October 31, 2016

Ms. Katherine K. Wallman
Chief Statistician
Office of Management and Budget
1800 G St. 9th Floor
Washington, DC 20503
Email: race-ethnicity@omb.eop.gov

Re: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (81 FR 67398)

Dear Ms. Wallman,

The Association of Asian Pacific Community Health Organizations (AAPCHO) respectfully submits the following comments on the Office of Management and Budget's federal register notice with regards to the Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, 81 FR 67398.

AAPCHO is a national not-for-profit association of 35 community-based health care organizations, including 29 Federally Qualified Health Centers, dedicated to promoting advocacy, collaboration, and leadership that improve the health status and access of medically underserved Asian Americans, Native Hawaiians, and Pacific Islanders (AA&NHPIs) in the U.S., its territories, and its freely associated states.

As health care providers, AAPCHO members focus on providing services that are uniquely appropriate to their patient populations, including: culturally and linguistically appropriate health care services, comprehensive primary medical care, and wrap-around enabling services for the medically underserved throughout the country. For the approximately 500,000 patients our members serve annually, AAPCHO advocates that the health care system provide access to comprehensive and linguistically and culturally competent care for our member community health center providers and their patients.

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Race and Ethnicity Data Collection

We strongly recommend OMB to move forward with disaggregating race and ethnicity data, in order to ensure better data collection accuracy for AA&NHPI populations. All federal departments and agencies should be required to collect data on race and ethnicity, as well as to analyze, report, use, and disseminate disaggregated data.

We support the Asian & Pacific Islander American Health Forum (APIAHF) in their comments, particularly in the following areas:

We encourage OMB to design standards that make clear that federal agencies can, and should, go beyond the minimums standards it sets out. The 1997 changes clarified that these standards were not "acceptable racial and ethnic categories," but rather "minimum categories for data on race." This needs to be strengthened. Greater disaggregation is essential for federal departments and agencies to understand and effectively serve diverse AA and NHPI communities. Further, covered entities should be required to assess (and update their assessments) of the populations they serve and are eligible to serve, so that they can appropriately plan how to meet the needs of their clients/patients. OMB should provide guidelines as to how to conduct an assessment and what data may be readily available to federal agencies.

Disaggregated data help community organizations and researchers better identify the needs facing different populations. Therefore, all federal departments and agencies should be required to collect and report out data at more granular levels. Even when disaggregated data are collected, they often are not analyzed, reported or disseminated, and therefore not useable by either the relevant federal department or agency, or by the communities impacted. For example:

- The National Center for Education Statistics oversampled Asian and Pacific Islanders in the 2007 National Household Education Survey, but it did not report group responses, nor did it do so in the National Assessment of Educational Progress (NAEP). On the NAEP "Nations Report Card" website, student groups were not broken separately into Asian and Pacific Islander populations and Native Hawaiians are not mentioned.[1]
- The National Center for Science and Engineering Statistics reported it did not use large enough sample sizes to report out disaggregated race data, though some surveys, such as the Survey of Doctorate Recipients, asked about 10 Asian and 4 Native Hawaiian and
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[1] National Center for Education Statistics. 2014 Civics Assessment: Proportions of Racial/Ethnic Groups Change Since 1988. Available at: http://www.nationsreportcard.gov/hgc_2014/#civics/groups#percentages.

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Pacific Islander groups.[2]

We urge OMB to develop resources and best practices to support the efforts of federal departments and agencies to collect, analyze, report and disseminate useful disaggregated data on AA and NHPI populations. Research exists on best practices for surveying AA&NHPI populations, but agencies may not be aware of their options.[3] OMB should encourage departments and agencies to adopt techniques such as designing oversamples of AA&NHPI populations and pooling multiple years of data for analyses and reporting. Rather than just acknowledge the nature of the minimum standards, OMB should actively encourage agencies to publish disaggregated data as frequently as possible, and at least annually.

We urge OMB to take a more active role in enforcing these standards. We note that many agencies have not fully complied with the 1997 standards and could benefit from more proactive monitoring and technical assistance from OMB to ensure the consistent application of the standards.

- The Center for Medicare and Medicaid Services "Mapping Medicare Disparities" tool aggregates Asians and Pacific Islanders into one category.[4]
- The CDC's latest National Vital Statistics Report aggregated Asians and Pacific Islanders into a single group to report on the leading causes of death in 2014.[5]

We encourage OMB to work with departments and agencies to ensure data is properly reported out in the minimum categories according to the standards. When methodological concerns arise, we encourage OMB to work with departments and agencies before an individual survey is conducted or data collected to allow for proper analyses and reporting.

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[2] National Center for Science and Engineering Statistics. Racial and Ethnic Diversity among U.S. Educated Science, Engineering, and Health Doctorate Recipients: Methods of Reporting Diversity. Available at: https://www.nsf.gov/statistics/infbrief/nsf12304/nsf12304.pdf.

[3] For example:

- Islam, Nadia S., et al. Methodological Issues in the Collection, Analysis, and Reporting of Granular Data in Asian American Populations: Historical Challenges and Potential Solutions." *Journal of Health Care for the Poor and Underserved*, 2010; 21(4): 1354-1381.
- Lee, Soo-Kyung, and Yu-Yao Cheng. "Reaching Asian Americans: Sampling Strategies and Incentives." *Journal of Immigrant and Minority Health*, 2006; 8(3): 245-25.
- Ngo-Metzger, Quyen, et al. "Surveying Minorities with Limited-English Proficiency: Does Data Collection Method Affect Data Quality among Asian Americans?" *Medical Care*, 2004; 43(9): 893-900.

[4] Centers for Medicare and Medicaid Services. Mapping Medicare Disparities. Updated September 30, 2016, available through: https://data.cms.gov/mapping-medicare-disparities.

[5] Centers for Disease Control and Prevention. Deaths: Leading Causes for 2014. June 2016. 65(5): 1-96. Available through: http://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65_05.pdf.

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In summary, along with APIAHF and many other partners, we make the following recommendations in regards to the minimum use categories. OMB should:

- ***Require all federal departments and agencies, when collecting, analyzing, using, reporting, and disseminating data on race or ethnicity, to collect, analyze, use, report, and disseminate disaggregated race and ethnicity data for AA&NHPI groups.***
- ***Emphasize that the standards set forth are only the minimum required and that agencies and departments are strongly encouraged to go beyond them.***
- ***Develop resources and best practices for departments and agencies to use in collecting, analyzing, reporting, and disseminating disaggregated data.***
- ***Work with agencies and departments to enforce compliance with the standards by training staff to collect granular demographic data, including explaining why this data is being collected.***
- ***Require agencies to publically justify any exclusion of the minimum categories.***

AA&NHPIs face a number of health disparities, which differ by population.

Overall, AA&NHPIs face health care disparities that are often invisible to mainstream society. AA&NHPIs are the fastest growing racial group in the United States with dozens of different cultures and languages.[6] Approximately 71% of Asian Americans speak a language other than English at home.[7] Due to barriers in health care access, cultural taboos, and a lack of culturally competent and linguistically concordant healthcare services, AA&NHPIs disproportionately experience preventable health care disparities.

This is further complicated by the lack of adequate disaggregated data by race and ethnicity, preventing health care professionals and ultimately patient populations from understanding what health issues impact the communities they serve. For example, Vietnamese American women have the highest rate of cervical cancer of any racial or ethnic group in the United States, yet also report persistently low Pap screening rates.[8] Filipino communities suffer disproportionately higher rates

[6] Ramakrishnan, K., and T. Lee. Public Opinion of a Growing Electorate: Asian Americans and Pacific Islanders in 2012, National Asian American Survey 3 (2012), http://naasurvey.com/resources/Home/NAAS12-sep25-election.pdf.

[7] Asian Americans Advancing Justice | Los Angeles & Asian Americans Advancing Justice | AAJC, *A Community of Contrasts Asian Americans in the United States: 2011*, at 25 (2011), available at http://www.advancingjustice.org/pdf/Community_of_Contrast.pdf.

[8] Ma, G., Fang, C., Feng, Z., Tan, Y., Gao, W., Ge, S., Nguyen, C. Correlates of Cervical Cancer Screening among Vietnamese American Women. Infectious Diseases in Obstetrics and Gynecology, 2012; 2012. http://www.hindawi.com/journals/idog/2012/617234/

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of many chronic diseases like diabetes.[9,10]

Health inequities are a focus of AAPCHO's work because of the health issues that many of our members' patient populations face. Patients visiting AA&NHPI serving health centers face higher rates of hepatitis B, hepatitis C, asthma, and tuberculosis.[11] As such, AAPCHO values accurate and granular health status data, categorized by race and ethnicity (or country of origin), to get a better picture of the health issues that face the many populations that AAPCHO member centers serve, from the Burmese population in Atlanta, to the Chinese population in Boston, to the Micronesian population in Hawaii. This picture provides AAPCHO members with an understanding of what type of care individual populations need to better manage and treat them, with the hope of reducing health inequities.

Use of Separate Questions versus a Combined Question to Measure Race and Ethnicity and Question Phrasing

The Census Bureau conducted a content test for how to improve the phrasing of questions about race and ethnicity. Asian Americans and Native Hawaiians and Pacific Islanders self-identified more often when they were posed a question that presented combined race and ethnicity.[12]

We are not commenting on a preference for either separate or a combined question to measure race and ethnicity, but rather support whichever format more accurately reflects AA&NHPI populations. For either separate or combined questions, we support the comments, like Advancing Justice | AAJC's, which encourage the maximum number of checkboxes, and the maximum number of examples to be noted, using the number recognized in the 2010 Census as a minimum. The final recommended question format must be structured in a way that encourages and increases the rates of AA&NHPI participation and self-identification. In addition, data collection for race should include an option for populations to choose outside of the examples given, to ensure the accuracy of self-reporting (e.g. if a Nepali or a Sri Lankan ends up choosing "Asian Indian" because they are unsure of what to choose).

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[9] Karter, A., Schillinger, D., Adams, A., Moffet, H., Liu, J., Adler, N., Kanaya, A. Elevated Rates of Diabetes in Pacific Islanders and Asian subgroups. Diabetes Care. Mar 2013; 36(3): 574-579.
[10] National Institutes of Health, Office of Research on Women's Health Women of Color Health Information Collection: Diabetes Mellitus (Apr. 2011), available at http://orwh.od.nih.gov/resources/policyreports/pdf/ORWH-HIC-Diabetes-Mellitus.pdf.
[11] Association of Asian Pacific Community Health Organizations. *The Health of Asian Americans, Native Hawaiians, and Pacific Islanders Served at Health Centers*, available at http://www.aapcho.org/resources_db/access-fact-sheet/.
[12] U.S. Census Bureau, 2015 National Content Test Preliminary Results on Race and Ethnicity, 2016, accessed at: http://www2.census.gov/cac/nac/meetings/2016-10/2016-nac-jones.pdf

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Additionally, we strongly support that the "roll up" of Native Hawaiians and Pacific Islanders is noted as a separate category from Asian Americans. Finally, in order to ensure accuracy for the populations that our members serve, we encourage the oversampling of AA&NHPIs by ethnic group.

Classification of a Middle Eastern and North African Group and Distinct Reporting Category

We support our partners' comments to recommend a separate Middle Eastern and North African (MENA) group and reporting category. Currently, people from these populations must select one of the current five race categories, regardless of their how they self-identify, and many of them had chosen "White" in the past. The MENA population is a unique community that warrants identification in federal surveys. Current standards do not allow federal agencies to identify the unique issues faced by this population and adequately serve them. Creating this category would allow agencies, as well as community-based organizations, to better identify needed programs and services for these populations. Therefore, we urge OMB to establish the new MENA category in revising the standards.

Other concerns

In addition, we also support APIAHF's recommendations to change the terminology used for Native Hawaiian and Pacific Islander populations (removing the word "Other"), and ending the use of the term "principal minority race."

OMB's Review Process for Changes to the Standards

We, along with many of our partners, are concerned about the speed at which OMB has proposed to change and finalize these standards. These standards have great consequences for the communities we work with, and time for careful and thoughtful consideration would allow time for more constructive feedback for OMB. OMB started collecting public comments and feedback in 1993 about the changes that were made in the 1997 standards.

We urge OMB to allow a greater period of time for public consideration and input, and to specifically solicit and make available for public comment the input and recommendations from federal departments and agencies that have experience with the potential changes to the standards being considered, including the Census Bureau with its National Content Testing surveys and HHS with its implementation of its ACA section 4302 standards. Once finalized, we urge OMB to work closely with agencies to start implementing changes to the standards as quickly

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as possible. Some agencies took years to adopt the 1997 standards, well beyond the 2003 effective date.

OMB must require agencies to establish work plans for implementing any changes to the standards and establish a process for correcting deficiencies. We also urge OMB to continue to review these standards on a regular basis in future years. As demographics continue to change, it is important to provide more frequent opportunities to evaluate and improve data collection standards. For example, it would be appropriate to review these standards ahead of each decennial census. OMB must continue to issue statistical working papers examining statistical trends and agency actions in the areas covered by the standards, as well as convening workgroups, institutionalized to allow agency resource sharing.

We greatly appreciate this opportunity to provide comments on the race and ethnicity standards. If you have any questions or concerns, please feel free to contact me at isha@aapcho.org.

Thank you,

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