belonging to different demographic groups respond. Its findings demonstrate that collecting information on race and ethnicity in one combined question results in more respondents selecting a specific race and ethnicity option and less respondents selecting “some other race.”<sup>4</sup> The “some other race” response indicates that the respondent did not see an accurate or appropriately descriptive response option or did not understand either the question or response options. The “some other race” response cannot be linked to a specific race, ethnicity, or tribal affiliation (or combination thereof), and therefore cannot be used to study the experiences of specific and intersectional populations. The prevalence of “some other race” as a response obscures data about underrepresented populations, primarily communities of color, and maintains the status quo where already underserved individuals are less likely to see themselves reflected in data.<sup>5</sup> Thus, reducing the number of “some other race” responses should be a goal for agencies seeking to understand the impact of their programs on underserved communities and communities of color.

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<sup>4</sup> Kelly Mathews et al., U.S. Census Bureau, *2015 National Content Test: Race and Ethnicity Analysis Report* (Feb. 28, 2017), <https://www.census.gov/programs-surveys/decennial-census/decade/2020/planning-management/plan/final-analysis/2015nct-race-ethnicity-analysis.html>; Nicholas Jones et al., U.S. Census Bureau, *2020 Census Illuminates Racial and Ethnic Composition of the Country* (Aug. 12, 2021), <https://www.census.gov/library/stories/2021/08/improved-race-ethnicity-measures-reveal-united-states-population-much-more-multiracial.html>. The Census Bureau’s findings have been reproduced in private research and additional studies by the Census Bureau and other agencies. See Agency for Healthcare Res. & Quality, *Chapter 3, Defining Categorization Needs for Race & Ethnicity Data, in Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement* (Apr. 2018, ed. Cheryl Ulmer, Bernadette McFadden, and David R. Nerenz), <https://www.ahrq.gov/research/findings/final-reports/iomracereport/reldata3.html>.

<sup>5</sup> Diana Elliott et al., Urban Inst., *Assessing Miscounts in the 2020 Census* (Jun. 11, 2019), <https://www.urban.org/research/publication/assessing-miscounts-2020-census>; Jones *supra* note 4.



In the health care context, race, ethnicity, and tribal affiliation data helps health programs and agencies understand access to, and impact of, their programs on the people they serve. For example, Centers for Medicare and Medicaid Services (CMS), which administers the Medicare, Medicaid, CHIP, and Marketplace programs, relies on the standards in Directive 15 to set a floor for demographic data collected by these programs. Race, ethnicity, and tribal affiliation data from these programs is used to stratify health care quality measures—such as how many children enrolled in CHIP have received preventive screenings—and monitor usage of services by various groups—such as whether individuals enrolled in Medicaid have a usual source of care.<sup>6</sup> CMS has outlined ways in which it will operationalize this data in its Framework for Health Equity 2022-2032.<sup>7</sup> By improving the accuracy of data through use of a combined question, OMB will enhance the work that CMS is doing to improve actionable information on which populations benefit from, or lack access to, its programs and services; monitor and address disparities in access and quality; enforce civil rights; tailor culturally and linguistically competent outreach and services to specific communities; and ultimately, improve health outcomes for all individuals enrolled in its programs.

NHeLP supports this change to Directive 15, which we believe will improve the quality of race, ethnicity, and tribal affiliation data that federal health programs and agencies, along with their state, local, and private partners, receive from respondents. OMB must continue to study roll out of this change to ensure that it is implemented in a way that does not diminish the accuracy of data for any population or subpopulation. As discussed further in Section III of this comment letter, OMB absolutely must invest in training and guidance to

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<sup>6</sup> Tricia Brooks, Georgetown Univ. Health Policy Inst.: Ctr. for Children & Families *Long-Awaited Rule on Mandatory Reporting of Child Core Set Quality Measures Proposed* (Aug. 19, 2022), <https://ccf.georgetown.edu/2022/08/19/long-awaited-rule-on-mandatory-reporting-of-child-core-set-quality-measures-proposed/>; Medicaid & CHIP Payment & Access Comm'n (MACPAC) *Access in Brief: Health Care Experiences and Satisfaction by Race and Ethnicity* (Apr. 2023), <https://www.macpac.gov/wp-content/uploads/2023/04/Access-in-Brief-Health-Care-Experiences-and-Satisfaction-by-Race-and-Ethnicity.pdf>; Neil P. Rowen et al., *How to Improve Race, Ethnicity, and Language Data and Disparities Interventions*, HEALTH AFFAIRS (Sept. 14, 2022), <https://www.healthaffairs.org/content/forefront/improve-race-ethnicity-and-language-data-and-disparities-interventions>.

<sup>7</sup> Ctrs. for Medicare & Medicaid Svcs., *CMS Framework for Health Equity 2022-2034* (2022), <https://www.cms.gov/files/document/cms-framework-health-equity-2022.pdf>.



help agencies effectively employ the question stem and responses in Directive 15. Particularly because individuals may approach how they respond to the combined question differently, agencies should do more to educate individual respondents on how to provide an accurate and complete response.

Some groups have expressed concern that the combined question would mask racial heterogeneity in the Latino community, obscuring racism’s impact on Latinos of different races, while simultaneously treating all Latinos as racialized. A combined question is still the best way to ensure that people of all experiences have the flexibility and agency to self-identify with as many labels as is meaningful to them. The new proposed language in the question stem—“Select all that apply” and “Note: you may report more than one group”—also works to ensure multiethnic, multiracial, and multidimensional experiences remain visible. Census Bureau research indicates that a combined question does not lead to reduction in the number of individuals who self-identify as both Black/African American and Hispanic/Latino.<sup>8</sup> Rather, the study indicates that self-identification as Latino alone and in combination with other identities increases with a combined question, making all Latinos more visible in the data.<sup>9</sup> To the extent that some Latino-identified individuals may skip selecting more than one identity group, or identifying with any group at all, outreach and education can provide an effective solution.<sup>10</sup> Cognitive interviews of respondents using the combined question show that some individuals who identify with more than one race, ethnicity, or tribal affiliation option express confusion and discomfort in selecting more than one response option.<sup>11</sup> This confusion sometimes come from how respondents understand the purpose and intent of the question, and sometimes comes from misreading the question stem.<sup>12</sup> Research shows that misunderstandings can be cleared up by providing

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<sup>8</sup> Mathews, *supra* note 4.

<sup>9</sup> *Id.*

<sup>10</sup> Stephanie Willson & Sheba K. Dunston, Nat’l Ctr. for Health Stat., Collaborating Ctr. for Questionnaire Design & Evaluation Res., *Cognitive Interview Evaluation of the Revised Race Question, with Special Emphasis on the Newly Proposed Middle Eastern/North African Response* 7, 21-22 (2017), [https://wwwn.cdc.gov/qbank/report/Willson\\_2017\\_NCHS\\_MENA.pdf](https://wwwn.cdc.gov/qbank/report/Willson_2017_NCHS_MENA.pdf).

<sup>11</sup> *Id.*

<sup>12</sup> *Id.* at 21-23.



assistance with responding, reading the question stem and response options, and prompting the respondent to select all that apply.<sup>13</sup>

To address these concerns, OMB should issue guidance on how to facilitate respondent self-identification with multiple responses to the combined question. We support mandatory language in the question stem, as is given in the examples in Figures 2 and 3 of the Notice, and a robust public education campaign that informs respondents may check and fill-in as many responses as are meaningful to them. OMB must also ensure that agencies receiving demographic data using this question understand how to analyze and report information from respondents with multidimensional and intersectional identities. Agencies need tools and resources to make meaningful use of such detailed data.

## **II. Adding “Middle Eastern/North African” (MENA) Response Option Promotes Inclusivity; Yields Better Data**

For decades, MENA communities have asked to be reflected in data collections in a way that acknowledges their unique ethnic experience.<sup>14</sup> In the current version of Directive 15, MENA respondents, whether multiracial, multiethnic, or not, must choose between White, Black, Asian, Native Hawaiian, or American Indian/Alaska Native—none of which may fully reflect how MENA respondents see themselves.<sup>15</sup> Many MENA respondents report having been instructed to select “White” or “Black” as a proxy for MENA, which may be inaccurate for the particular respondent and masks the specific ways that MENA populations experience discrimination, mistreatment, and other disparities.<sup>16</sup> Though some agencies, states, and programs currently provide a MENA response option in demographic questions,

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<sup>13</sup> *Id.*, and see Colin Planalp, State Health & Value Strategies, *New York State of Health Pilot Yields Increased Race and Ethnicity Question Response Rates* (Sept. 9, 2021), <https://www.shvs.org/new-york-state-of-health-pilot-yields-increased-race-and-ethnicity-question-response-rates/>; David W. Baker, Romana Hasnain-Wynia, Namratha R. Kandula, Jason A. Thompson, and E. Richard Brown, *Attitudes Toward Health Care Providers, Collecting Information About Patients’ Race, Ethnicity, and Language*, 45 MED. CARE 1034 (Nov. 2007).

<sup>14</sup> Germine H. Awad et al., *Lack of Arab or Middle Eastern and North African Health Data Undermines Assessment of Health Disparities*, 112 AM. J. PUB. HEALTH 209 (Feb. 2022), [https://ajph.aphapublications.org/doi/10.2105/AJPH.2021.306590?url\\_ver=Z39.88-2003&rfr\\_id=ori%3Arid%3Acrossref.org&rfr\\_dat=cr\\_pub++0pubmed](https://ajph.aphapublications.org/doi/10.2105/AJPH.2021.306590?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub++0pubmed).

<sup>15</sup> See Willson & Dunston, *supra* note 10 at 16.

<sup>16</sup> *Id.* at 17-18.



without a broader, national requirement to include MENA populations on race and ethnicity data collections, the MENA population cannot achieve an equitable level of study and consideration in allocation of resources, enforcement of civil rights laws, or understanding of population health.

Without data collection that distinguishes MENA communities in health programs, policymakers, researchers, and advocates cannot effectively study the ways that MENA communities experience differences and disparities compared to other populations. From studies conducted using national surveys and independent data collections, research indicates that MENA populations face health disparities in access to and utilization of care, as well as in health outcomes.<sup>17</sup> However, these studies are limited by scope, geography, and quality of data. Few studies exist that examine the specific health care issues MENA individuals face in public health programs simply because MENA is not typically used as a response option on demographic questions, and it is not presently required. Without MENA as a response option on more national forms, surveys, and data collection, agencies miss out on a richer picture of the MENA community that comes with more data from a broader geographic region. Were MENA a required option, public health programs could employ better analysis of how MENA individuals access and experience these programs, and what improvements might be necessary to address equitable access.

NHeLP supports the addition of a MENA response option in the proposed revision to Directive 15. Adding MENA as a response option in a combined question has been shown to reduce the number of “some other race” responses, thereby increasing the value and quality of demographic data. While implementing revisions in Directive 15, OMB must continue to study roll out of this change to ensure that it is effective at measuring MENA populations and that it does not diminish accuracy of responses for any other category or subgroup. Equally important, OMB must solicit feedback from the MENA community and related populations to ensure that both the broader MENA category and the detailed checkboxes use current and appropriate terminology and effectively represent a diverse range of MENA subpopulations.

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<sup>17</sup> Awad, *supra* note 14, and see Goleen Samari et al., *Racial and Citizenship Disparities in Healthcare among Middle Eastern Americans*, 58 MED. CARE 974 (Nov. 2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7572888/>; Minal R. Patel et al., *A Snapshot of Social Risk Factors and Associations with Health Outcomes in a Community Sample of Middle Eastern and North African (MENA) People in the U.S.*, 24 J. IMMIGRANT & MINORITY HEALTH 376 (2022), <https://link.springer.com/article/10.1007/s10903-021-01176-w>.



To ensure the success of an added MENA category in Directive 15, OMB must provide adequate support and guidance to federal, state, and local agencies that must roll out this change. Agencies will need information and training on best practices for how to collect this data and speak to respondents about how to self-identify using all appropriate options given in the race/ethnicity question and response options. Given that MENA is considered an ethnicity, agencies must receive information on ways that MENA respondents can identify themselves as MENA and other racial, ethnic, and tribal identities. For example, an individual can identify as MENA and Black, and select detailed checkboxes in a non-MENA category. Particularly for agencies not currently collecting data on MENA populations, OMB must provide a comprehensive geographic definition of MENA that includes persons with origins in the League of Arab States (Algeria, Bahrain, Comoros, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, United Arab Emirates, and Yemen), Non-Arab MENA states (Iran, Israel, and Turkey), and Trans-national communities (Assyrians/Chaldeans, Kurds, Berber/Amazigh).<sup>18</sup> MENA should be represented in reporting and discussion of demographic data as an ethnicity, not a race.

### **III. Requiring Collection of More Detailed Responses by Default Provides More Useable, Higher Quality Data**

Demographic data allows for better understanding of the experiences of diverse racial and ethnic subgroups and members of Indigenous communities and nations. The current version of Directive 15 set a floor for collecting data on larger racial, ethnic, and tribal demographic groups in the U.S. However, more detailed information is needed to improve understanding of subpopulations with distinctly different experiences. For example, within the Asian community, Chinese and Japanese populations have vastly different experiences and demonstrate significantly different needs in the health care setting than Indian and other South Asian populations.<sup>19</sup> Detailed information can also provide better information on distinct multiracial, multiethnic, and multidimensional populations, such as individuals

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<sup>18</sup> See Arab American Institute, *Updating OMB's Race and Ethnicity Statistical Standards and the Addition of a MENA Category 5* (Feb. 21, 2023),

<https://drive.google.com/file/d/1dIm5DxSAUZAxm9KPGGrLoInchenMT0ofi/view?pli=1>.

<sup>19</sup> See Kathleen Malloy and Terry Ao Minnis, The Leadership Conference on Civil & Human Rights, *Data Disaggregation Deconstructed: AANHPI Communities* (Jun. 16, 2022),

<https://civilrights.org/blog/data-disaggregation-deconstructed-aanhpi-communities/>.





who identify as Black and MENA or Black and Indigenous, to inform future consideration of how race, ethnicity, and tribal affiliation inform access to resources, civil rights protections, and policy.

NHeLP strongly supports the proposed use of the more detailed checkboxes shown in Figure 2 of the Notice. Collecting disaggregated data as a default allows individuals more agency in how they choose to self-identify. Use of the fill-in response within each response category further advances that agency and enables OMB and other agencies to study fill-in responses to understand the effectiveness of the question and to inform future revisions to the data collection standards.<sup>20</sup> OMB should, in its guidance, clarify that the detailed question in Figure 2 must be the default method of race, ethnicity, and tribal affiliation data collection for federal agencies and that agencies have flexibility to adopt additional responses within each category but not to remove response options.

OMB proposed allowing agencies to opt out of use of the more detailed question in Figure 2 if the agency determines that “the potential benefit of the detailed data would not justify the additional burden to the agency and the public or the additional risk to privacy and confidentiality.” Instead, OMB should:

- provide written guidance to clarify the factors that an agency must consider in its determination of whether the detailed data collection would be a “burden” or a “benefit;”
- work with agencies to determine which forms, surveys, or other data collections must include the detailed question;
- provide additional resources to assist with implementation of the more detailed question, including training on how to explain the purpose of the question and facilitate responses; and
- provide tools to implement appropriate privacy and confidentiality measures that account for the risks of collecting more detailed demographic information.

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<sup>20</sup> See, e.g., Bliss Kaneshiro et al., *The Challenges of Collecting Data on Race and Ethnicity in a Diverse, Multiethnic State*, 70 HAWAII MED. J. 168 (2011), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3158379/>.



#### **IV. Updating Terminology Promotes More Inclusive Data Collection Practices**

NHeLP supports the proposed revisions of terminology used in Directive 15. Individual, collective, and societal understanding of racial and ethnic identity and tribal affiliation shifts over time, as does terminology. OMB must continue to examine the ways in which in-group language shifts to maintain the most inclusive data collection practices. Inclusive data collection practices, which continually study responses, center priorities of underserved groups, and solicit feedback from affected communities, in turn produce more accurate and useable data.<sup>21</sup> It benefits all communities to have a government that is responsive to evolving ways of understanding identity.

#### **V. OMB Must Provide Guidance and Additional Resources to Ensure the Success of a Directive 15 Update**

Cognitive testing of the question proposed in Figure 3 of the Notice demonstrates that individuals have different understandings of what the question is asking and, as a result, may provide different answers.<sup>22</sup> For example, an individual who is ethnically Moroccan but whose race is Black may identify themselves only as Black if they believe the question prioritizes answers based on skin tone. Another individual of the same demographic background may identify only as MENA if they believe the question prioritizes answers based on cultural identity and practices; yet another may identify as both Black and MENA for a combination of reasons. While it should always be the individual's choice how they wish to identify themselves, and the information should always be voluntarily provided, guidance on how to explain the purpose and meaning of the demographic question can help both assisters and respondents collect more uniform and accurate data.

OMB's guidance to support implementation of the Directive 15 revision should, at a minimum, include:

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<sup>21</sup> Stella S. Yi et al., *The Mutually Reinforcing Cycle of Poor Data Quality and Racialized Stereotypes that Shapes Asian American Health*, HEALTH AFFAIRS (Feb. 2022), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01417>; Karen Wang et al., *Centering Equity in the Design and Use of Health Information Systems: Partnering with Communities on Race, Ethnicity, and Language Data*, HEALTH AFFAIRS (May 19, 2019), <https://www.healthaffairs.org/doi/10.1377/forefront.20210514.126700/>.

<sup>22</sup> Willson and Dunston, *supra* note 10.



- clear, timely guidance to federal agencies and data users on how to report, tabulate and bridge data collected under previous standards, with data collected under revised standards, to ensure consistent and meaningful comparisons of data over time that accurately reflect demographic trends, as well as appropriate interpretations of those trends;<sup>23</sup>
- instructions on how to tabulate and analyze data from individuals with multiple, intersectional identities, ensuring that intersectional communities remain visible in analysis;
- clarification that MENA and Hispanic/Latino categories, and the subcategories within, must be reported as ethnicities;
- instructions and best practices for data collectors assisting respondents in answering the race/ethnicity question, including guidance on:
  - assisting those who identify with multiple racial, ethnic, and tribal categories;
  - sharing information on the purpose for which the data is being collected;
  - noting any relevant privacy and confidentiality laws, regulations, or policies that apply to the data being collected;
  - encouraging fill-in responses over selection of “some other race” where appropriate; and
  - explaining self-identification and voluntary response;
- explanations of geographic, cultural, and other considerations that may be relevant to particular ethnic, racial, or tribal categories, including:
  - ensuring that the collection of data from all categories, but particularly within the Black and Latino categories, allows for populations to indicate more than one national origin or sub-group within each category as desired by the respondent;
  - ensuring that diverse Black or African American populations from the African diaspora have equal opportunities (via checkboxes *and* examples) to self-identify;
  - issuing guidelines for the collection of detailed MENA ethnicity data that treats the MENA region as one diverse geographical area and that requires

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<sup>23</sup> See State Health Access Data Assistance Ctr. (SHADAC), *Considerations from SHADAC: Proposed Revisions to Federal Standards for Collecting Race/Ethnicity Data* (Mar. 23, 2023), <https://www.shadac.org/news/revisions-OMB-standards-RE-data>. NHeLP endorses SHADAC’s recommendations contained in the cited document.



- checkboxes for the largest groups by population in the U.S. (e.g., Lebanese, Iranian, Egyptian), while also using examples that include a trans-national group (e.g., Assyrian/Chaldean), a Gulf population (e.g., Iraqi, Yemeni) and an Arabic-speaking country in Sub-Saharan Africa (e.g., Sudan, Somalia);
  - instructing that immigrants to the U.S. may select as many subcategories as are relevant to them and also fill-in additional responses;
  - allowing appropriate self-identification of American Indians or Alaska Natives regardless of tribal enrollment; and
  - consulting with Tribal Nations on collection and use of demographic information on American Indian, Alaska Native, and Native Hawaiian populations, to fulfill the United States' unique trust responsibilities to Tribal Nations.
- requirements for data privacy and confidentiality that limit disclosure of personally identifying information and reduce re-identification risk;<sup>24</sup> and
  - expectations for updates to data collection, storage, protection, and reporting infrastructure.

In addition, OMB must provide resources in the form of staff time, technical assistance, instructions, scripts, and other written and demonstrative guidance to ensure successful implementation of the new Directive 15. Agencies will need significant resources to update the many data collections that employ the current Directive 15 race/ethnicity question. Many federal, state, and local agencies have lagged in adopting standardized race/ethnicity data collection, let alone in the form required by Directive 15.<sup>25</sup> Particularly for smaller surveys, forms, and data collections, agencies may not have the bandwidth to engage in the work needed to update language, train staff, and reprint and disseminate materials. OMB should identify priority data collections, set timelines appropriate to the size and

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<sup>24</sup> See Farah Kader et al., *Disaggregating Race/Ethnicity Data Categories: Criticisms, Dangers, and Opposing Viewpoints*, HEALTH AFFAIRS, (Mar. 25, 2022), <https://www.healthaffairs.org/doi/10.1377/forefront.20220323.555023>.

<sup>25</sup> Medicaid & CHIP Payment & Access Comm'n (MACPAC), *Report to Congress on Medicaid and CHIP 3-18* (Mar. 2023), [https://www.macpac.gov/wp-content/uploads/2022/12/02\\_Possible-Recommendations-for-Improving-Medicaid-Race-and-Ethnicity-Data-Collection-and-Reporting.pdf](https://www.macpac.gov/wp-content/uploads/2022/12/02_Possible-Recommendations-for-Improving-Medicaid-Race-and-Ethnicity-Data-Collection-and-Reporting.pdf); and see Claudia Williams, *How to Get Health Data Infrastructure Right for This Moment of Medicaid Transformation*, HEALTH AFFAIRS (Jan. 18, 2022), <https://www.healthaffairs.org/doi/10.1377/forefront.20220113.723542/>.



scope of the data collections, and provide sufficient resources to ensure the Directive 15 update actually occurs.

## **VI. Regular Review, Study, and Feedback are Necessary to Promote Ongoing Equitable Data Collection**

The dynamic understanding of race, ethnicity, and tribal affiliation means that OMB must regularly look at how respondents engage with demographic data collection. After implementing the revisions to Directive 15, OMB must continue to study the way the public responds to the demographic question in different contexts. OMB must also conduct research on ways to further improve demographic data collection on race, ethnicity, and tribal affiliation in partnership with impacted communities. Along with fluctuations in terminology and population, there may be an evolving understanding of which populations are better served by being identified in named response options. As part of a robust public education and outreach campaign to promote understanding of demographic data collection, OMB must also spearhead regular engagement with a diverse array of communities to ensure appropriate and equitable representation in demographic data.

In the years since Directive 15 was last updated, changes in individual-level, community-level, and society-level understanding of race, ethnicity, and tribal affiliation has resulted in shifts in how individuals identify themselves on demographic questionnaires. For example, a recent poll echoes what many MENA and Arab communities have been saying for years: MENA or Arab Americans see MENA as distinct from labels such as “white” or “Black.”<sup>26</sup> Research confirms that MENA individuals are more likely to select “MENA” in response to a combined demographic question.<sup>27</sup> In the future, there will be other instances where individuals of particular intersections of race, ethnicity, and tribal affiliation may respond to demographic questions in ways that expose a gap or tension in the current response options. Cognitive testing may also reveal a need for particular public education or training that can improve understanding of how to respond to the present demographic question.

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<sup>26</sup> Nat'l Network for Arab American Communities (NNAAC), *Minority Population Profiles: Middle Eastern and North African (MENA) Health*, [https://drive.google.com/file/d/1YTCdf\\_Nt9sUbGnZscacpKvizF5y5Hbxj/view](https://drive.google.com/file/d/1YTCdf_Nt9sUbGnZscacpKvizF5y5Hbxj/view) (last visited Mar. 31, 2023).

<sup>27</sup> Neda Maghbouleh et al., *Middle Eastern and North African Americans may not be perceived, nor perceive themselves, to be White*, 119 PNAS (Feb. 7, 2022), <https://www.pnas.org/doi/10.1073/pnas.2117940119>.



OMB must conduct ongoing testing of responses to the question to keep current and ensure the question is as useful as it can be in its present form.

OMB should consider research-based approaches to update Directive 15 on a more regular basis. For example, the option to fill-in responses in the more detailed question displayed in Figure 2 of the Notice will enable researchers to study open-ended responses.

Researchers can look for issues in comprehension of the present question and response options (e.g., a respondent fills in “Middle Eastern” even though “MENA” is a present response option) or study new potential response options (e.g., researchers identify that a significant number of respondents fill in “Brazilian” as a response option).

OMB must ensure that this and any future updates of Directive 15 prioritize the agency and autonomy of the communities reflected and not reflected in the question and response options. We support OMB’s proposed changes in this Notice because they are based on longstanding requests from Latino and MENA community to increase the likelihood that they are represented in data. The changes are also supported by research from the Census Bureau, the CDC, and private academic researchers, among others. OMB should continue to engage communities of all races, ethnicities, tribal affiliations, and intersections thereof to gather feedback to inform future changes. OMB should especially engage feedback from underserved and underrepresented communities, Indigenous communities, and Tribal Nations, who may wish to exert sovereignty over their data.

Finally, OMB must consider standards for demographic data collection beyond race, ethnicity, and tribal affiliation. Best practice, research-validated standards exist for collection of demographic information on preferred language, sexual orientation, gender identity, sex characteristics, and disability and functional status.<sup>28</sup> OMB should review

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<sup>28</sup> See Institute of Medicine: Board on Health Care Service; Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement* (2009, eds. Cheryl Ulmer, Bernadette McFadden, and David R. Nerenz), <https://nap.nationalacademies.org/catalog/12696/race-ethnicity-and-language-data-standardization-for-health-care-quality>; Nat’l Academies of Sciences, Engineering, & Medicine, Division of Behavioral & Social Sciences & Education, Committee on Nat’l Statistics, *Measuring Sex, Gender Identity, and Sexual Orientation* (2022, eds., Nancy Bates, Marshall Chin, & Tara Becker), <https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and->

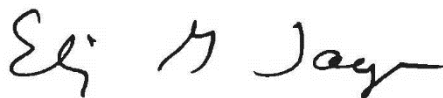


existing literature and develop guidelines and expectations for agencies to collect information on other demographic categories. In doing so, OMB can help remedy the lack of information, data, and study on underserved populations and promote the Administration's goal of improved visibility of and attention to the needs of woefully undercounted intersectional groups.

## Conclusion

NHeLP supports OMB's initial proposals for revision of Directive 15. The proposed changes will advance the Administration's goal of increasing data equity and will benefit the overall health and wellbeing of historically and presently underserved populations. We ask that you consider all material cited within as part of our comments. For questions or follow up related to our comments, please contact Staff Attorney Charly Gilfoil at [gilfoil@healthlaw.org](mailto:gilfoil@healthlaw.org).

Sincerely,



Elizabeth G. Taylor  
Executive Director

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[sexual-orientation](#); U.S. Census Bureau, *How Disability Data are Collected from The American Community Survey* (Nov. 21, 2021), <https://www.census.gov/topics/health/disability/guidance/data-collection-ac.html>.

