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Interagency Technical Working Group on
Race and Ethnicity Standards
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Washington, DC 20500

Submitted via Regulations.gov

The Medical Library Association (MLA) is pleased to submit comments addressing some of the initial proposals for Updating OMB’s Race and Ethnicity Statistical Standards. We applaud OMB for undertaking this much needed initiative which will open up the ability of health sciences librarians, researchers, and health professionals to find relevant, accurate, and timely health equity research that impacts communities of color. Our comments address these three sections of the Request for Information (RFI):

1. Requests for public comment on adding "Middle Eastern or North African" category
2. Requests for public comment on minimum level of detail collected
3. Request for comment on updates to terminology

1. "Middle Eastern or North African" category

MLA supports the addition of new categories that allow for the capture of racial/ethnic data not otherwise readily available that supports addressing health disparities and inequities research. The “Middle Eastern or North African” category has become a prominent term within biomedical literature. MLA affirms the position of the Association of American Medical Colleges (AAMC) proposing the addition of MENA to the minimum reporting categories, and our organizations continue to urge adoption of this new category (https://www.aamc.org/advocacy-policy/washington-highlights/white-house-issues-revisions-race-and-ethnicity-standards).

Though we cannot speak to whether this term can be “likely to continue to be understood and accepted by those in this community...[OR] consistently [be] understood and acceptable among
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"those with different experiences…” we did locate several examples that should be considered by the working group as evidence for possible addition:

**PubMed/Medline:**

<table>
<thead>
<tr>
<th>Term or Phrase</th>
<th>Records Found</th>
<th>Date searched:</th>
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<tr>
<td>&quot;MENA&quot; AND &quot;Middle East&quot;** (to disambiguate from other “mena” meanings)</td>
<td>700</td>
<td>04/20/2023</td>
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<tr>
<td>&quot;MENA&quot; AND &quot;North Africa&quot;**</td>
<td>668</td>
<td>04/20/2023</td>
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<tr>
<td>&quot;MENA region&quot;</td>
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<td>04/20/2023</td>
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<tr>
<td>&quot;Middle eastern and north african&quot;</td>
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<tr>
<td>&quot;middle eastern and north african countries&quot;</td>
<td>27</td>
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<td>&quot;middle eastern and north africans&quot;</td>
<td>2</td>
<td>04/20/2023</td>
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**Scopus**

| TITLE-ABS-KEY ( "mena" ) AND TITLE-ABS-KEY ( "middle east" )                 | 3,213         | 04/20/2023     |
| ( TITLE-ABS-KEY ( "mena" ) AND TITLE-ABS-KEY ( "north africa" ) )            | 3,068         | 04/20/2023     |

**Web of Science Core Collection**

| “MENA” (All Fields) and “Middle East” (All Fields)                           | 2,623         | 04/20/2023     |
| “MENA” (All Fields) and “North Africa” (All Fields)                         | 2,430         | 04/20/2023     |

**Google Scholar**

| "MENA" and "Middle East"**                                                  | 126,000       | 04/20/2023     |
| "MENA" and "North Africa"**                                                 | 91,000        | 04/20/2023     |
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</tr>
<tr>
<td>kw:&quot;MENA&quot; AND kw:&quot;North Africa***&quot;</td>
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</table>

This terminology is also in use by various professional and cultural organizations such as the ones listed below:

- The term “MENA” or “Middle East and North Africa” is used to regionally describe this population by international organizations like the IMF, OECD, EU, World Bank, Office of the US Trade Representative, and the NIH Fogarty International Center.

2. Minimum level of detail collected

From OMB document:

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

MLA supports any changes that improve the inclusivity and flexibility of individuals to self-report multiple racial and ethnic identities.

The example provided in Figure 2 provides enough inclusive detail such that it allows individuals to self-report additional data. Surveys which provide space for self-identified racial and ethnic identities accommodate how people perceive themselves. These perceptions change over time as the nomenclature for racial and ethnic identification evolves (Flanagin et al., 2021; Lu et al., 2022). (Jarrín et al., 2020) emphasize that “self-reported data [is] the preferred source for accuracy and the gold standard,” especially noted in federal and standard healthcare surveys. They found that surveys which do not allow for self-report have been problematic for AAPI and AIAN populations and can be perceived to impact the healthcare data of all racial and ethnic categories

The example in Figure 2 does require changes. The most vital change to the example is that it should ask “What is your race AND ethnicity?” The terms race and ethnicity should be defined for all survey users to clarify the researchers intent and application of these terms. The Journal of the American Medical Association (JAMA) guidelines on reporting racial and ethnic terminology usage and word choice are critically important. Author guidelines for this journal require the use of “specific racial and ethnic classifications” (Flanagin et al., 2021). These guidelines also state that, “content published in medical journals, language and terminology must be accurate, clear and precise and must reflect fairness, equity and consistency in use
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and reporting” (Flanagin et al., 2021). The American Medical Association (AMA) manual of style supports the JAMA guidelines by reiterating the use of inclusive language such that racial and ethnic terms are “dynamic and shaped by geographic, cultural and sociopolitical forces” (Frey & Young, 2020).

This statement of the fluidity of racial and ethnic terminology is supported in Lu, et al’s research (2022) where they state that how people perceive themselves changes. The AMA manual of style goes on to state that, “many people may identify with more than one race and ethnicity; therefore, categories should not be considered absolute or viewed in isolation” and 11.12.3.3 in the style manual emphasizes the need for “specific racial and ethnic categories over collective terms” (Frey & Young, 2020). Default structures and minimal categories should specifically follow the JAMA and AMA guidelines for all researchers regardless of journal of publication as these organizations are considered the gold standard of medical and healthcare research.

In addition, the OMB should clearly define what it means by race and by ethnicity. The geographic affiliations should clarify that they refer to the person’s ancestry, rather than to the person’s own national origin (Eg, Not everyone who is English is white). Offering assessment questions in relevant languages increases response rates for self-identification for race and/or ethnicity and would therefore be more inclusive (Adia AC, Nazareno J, Operario D, et al 2020; Islam NS, Khan S, Kwon S, et al 2010; Holland AT, Palaniappan LP 2012; Klinger EV, Carlini SV, Gonzalez I, et al 2015).

“Select all that apply” and combining “Hispanic or Latino” with the options for races, and with options to select country of origin, is more inclusive than previous versions of the census, as it does not limit the options that people may select and addresses the concern that many Hispanic or Latino respondents were selecting “some other race” when ethnicity was asked as a separate question (https://www.theatlantic.com/politics/archive/2016/08/the-rise-of-the-others/497690/).

The 2020 census inadvertently contributed to the false idea that people of Hispanic origin are all the same race or color, because the census did not include any Hispanic origin group under the “White” or “Black” race box (Lopez N 2021). Allowing people to check both Hispanic and White and/or Black corrects this misassumption. People whose lineage comes from Mexico, Puerto Rico, or Cuba sometimes prefer to self-identify using their specific ancestry, rather than as Hispanic or Latino (Kauh et al., 2021). The term “Hispanic” may not be understood by immigrants, as it is not well known outside the United States (AHRQ 2018). Furthermore, it is not always clear which countries or subpopulations are included when describing someone as Latino (Ford CL, Harawa NT 2010). People who do not trace their Latin American ancestry to colonial periods also live in these countries, including a large population of people with Japanese ancestry in Brazil and Peru. Between 2010 and 2020, the number of people of Hispanic or Latino origin reporting more than one race increased 567% to 20.3 million (32.7%) (Jones N, Marks R, Ramirez R, et al. 2021).

A Pew survey depicts ‘Hispanic’ as a race, rather than as an ethnicity, because many Hispanic people did not identify with any of the race options offered by the US Census Bureau (Mays VM,

Other dimensions of race may need to be recognized when defining race as a social construct. Goldstein and Morning (2000) recommend distinguishing between three components of multiple-race populations: geographic origins, awareness of racial ancestry, and strength of identification with multiple races. Immigrant generation level also impacts how people identify their race and/or ethnicity (Bobo LD and Fox C 2003).

From OMB document:

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 condition?

Yes.

From OMB document:

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

The positives and negatives of collecting granular data are reflected in the impact on individuals’ ability to self-identify themselves and the impact on progress to address health disparities (Davis, 2016). Techniques for collecting or providing detailed race and ethnicity data for categories with smaller population sizes within the US are addressed in a study by Elliott et al., (2008) which supports the use of the Kalman filter to address issues with small sample sizes. This study states that “single-year estimates of health disparities in small racial/ethnic groups are often insufficiently precise to guide policy, whereas estimates that are pooled over multiple years may not accurately describe current conditions. While collecting additional data is costly, innovative analytic approaches may improve the accuracy and utility of existing data. We developed an application of the Kalman filter in order to make more efficient use of extant data.” A modified Kalman Filter, applied to analyses of large datasets like the National Health Interview Survey, could enable the analysis of trends across time to data pooled over a number of years.

The following methods may also assist with collection/provision of detailed race and ethnicity data for smaller population sizes and it should be noted that they carry limitations:

3. When surname and address information are available in Medicare administrative data, Bayesian Improved Surname Geocoding (BISG) or Medicare Bayesian Improved Surname Geocoding (MBISG) can be used to impute missing race and ethnicity data. However, current methods for improving algorithmic equity are not designed with multiracial people in mind. Note also, that this method is not accurate for all race/ethnic groups (Elliott MN, Fremont A, Morrison PA, et al. 2008; Cabreros I, Agniel D, Martino SC, et al. 2022; U.S. Census Bureau, 2002, Rand Corporation, 2023).

References:


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Klinger EV, Carlini SV, Gonzalez I, Hubert SS, Linder JA, Rigotti NA, Kontos EZ, Park...


3. Updates to terminology

MLA supports removing problematic language within the minimum reporting category definitions. In our December 18, 2022 presentation before the Interagency Working Group, we stressed the need to remove “Negro” from the Black or African American minimum reporting category definition. We also affirm the Working Group’s decision to remove the following terms:

From OMB document:

Terminologies Used Within Minimum Categories
The Working Group proposes that SPD 15 remove:

—“Negro” from the Black or African American definition
—“Far East” from the Asian definition, replacing with “East Asian”
—“Other” from “Native Hawaiian and Other Pacific Islander”

From OMB document:

“Majority/Minority”

The Working Group proposes that SPD 15 discontinue use of the terms “majority” and “minority.”

Given the limited subject-matter expertise for this specific population, MLA cannot speak to whether or not this phrase should be removed, but we do recommend reviewing terminology projects for indigenous communities that could provide insight to this phrasing and the existing terms used to describe this population.

We also recommend any changes have the input of those who represent indigenous communities in the United States.

From OMB document:

—The phrase “who maintain tribal affiliation or community attachment” in the American Indian or Alaska Native definition, making this minimum category’s definition consistent with all minimum categories

From OMB document:

The Working Group proposes that the American Indian or Alaska Native minimum category description be changed to: “The category ‘American Indian or Alaska Native’ includes all individuals who identify with any of the original peoples of North, Central, and South America.”

MLA supports the Working Group’s proposal to change “The category “American Indian or Alaska Native” to include all individuals who identify with any of the original peoples of North, Central, and South America,” and recommends these resources for further study:

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Misrepresentation in the Surrogate: Author Critiques of “Indians of North America” Subject Headings: https://www.tandfonline.com/doi/full/10.1080/01639374.2022.2090039

Improving Library Subject Headings for Iowa Indigenous Peoples: https://www.iastatedigitalpress.com/iscore/article/id/14466/

Rooted in the Past: Use of “East Indians” in Library of Congress Subject Headings: https://www.tandfonline.com/doi/full/10.1080/01639374.2017.1386253?casa_token=Dn7ZioUMX2AAAAAAA%3AO6irfr7J2uAzmU1Sx9nUo0P0NTI2tmgzoLwEisDGsBE4kD-C3IOgKk76_RDxMrR9PZOMYBA3dec


MLA agrees with the removal of “Cuban” being listed twice.

We also ask the Working Group to again consider inclusivity of identities within the Hispanic/Latino/a/e/x diaspora and the focus on Latin American countries of origin and Spanish/Portuguese imperial influence to better describe the socio/political dimensions of this population which is in part supported by this project:

Hispanic/Latinx Inclusive Terminologies Project https://osf.io/9mgwq/

From OMB document:

• The Working Group proposes that SPD 15 correct “Cuban” being listed twice in the minimum category definition for “Hispanic or Latino.”

Additional recommendations:

Because these changes have a direct impact on medical subject headings that are used by the largest biomedical and health sciences indexing database in the world, MLA recommends the following strategies be considered for any future changes of minimum reporting categories and their federal definitions:

• Communicate changes directly to the National Library of Medicine
• Encourage federal/non-federal partnerships such as the MLA/NLM when reviewing terms
• Have non-federal librarians involved in the process
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The Medical Library Association (MLA) is a nonprofit, educational organization with 2,500 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledgebase of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the health care community and the public.