Improving the Collection of National Health Data: The Case for the Middle Eastern and North African Checkbox in the United States

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Research Article

Keywords: Middle Eastern and North African, Arab American, US Census

Posted Date: April 10th, 2023

DOI: https://doi.org/10.21203/rs.3.rs-2790994/v1

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Abstract

On June 15, 2022, the Chief Statistician of the United States announced that the Office of Management and Budget would conduct a formal review of the current minimum standards for collecting race/ethnicity data on the US Census and other federal forms. This review is extremely important for communities that have been overlooked and unable to receive federal funding for their programs, most notably Middle Eastern and North African (MENA) Americans. MENA individuals are defined as “White” in the US, which is particularly concerning given that research continues to identify that their health behaviors, disabilities, health conditions, mortality and lived experiences differ from Whites. The initial OMB proposals were published in January 2023 with a request for public comment for up to 75 days. Specifically, the OMB is requesting comments on a separate MENA checkbox. The purpose of this study was to summarize the initial comments posted on the federal registrar’s website during February 2023. Comments were reviewed to determine whether MENA was mentioned, whether comments indicated support for the MENA checkbox, and whether comments mentioned support for reasons related to health. There were 2,950 comments reviewed. Most (71.76%) mentioned the inclusion of a MENA checkbox. Of those, 98.82% were in support of adding the MENA checkbox. Among those, 31.98% mentioned the need for a MENA checkbox to improve data collection for health-related topics. These findings are encouraging and indicate strong support for including a MENA checkbox on the next US Census and other federal forms.

Introduction

The ability to collect accurate data on the health of Middle Eastern and North African (MENA) Americans is in our nation’s reach. On June 15, 2022, the Chief Statistician of the United States (US) announced that the Office of Management and Budget (OMB) would conduct a formal review of the current minimum standards for collecting race and ethnicity data on the US Census and other federal forms. The current standards are outlined in Statistical Policy Directive No. 15 (SPD 15), which has not been updated since 1997. These standards are used for the allocation of billions of dollars in federal funds to communities across the country for arts, education, school lunches, health research, medical services, mental health programs, and many other assistance programs. The review by the Chief Statistician includes the development of an Interagency Technical Working Group of Federal Government staff and engagement opportunities with the public through listening sessions and an open comment period for community members to provide feedback on proposed changes. Several themes emerged from the initial listening sessions during Fall 2022, including the need for data disaggregation in general, data disaggregation for the Black or African American population, and the need for data on MENA and multiracial/ethnic populations. The target date for completing the revision is Summer 2024. The goals of the OMB review of SPD 15 are to determine whether the: 1) minimum reporting categories should be changed; 2) wording for each category should be changed; and 3) guidance for collecting data can be improved, particularly when self-identification of race/ethnicity is not possible. This review is extremely important for communities that have been overlooked and unable to receive federal funding for their programs, most notably MENA Americans.

SPD 15 currently requires six minimum reporting categories to be collected to describe race/ethnicity among individuals who complete decennial US Census and other federal forms, including: 1) American Indian or Alaskan Native; 2) Asian; 3) Black or African American; 4) Hispanic or Latino; 5) Native Hawaiian or Other Pacific Islander; and 6) White. The White category includes a heterogeneous group of individuals with origins from the “original peoples of Europe, the Middle East or North Africa.” Classifying MENA individuals as White is particularly concerning given that research continues to identify that their health behaviors, disability/limitations, health
conditions, mortality and lived experiences differ from Whites. Research has shown that many MENA individuals do not perceive themselves as White nor do others perceive them as White. These differences underscore the need for a separate checkbox for MENA Americans on the US Census and other federal forms.

The initial OMB proposal was published in January 2023, with request for public comment for up to 75 days. The initial proposal outlines six specific proposals for consideration, including; 1) collection of race and Hispanic/Latino ethnicity using one question; 2) addition of MENA as a new minimum category; 3) requirement of collecting detailed race/ethnicity categories by default; 4) updates to terminology to remove duplicates, inaccurate, or offensive terms; 5) guidance on data collection in a centralized location; and 6) request for comments on any additional topics or future research, such as ordering of categories alphabetically versus a standard order.

For the proposed MENA category (initial proposal 2), the proposal requests for public comment on: 2a) the acceptability of the term MENA due to the heterogeneity of populations originating from both Arab and non-Arab countries in this region; 2b) the adequacy of the examples provided as subcategories with the checkbox (currently Lebanese, Iranian, Egyptian, Syrian, Moroccan, and Israeli) and comment box to include other origins (‘Enter, for example, Algerian, Iraqi, Kurdish, etc.); and 2c) whether the definition will allow for an accurate reflection the well-being of the population.

The purpose of this study is to describe the comments posted during the first month (February 2023) to determine the proportion of comments that 1) mention including a MENA checkbox; 2) support including a MENA checkbox; and 3) mention support for a MENA checkbox for reasons related to the collection of health-related data.

Methods

Comments posted on the Federal Reserve website during February 2023 were reviewed. Comments were reviewed to create three dichotomous variables. First, comments were reviewed to determine whether MENA was mentioned (yes/no). Search terms included “MENA,” “Middle East,” “North Africa,” “Arab,” and each of the proposed countries or ethnic groups in the region identified by the US Census Bureau (e.g., Iran, Israel, Lebanon, Palestine, Chaldean). Second, comments that mentioned MENA were reviewed to determine whether they indicated support (yes/no) for the checkbox. Third, comments that supported including a MENA checkbox were evaluated to determine whether health-related topics were mentioned (yes/no). Basic search terms included “health,” “healthcare,” “health care,” “medicine,” “medical,” and “research.”

Frequencies and percentages were used to report whether individuals who provided a comment: 1) mentioned including a MENA checkbox; 2) supported including a MENA checkbox; and 3) supported adding a MENA checkbox for the collection of health-related data. Statistical analyses were conducted using STATA 14.0. The institutional review board deemed this project using publicly available data not subject for review.

Results

Initial findings are presented in Table 1. There were 2,950 comments reviewed that were posted on the Federal Registrar’s website during February 2023. Among the comments reviewed, most (71.76%) mentioned the inclusion of a MENA checkbox. Of those, 98.82% were in support of adding the MENA checkbox. Among the comments that mentioned support for adding a MENA checkbox, 31.98% mentioned the need for a MENA checkbox to improve data collection for health-related topics.
Table 1
Description of initial OMB public comments posted, n = 2,950.

<table>
<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments acknowledges adding a MENA checkbox</td>
<td>2,117</td>
<td>71.76</td>
</tr>
<tr>
<td>Supports MENA checkbox</td>
<td>2,092</td>
<td>98.82</td>
</tr>
<tr>
<td>Supports MENA checkbox for health data</td>
<td>669</td>
<td>31.98</td>
</tr>
</tbody>
</table>

Abbreviation: MENA = Middle Eastern and North African

An assessment of the content and full qualitative analysis of comments posted is beyond the scope of this study. In general, common themes related to need for inclusion of a MENA checkbox for health data specifically mentioned the following topics: cancer screenings; health behaviors; influenza; COVID-19; functional disability; mental health; and maternal mortality.

Discussion

The purpose of this study was to provide a preliminary assessment of the comments submitted to the OMB during the first month of its comment period as they relate to adding a separate MENA checkbox for race/ethnicity on federal forms. Overall, the findings showed strong support for the inclusion of the MENA checkbox. Implications of the addition of the MENA category for health research are provided in the following paragraphs.

First, the approval of a separate MENA checkbox will allow for the first comprehensive nationally representative baseline estimates that capture the health needs of MENA adults and children. There are only two national surveys that allow for MENA health outcomes to be determined, the American Community Survey (ACS) and National Health Interview Survey (NHIS). The ACS is funded by the US Census Bureau and collects monthly samples to produce annual national estimates of demographic and socioeconomic factors from a random sample of households. MENA individuals have been identified using the ACS using questions on race, ethnicity, place of birth, and ancestry in previous research. However, the ACS is limited for health research because it only collects information on health insurance, health care access, and disability. From 2000–2018, the NHIS allowed for the assessment of several health topics among MENA individuals. Funded by National Center for Health Statistics (NCHS), the NHIS collects a wide range of demographic, socioeconomic, health care access and utilization, health behaviors, and health outcomes across the life course from a representative sample of US adults and children. MENA individuals have been identified by using questions on race, ethnicity, and country of birth in previous research. US-born MENA individuals could not be identified in the NHIS due to the lack of ancestry question. Furthermore, the NHIS was redesigned in 2019 and questions on place of birth have been removed. Other surveys sponsored by the Centers for Disease Control and Prevention (CDC) and NCHS do not collect data on MENA individuals. During the latest solicitation period (April 2022) to submit proposals to add content to the National Health and Nutrition Examination Survey (NHANES), a proposal was submitted to add a MENA checkbox to the race/ethnicity questions by leading MENA health researchers. However, no response was received, or feedback provided as to why a MENA checkbox would not be considered for future data collection efforts.
Second, among the comments submitted in support of a MENA category, 31.98% mentioned support for the checkbox for the collection of health-related data. The health-related topics mentioned most were cancer screening, health behaviors, influenza, COVID-19, functional disability, mental health, and maternal mortality. On a national level, functional disability is the only one of these topics that can currently be measured for MENA individuals using ACS data, with ancestry and place of birth used to create a MENA category. Until 2019, cancer screenings, health behaviors, influenza, functional disability and mental health could be measured among foreign-born MENA individuals, but with the removal of the question on country of birth, current and future trends cannot be examined. In 2021, the NHIS included questions on COVID-19. Without the accompanying country of birth question, national estimates for MENA individuals will not be able to be measured.

Third, it is also important to acknowledge that including a MENA checkbox may not only provide health data for MENA populations, but it may also allow for a truer assessment of health disparities between other populations and White individuals. To determine the prevalence of health outcomes, the numerator (e.g., number of COVID-19 cases) and denominator (e.g., number of individuals in a specific racial/ethnic group) are needed. If MENA individuals are considered White, they contribute to both the numerator and denominator. By removing MENA from the White category, results may indicate a lower prevalence of specific health burdens among White individuals and create a larger disparity between other minority groups and White individuals. Future studies on MENA health should consider using methods to remove MENA individuals from the White category and make comparisons with all other racial/ethnic groups required for federal reporting (Hispanic or Latino; American Indian or Alaskan Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander) to further the science on health disparities.

To our knowledge, this is one of the first attempts to compile the comments related to the addition of a MENA checkbox during the OMB’s 2023 request for public comments on SPD 15. The full-text of each comment is available on the Federal Registrar’s website currently and will be included as part of the public report at the end of the comment period. This analysis was limited to reporting aggregate data submitted and posted during the first 30 days of the 75-day comment period. As of this writing, it represents 23.49% of the public comments currently posted (n = 12,557) with five days remaining during the comment period. This research team is continuing to review and compile the remaining comments posted and expect that similar trends will appear when all comments are analyzed. We selected to compile the first month of comments for review to contribute to the timely scientific dialogue and advocacy efforts prior to the completion of the 75-day comment period and full review by the OMB. Another limitation of this study is that the analysis of comments was purely descriptive. The analysis of content was only limited to health-related topics. Future analyses of the comments should fully address the other concerns mentioned by individuals who supported a MENA checkbox, such as its support for small businesses, education services, and voting rights.

This is one of the first attempts to evaluate the OMB public comments addressing the proposed MENA checkbox as a minimum reporting category for the US Census and other federal forms. This study focused on the need for a MENA checkbox for health data, because the approval of a separate MENA category will allow for the first nationally representative baseline estimates for health of US- and foreign-born MENA adults and children. Results indicated strong support for including a MENA checkbox among those who submitted comments. Results are encouraging, but it remains unknown whether the OMB will make the changes to uncover the health needs of this vulnerable underrepresented population.

Declarations
Conlicts of Interest: The author has no conlicts of interest to declare.

Financial Disclosure: No fnancial disclosures were reported by the author of this paper.

Funding: This research did not receive any specic grant from funding agencies in the public, commercial, or not-for-profit sectors.

References


