VIA ELECTRONIC SUBMISSION
April 28, 2017

Office of the U.S. Chief Statistician
Office of Information and Regulatory Affairs
Office of Management and Budget
1800 G Street, 9th Floor
Washington, D.C. 20503

Re: OMB–2016–0008 Proposals from the Federal Interagency Working Group for Revision of the Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (82 FR 12242)

To the Office of the U.S. Chief Statistician:

The Asian & Pacific Islander American Health Forum (APIAHF) appreciates the opportunity to submit additional comments on potential changes to the Office of Management and Budget's (OMB) Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity. APIAHF is the nation's leading health policy group working to advance the health and well-being of over 20 million Asians and Native Hawaiians and Pacific Islanders across the U.S. and its territories. Because we work with many different Asian and Native Hawaiian and Pacific Islander communities and populations in the U.S., we are acutely aware of the importance of these federal standards. Disaggregated data for Asian and Native Hawaiian and Pacific Islander populations beyond the 1997 OMB minimum race and ethnicity classifications are vital for federal departments and agencies to understand the needs of diverse communities and to effectively meet their obligations to serve the American people. We and our community partners rely on the race and ethnicity data collected by federal departments and agencies in all the work that we do.

Our comments primarily focus on the third issue for which OMB is seeking comments, regarding requiring additional minimum race and ethnicity classifications. We also comment on the proposals to combine the race and ethnicity questions, to create a distinct Middle Eastern and North African classification, and to update some of the terminology used for race and ethnicity classifications.

Additional Minimum Race and Ethnicity Reporting Categories

We strongly urge OMB to require ALL federal departments and agencies to collect, analyze, use, report, and disseminate disaggregated data for Asian and for Native Hawaiian and Pacific Islander populations. Specifically, we urge OMB to require agencies to follow the question format used in the U.S. Census's National Content Test (NCT) Final Report that resulted in optimal response rates (Figure 26, page 88). This includes check boxes for Chinese, Filipino, Asian Indian, Vietnamese, Korean, and Japanese under Asian, with

"Pakistani, Cambodian, Hmong, etc." listed as "for example" write-in groups, and check boxes for Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, and Marshallese, with "Palauan, Tahitian, Chuukese, etc." listed as "for example" write-in groups.[1]

It is critically important that disaggregated data for Asian and for Native Hawaiian and Pacific Islander (NHPI) populations are thoroughly collected and made more readily available. Greater disaggregation is essential for federal departments and agencies to understand and effectively serve diverse Asian and NHPI communities. Disaggregated data also help state agencies, community-based organizations, and researchers better identify the needs facing different populations. The 2015 National Content Test demonstrates that using the six most populous classifications, plus listing the next three most populous populations as "for example" write-in options, resulted in the greatest number of responses from these disaggregated groups. Therefore, all federal departments and agencies should be required to collect, analyze, use, report, and disseminate data at these more granular levels.

We also recommend that these categories should not be static. We have seen both extensive population growth in Asian & NHPI communities, as well as shifts in which communities are growing the fastest and in which regions. The new standards should account for future predictions. The Asian population is projected to grow 137% between 2015 and 2060, while the NHPI population is projected to grow 97%.[2] These are rates faster than any other race group. We urge OMB to require that these standards be regularly updated so that when Asian & NHPI groups change in relative size over time, new check boxes are added to reflect new populations. To ensure consistent data over time, the six groups in the NCT format should remain, but influxes of new groups due to global factors may mean additional check boxes may be necessary.

We encourage OMB to issue guidelines that make it clear these are minimum standards and encourage programs or surveys collecting state or other regional data to add additional check boxes and examples of groups that may have larger representation in those states or regions, but are not represented in the NCT standards. For example, states like Hawaii and Oregon have large groups of people residing under the Compact of Free Association (COFA) who come from the Marshall Islands, Federated States of Micronesia and Palau. While Marshallese are included in the standards, other populations from COFA jurisdictions, such as those from the islands of Chuuk and Pohnpei of the Federated States of Micronesia are not. Surveys and programs collecting information specifically from regions with high COFA populations should add those options under Native Hawaiian and Pacific Islander as such data can assist federal agencies in tailoring their programs to the target audiences served.

We wish to note the important responsibility the federal government plays in the lives of people originating from COFA jurisdictions. Under COFA, the United States has exclusive military access to the regions under the compact jurisdictions, which are of great strategic importance. In exchange, residents of those countries, may freely reside and work in the United States without a visa. The federal government has a particular responsibility to ensure the well-being of these communities, whom are often not counted in most federal surveys. By adding the detailed check boxes and write-

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[1] U.S. Census Bureau. 2015 National Content Test Race and Ethnicity Analysis Report. (2017), https://www.census.gov/programs-surveys/decennial-census/2020-census/planning-management/final-analysis/2015nct-race-ethnicity-analysis.html

[2] U.S. Census Bureau. Population Projections. (2015), http://www.census.gov/population/projections/data/national/2014/summarytables.html

in examples, community groups and government agencies serving these populations will be able to better understand and address their needs.

OMB should issue guidelines emphasizing that these standards are the minimum categories and federal agencies can and should continue to go beyond them in their data collection where practicable. There are times when making a larger number of race and ethnicity options available both provides important data and would not be burdensome. For example, including a greater number of race and ethnicity categories available as selections or checkboxes in online surveys or digital program intake forms would result in lower level burden than on paper surveys. Agencies collecting data online should be expected, therefore, to collect data beyond the minimum standards we are recommending, where practicable.

Examples demonstrate the importance of collecting disaggregated data

Research has shown that disaggregated data on Asian and on Native Hawaiian and Pacific Islander populations have an important and meaningful impact on how programs and services are made available to specific Asian and Native Hawaiian and Pacific Islander groups and in dispelling the "model minority" myth that all Asians are well-educated, wealthy, and healthy.[3] This harmful stereotype masks the social and medical consequences faced by Asians and Native Hawaiian and Pacific Islanders experiencing disparities.[4] For example:

- An analysis of U.S. Census and other available disaggregated data by the Asian American Center for Advancing Justice (now Asian Americans Advancing Justice) demonstrated differences in poverty, education, health insurance, and home ownership among Asian and Native Hawaiian and Pacific Islander groups.[5]
- In education, research reveals that many Asian groups have lower achievement levels than their White peers, which is not apparent at the aggregated group level.[6] A Washington state analysis of disaggregated data found large differences in income and eligibility for free and reduced meals, discipline, absences, and college enrollment among Asian and Native Hawaiian and Pacific Islander groups.[7]
- The U.S. Department of Education has found that while 67% of Asians, 18-24 years old, were enrolled in college, there is a 55 percentage point difference between Chinese enrolled at a 75% percent rate and Bhutanese at 20%, with other groups varying widely as well.[8]

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[3] Linshi, J. The real problem when it comes to diversity and Asian-Americans. Time. Oct 14, 2014, http://time.com/3475962/asian-american-diversity/

[4] Yi, SS, Kwon SC, Sacks R, Trinh-Shevrin C. Persistence and health-related consequences of the model minority stereotype for Asian Americans. Ethn Dis, 2016;26(1):133-138

[5] Asian Pacific Center for Advancing Justice. A Community of Contrasts Asian Americans in the United States, (2011), http://www.advancingjustice.org/pdf/Community_of_Contrast.pdf

[6] Pang VO, Han PP, Pang JM. Asian American and Pacific Islander students: Equity and the achievement gap. Educational Researcher. 2011;40(8):378-389

[7] ETS and CARE, The Hidden Academic Opportunity Gaps Among Asian Americans and Pacific Islanders: What Disaggregated Data Reveals in Washington State (2015), accessed at http://care.igeucla.org/wp-content/uploads/2015/09/iCount-Report_The-Hidden-Academic-Opportunity-Gaps_2015.pdf

[8] Bairu, G. Forum Guide to Collecting and Using Disaggregated Data on Racial/Ethnic Subgroups. National Forum on Education Statistics, U.S. Department of Education (2016), https://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=NFES2017017

- The Center for American Progress found a $50,000 difference between the Asian group with the highest average income and the group with the lowest.[9]
- APIAHF analysis of the National Health and Nutrition Examination Survey revealed that, overall, about 20% of Asian children in the U.S. were overweight. However, when we examined data for disaggregated Asian groups, we found that Filipinos (29%) and Southeast Asians (27%), including individuals of Indonesian, Malaysian, and Thai descent, had a significantly higher prevalence of overweight children.[10]
- A National Institutes of Health study found that, while overall cancer mortality for Asian and Native Hawaiian and Pacific Islander men was lower than non-Hispanic White men, cancer mortality rates were higher for Samoan (293.9 per 100,000 persons) and Native Hawaiian men (263.7 per 100,000 persons) than for non-Hispanic White men (241.3 per 100,000 persons) and for all other Asian groups.[11]
- Breast cancer rates vary widely among women by disaggregated Asian group and immigration status. While Asians as an aggregated group have some of the lowest rates in the United States; one study found breast cancer rates are higher among foreign-born Chinese women and Filipina women than White women.[12]
- The University of Michigan Institute for Social Research found that Samoans and Tongans had higher rates of hypertension than Californians at large, smoked at about four times the rate of Californians, were less likely to have health insurance, and used available health care services at lower rates, relying heavily on emergency room care.[13]
- A review of Asian and NHPI involvement in the justice system by the Substance Abuse and Mental Health Services Administration found that Laotians have the highest Asian and NHPI incarceration rates as a percent of their population, while Filipinos have the largest subgroup of Asian American incarcerated adult males.[14]

These examples demonstrate the need for disaggregated data to identify and meet the needs of diverse Asian and Native Hawaiian and Pacific Islander communities. Moreover, state agencies, as well as community-based organizations, also need disaggregated data to develop focused interventions and allocate resources appropriately to address the varying needs of Asian and Native Hawaiian and Pacific Islander groups. For example:

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[9] Center for American Progress. State of Asian Americans and Pacific Islanders (2014), https://cdn.americanprogress.org/wp-content/uploads/2014/08/AAPI-IncomePoverty.pdf

[10] Asian & Pacific Islander American Health Forum, Obesity and Overweight Among Asian American Children and Adolescents (2016), http://www.apiahf.org/resources/resources-database/obesity-and-overweight-among-asian-american-children-and-adolescents

[11] Miller BA, Chu KC, Hankey BF, Ries LA. Cancer incidence and mortality patterns among specific Asian and Pacific Islander populations in the U.S. Cancer Causes Control. 2008;19(3):227–256

[12] Gomez, SL, Quach T, Horn-Ross PL, Pham JT, Cockburn M, Chang ET, Keegan THM, Glasser SL, Clarke CA. Hidden breast cancer disparities in Asian women: Disaggregating incidence rates by ethnicity and migrant status. Am J Pub Health. 2010;100(S1): S125-S131

[13] Panapasa, S. Health Disparities in Two Pacific Islander Populations in California (2016), http://www.ns.umich.edu/new/releases/24748-survey-finds-health-disparities-in-two-pacific-islander-populations

[14] A Snapshot Of Behavioral Health Issues For Asian American/Native Hawaiian/Pacific Islander Boys And Men: Jumpstarting An Overdue Conversation. Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. 2016. http://store.samhsa.gov/shin/content/SMA16-4959/SMA16-4959.pdf

- A community college in California used disaggregated data to improve its design of programs for the college's diverse Asian and Native Hawaiian and Pacific Islander populations.[15]
- A community-based organization, Asian Americans for Community Involvement in San Jose (AACI), learned through disaggregated data that Vietnamese women were at the greatest risk for cervical cancer, but had the lowest cervical cancer screening rates among Asian groups. AACI was then able to secure grant funding and collaborate with the University of California San Francisco to implement a culturally competent cervical cancer education program that increased cervical cancer screening among Vietnamese women.
- When New York City conducted an anti-smoking campaign, overall smoking rates dropped but rates among Asian Americans did not. A study using data from the REACH US Risk Factor Survey was able to identify differences among trends in different Asian groups, including gender trends. For example, Korean men had smoking rates twice that of Chinese men and three times that of Asian Indian men.[16] Asian American advocacy groups and providers were able to use these data to work with the city Department of Health to better target their anti-smoking efforts.

When OMB last updated these standards in 1997, it required that federal departments and agencies collect and report separate data on Asians from Native Hawaiians and Pacific Islanders, rather than as a combined group. In doing so, and in examining other questions about race, OMB made numerous references to changing demographics and the need for data on smaller groups, such as Native Hawaiians, that were facing different experiences than the aggregated Asian and Pacific Islander classification revealed.[17] For example, OMB noted differences in educational outcomes, income, and poverty between the two groups, not unlike the research cited above. It also considered the statistical methodology challenges with collecting data on smaller groups, but decided that disaggregation was both feasible and justified. It is for these same reasons that the standards should now be updated to require collection of disaggregated Asian and Native Hawaiian and Pacific Islander data.

The collection, analyses, use, reporting, and dissemination of disaggregated race and ethnicity data has increased at the federal level.

OMB's 2012 Statistical Policy Working Paper found that it was common for federal departments and agencies to collect, analyze, use, report, and disseminate disaggregated Asian and Native Hawaiian and Pacific Islander data in meaningful ways:

- Data from the Census 2010 Summary File 2 identify 47 Asian and 43 Native Hawaiian and Pacific Islander groups; the 2010 decennial census included disaggregated classifications for 6 Asian groups and 4 Native Hawaiian and Pacific Islander groups.

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[15] Nguyen BD, Nguyen MH, Nguyen TK. Advancing the Asian American and Pacific Islander Data Quality Campaign: Data disaggregation practice and policy. Asian American Policy Rev. 2014;24:55-67

[16] Li, Shijan et al. Smoking Among Asian Americans: Acculturation and Gender in the Context of Tobacco Control Policies In New York City. Health Promot Pract. 2013; 14: 18S.

[17] Office of Management and Budget. Recommendations from the Interagency Committee for the Review of the Racial and Ethnic Standards to the Office of Management and Budget Concerning Changes to the Standards for the Classification of Federal Data on Race and Ethnicity. 62 Fed. Reg. 36874-36946, July 7, 1997, https://www.gpo.gov/fdsys/pkg/FR-1997-07-09/pdf/97-17664.pdf

- The American Community Survey utilizes multi-year estimates to provide more detailed information about race and ethnic groups.
- The Department of Labor uses the Current Population Survey to collect and releases annual information on labor trends for specific Asian groups including Asian Indians, Chinese, Filipinos, Japanese, Koreans, and Vietnamese. They survey uses multi-year estimates to provide more detailed information.
- The National Health Interview Survey asks specifically about 6 Asian groups and 3 Native Hawaiian and Pacific Islander groups. The survey utilizes oversampling and multi-year pooling techniques to report on smaller groups
- The Department of Health and Human Services (HHS) has recommended using 6 Asian and 3 Native Hawaiian and Pacific Islander groups in federal health surveys; HHS' implementation guidance states that "While data alone will not reduce disparities, it can be foundational to our efforts to understand the causes, design effective responses, and evaluate our progress."[18]
- The HHS Office of the National Coordinator for Health Information Technology 2015 certification requirements for health information technology requires that electronic health records have the capability to use the Centers for Disease Control and Prevention (CDC) Race and Ethnicity Code Set, which contains 921 detailed races and ethnicities.[19]

The federal government has prioritized the use of disaggregated data.

The federal government has consistently recognized that racial and ethnic disparities, such as in health care, are some of the greatest public policy problems facing our country, creating both a human and economic toll. Many agencies have identified the lack of consistent, accurate data as a major barrier to addressing expensive disparities. By adopting the Census NCT optimal question format and requiring that agencies use it as a threshold for data collection, OMB would ensure the level of data consistency that currently does not exist within the federal government, but is necessary to achieving equity in public policies and government services.

For example, the CMS Equity Plan for Improving Quality in Medicare, the Centers for Medicare & Medicaid Services Office of Minority Health states that the "comprehensive patient data, including race, ethnicity, language… are required to plan for quality improvements, and to address changes among the target populations over time."[20] The CMS National Quality Strategy, for goals 1 and 6, includes the collection of quality race and ethnicity data in its foundational principles.[21] The 2018

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[18] U.S. Department of Health and Human Services, Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status (2011), accessed at https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status

[19] Office of National Coordinator for Health Information Technology, 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications; Final Rule, 80 Fed. Reg. 62602-62759, October 16, 2015, https://www.gpo.gov/fdsys/pkg/FR-2015-10-16/pdf/2015-25597.pdf

[20] Centers for Medicare & Medicaid Services Office of Minority Health. The CMS Equity Plan for Improving Quality in Medicare. (2015), https://www.cms.gov/About-CMS/Agency-Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf

[21] Centers for Medicare and Medicaid Services. CMS Quality Strategy. (2016), https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Quality-Strategy.pdf

Medicare Final Call Letter notes that, "CMS also expects MAOs to analyze enrollee data to identify disparities among their enrollees and undertake quality improvement and outreach activities to increase enrollee engagement so that appropriate care, including preventive services, can be provided to enrollees who have been identified as having worse health outcomes."[22]

The Department of Education has provided grants to state education agencies to collect and analyze disaggregated data on English learner Asian and Native Hawaiian and Pacific Islander groups.[23] In response to a Request for Information on the use of disaggregated Asian and Native Hawaiian and Pacific Islander student data in school planning and programming, the Department of Education received over 700 comments, overwhelmingly in support of data desegregation.[24]

The collection, analyses, use, reporting, and dissemination of disaggregated race and ethnicity data is also increasingly common at the state level.

Strong standards that include disaggregated racial classifications also are emerging at the state level. Oregon requires data collection and intake forms to include 9 Asian and 3 Native Hawaiian and Pacific Islander groups. In addition, all covered programs must report biannually on progress, challenges and plans for addressing challenges in implementing the standards.[25] California recently passed a law strengthening its data disaggregation requirements for its Department of Public Health, Department of Fair Employment and Housing, and Department of Industrial Relations, adding 8 Asian and 2 Pacific Islander groups.[26] New York City passed a resolution in 2016 requiring agencies collect data on the city's top 30 ethnicities and language speakers.[27] The Hawaii Department of Education reports on students and teachers using 7 Asian and 7 Native Hawaiian and Pacific Islander groups.[28] This year, the state of Washington's Healthy Youth Survey started collecting disaggregated data on Asian students, to reflect its diverse and growing population.[29]

Oregon, in its 2013 legislation setting out standards requiring collection of detailed race and ethnicity data made the following findings:[30]

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[22] Centers for Medicare and Medicaid Services. Announcement of Calendar Year (CY) 2018 Medicare Advantage Capitation Rates and Medicare Advantage and Part D Payment Policies and Final Call Letter and Request for Information. (2017), https://www.cms.gov/Medicare/Health-Plans/MedicareAdvtgSpecRateStats/Downloads/Announcement2018.pdf

[23] U.S. Department of Education, Asian American and Pacific Islander Data Disaggregation Initiative Frequently Asked Questions, http://www2.ed.gov/programs/d2/faq.html

[24] U.S. Department of Education, Request for Information To Gather Technical Expertise Pertaining to the Disaggregation of Asian and Native Hawaiian and Other Pacific Islander Student Data and the Use of Those Data in Planning and Programmatic Endeavors. 77 Fed. Reg. 26531-26534, May 2, 2012, https://www.gpo.gov/fdsys/pkg/FR-2012-05-04/pdf/2012-10835.pdf

[25] Oregon Health Authority Office Of Equity And Inclusion, Race, Ethnicity, Language, And Disability Demographic Data Collection Standards, http://www.oregon.gov/oha/oei/policyprocedures/Race%20Ethnicity%20Language%20Disability%20Data%20Collection%20Standards.pdf

[26] California Assembly Bill 1726 (2016), http://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201520160AB1726

[27] Intro 251-A. New York City Council, http://legistar.council.nyc.gov/LegislationDetail.aspx?ID=1709693&GUID=DF6A0998-A600-43B1-96FD-8C3F91F3A7B5

[28] Hawaii State Department of Education, 2015 Superintendent's 26th Annual Report Data Tables (2015), http://arch.k12.hi.us/PDFs/state/superintendent_report/2015/2015AppendixCDataTbl.pdf

[29] Washington State Commission on Asian Pacific American Affairs, 2016 Healthy Youth Survey to begin collecting disaggregated data on Asian American youth, October 14, 2016, http://capaa.wa.gov/2016-healthy-youth-survey-to-begin-collecting-disaggregated-data-on-asian-american-youth/

[30] HB 2134. Oregon Legislative Assembly. 2013 Regular Session, https://olis.leg.state.or.us/liz/2013R1/Downloads/MeasureDocument/HB2134

- data collection standards used by state agencies are inconsistent and insufficient to adequately assess the status and needs of Oregon's communities of color, and immigrant and refugee communities;
- inadequate data collection standards make it difficult to analyze how race, ethnicity and language impact individual and community health, making services more expensive and less effective in addressing community needs;
- improved data collection supports more effective interventions to address persistent disparities and protects public entities from liabilities arising from violation of civil rights laws;
- improvements in data collection standards are needed to ensure state of the art, efficient, uniform and consistent data collection by race, ethnicity and preferred language…

New York City's legislative findings included in the 2016 resolution state "…Existing data often do not provide City government and others with full information about the demographics of the individuals served by City agencies. Detailed information about the ancestral/ethnic and linguistic makeup of an agency's client population can help agencies and community organizations to make ongoing adjustments to their outreach and service delivery models. This legislation will help the City and its partners to better understand and serve residents of all backgrounds and identities." [31]

If OMB adopts standards that require the collection of disaggregated data, state and local governments that already require this collection will see reductions in complexity of implementation, both as they benefit from being able to follow the best practices laid out by OMB and because their data systems will match the federal government's.

We also wish to note that national data provides insights that state and local data do not, and that state efforts cannot substitute for federal disaggregation standards. It is important to understand trends of specific populations throughout the entire country so that targeted efforts can be undertaken to assist them. For example, Kevin Nadal, professor of psychology at the City University of New York and President of the Asian American Psychological Association, testifying in favor of New York City's data standards bill, stated that the "disaggregated data that does exist tends to focus on Asian Americans on the West Coast, which are often not generalizable to Asian Americans on the East Coast."[32]

The lack of disaggregated data has hampered efforts to further the public good

We have consistently heard from our partners working directly to reduce health disparities and improve public health about how the lack of disaggregated data from federal surveys and programs has hampered their efforts. The following examples illustrate these experiences:

> Currently, there is no health data available for the Vietnamese community in the Gulf Coast, nor they are being collected by the local health department. When BPSOS, a community based organization working in Mississippi and Alabama, applied for funding to address the

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[31] Intro 251-A. New York City Council, http://legistar.council.nyc.gov/LegislationDetail.aspx?ID=1709693&GUID=DF6A0998-A600-43B1-96FD-8C3F91F3A7B5

[32] Kevin Nadal. Testimony before the New York City Council - Joint Hearing of the Governmental Operations and General Welfare Committees. May 11, 2015, http://legistar.council.nyc.gov/View.ashx?M=F&ID=3754113&GUID=2543CD89-617C-4695-87B1-B7CEC8D73225

health issues and needs in the local Vietnamese community, they were forced to rely on anecdotal and self-reported information as evidence. In many cases, their proposals were rejected because they could not provide statistics and data to substantiate the issues and problems. Their most recent proposal for funding to address cardiovascular diseases (education, prevention and treatment) was rejected because they did not have any relevant data for Vietnamese Americans in Mobile County. Furthermore, because of lack of critical health data, they are often hesitant to apply for funding opportunities even when they know issues are rampant.

Chien-Chi Huang, Executive Director, Asian Women for Health, reports that her organization has been unable to get funding to provide the much needed cancer prevention and screenings services for the community because of the lack of data on the populations they serve. Particularly, Asian Women for Health provides services around cancer, the leading cause of death for Asians, but data is rarely collected or reported in a way that allows the organization to demonstrate its needs quantitatively. The organization has conducted focus groups in Chinese, Vietnamese, and South Asian communities that have shown that culture and language barriers are preventing them from accessing services. They have found that there are differences among Asian groups. Asian Women for Health would like to be able to fill these needs, but is unable to, because data does not exist to quantitatively prove their needs.

Karen E. Kim MD, a professor of Medicine and Director of the Center for Asian Health Equity at the University of Chicago has also found the lack of disaggregated data a major impediment. Because there is no nationally available data suitable on the colorectal cancer screening among Korean Americans, Dr. Kim was forced to use local data in a grant submission. The grant was rejected, specifically including comments that the population appeared to small, an inaccurate assertion that could have been countered if national disaggregated data was available.

The New Mexico Asian Family Center has had to rely on disparate data sources to make their case to funders. While they have worked with their state department of health to make improvements, such as being able to identify Hispanic Asians, they have primarily relied rely on community members to assist in pulling together data sources. Unless they are able to pull together numbers, they are not able to get funding for their direct service work.

HOPE Clinic in Houston, TX wants to better understand cancer data on Asian groups in order to better serve their clients and improve health care outcomes. Yet because the data they have found usually does not disaggregate Asian groups, they have had trouble identifying the specialized issues faced by specific groups, particularly around specific types of cancer. They have started to sample their own client intake data, but because it is limited to their service area, it is limited. While they would be able to have broader conclusions from broader data, they have been able to bring more resources to their community by highlighting trends in their own data.

Than Tan, a Seattle Times columnist, has covered the importance that disaggregated data has in education.[33] In describing a report that failed to recognize opportunity gaps faced by different Asian populations, Tan quotes James Hong of the Vietnamese Friendship Association. "Funders might see this and think Asian students are doing great. Reporting bad data is really harmful to communities." Tan also points to the example of the University of Washington's decision to reverse its Southeast Asian recruiting efforts, after it incorrectly assumed that population had achieved parity with Whites, when presented with evidence to the contrary.[34]

It is difficult for groups and agencies working to provide services to or conduct research on specific Asian & NHPI populations to receive funding without sufficient data that can be used to justify the need for that work. In the experience of our partners and our own experience, access to both private and public resources are constrained for groups because the data often does not exist. For example, APIAHF analysis of CDC funding profiles found that only 24 of the agency's 8,679 available grants were awarded to organizations focusing on Asian and NHPI communities.[35]

Minimizing cost and burden and factors in feasibility

The notice requests comments on the costs and benefits of requiring federal agencies to collect disaggregated data. The important benefits to government programs, communities, researchers, and advocates, described above, outweigh costs and burdens to implementing agencies. Indeed, we echo the comments of Asian Americans Advancing Justice | AAJC that NOT collecting disaggregated data would result in a burden to communities, researchers, advocates and policy makers.

For example, when the state of Oregon began implementing its standards, the Oregon Department of Human Services undertook a comprehensive review of its data collection systems, including an analysis of whether or not the datasets collected the newly required categories, identified the challenges in implementation and laid out steps towards addressing the challenges.[36] The federal government could follow a similar prioritization process. It could also issue guidelines that permit agencies to implement the new disaggregation standards during other system upgrades, minimizing the burdens that would be produced from modifying databases for the sole purpose of following the standards.

Technical assistance can support implementation of changes.

We also trust that OMB can work with agencies to provide assistance to support implementation of any changes to these standards. It took several years to adopt the 1997 changes to the standards and we expect a similar incremental adoption of these proposed changes. Adding additional disaggregated categories also should not be viewed in isolation. If the other working group recommendations to combine the race and ethnicity question and create a new MENA category are adopted, then many federal departments and agencies would already be making changes to their

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[33] Tan, Thanh. How to fight Asian stereotypes: Disaggregate data on Asians. The Seattle Times. March 25, 2016. http://www.seattletimes.com/opinion/how-to-fight-asian-stereotypes-disaggregate-data-on-asians/
[34] Vo, Tony. Commentary: All eyes on UW, Southeast Asian recruiter position reinstated. International Examiner. August 5, 2014. http://www.iexaminer.org/2014/08/uw-southeast-asian-recruiter-position-reinstated/
[35] Centers for Disease Control and Prevention. Grant Funding Profiles. 2017. https://wwwn.cdc.gov/FundingProfilesApp/
[36] Oregon Department of Human Services. Report to the Oregon Legislature: Race, Ethnicity, Language and Disability (REAL+D) Data: House Bill 2134 Baseline Assessment. (2014), library.state.or.us/repository/2014/201412311144213/

data collection and reporting systems. Adding disaggregated data checkboxes would not present as a substantial incremental cost or burden when all these changes are made together.

As we noted above, Oregon has actively supported the implementation of its new race and ethnicity data standards, which included a series of community meetings. One result is that the state is updating its Medicaid systems first, before moving on to other enrollment systems, as they found Medicaid enrollees are mostly also enrolled in other programs. They are also focused on future cost savings by combining eligibility systems into a unified data collection platform, avoiding the costs of keeping multiple systems updated.

In considering how to best implement the new standards, OMB should follow Oregon's example and include community input for prioritizing which databases OMB should proactively support adoption of these changes. Community groups, as well as researchers, policy makers and state and local agencies, have significant expertise to help the federal government identify which surveys and data collections would provide the most benefit if they collected additional disaggregated data.

We recommend, in terms of prioritization and minimization of burden and cost, the government apply the new Census National Content Test optimal question format to the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys when they are next updated. At least four of the most common surveys, the health plan commercial, health plan Medicaid, clinician and group, and hospital CAHPS surveys use the current OMB standards but do not ask for disaggregated Asian or NHPI groups. Such knowledge is important both for individual providers, to ensure their services are available to all groups, as well as for researchers, government agencies and advocates wishing to understand whether the diverse needs of Asian and NHPI subgroups are being met by providers. Since these CAHPS surveys are on a regular cycle for updates, the additional disaggregated categories should be added in the next updates.

We also would prioritize collection and reporting of the Census National Content Test optimal question format for the following surveys and data collection instruments, which, from our experience and that of researchers working on Asian & NHPI issues, would be important for identifying trends in specific groups:
- All Census administered surveys, such as the American Community Survey and the Current Population Survey.
- The National Health Interview Survey, which currently already collects data on six Asian groups but only three NHPI groups.
- The National Health and Nutrition Examination Survey
- The Integrated Postsecondary Education Data System
- The Youth Risk Behavior Surveillance System
- The National Notifiable Disease Surveillance System
- The Pregnancy Risk Assessment Monitoring System
- The National Crime Victimization Survey

Current burdens fall on community groups

Currently, because of the lack of disaggregated data for the populations they serve, many community groups undertake time consuming and expensive data collections of their own. Because these groups typically lack the expertise on data issues, they must put greater relative resources into

data collection efforts than government agencies that are already engaging in data collection. OMB should consider the reduction in the burden on community based organizations when considering new requirements for government agencies.

For example, Dr Tsu-Yin Wu, a professor with Eastern Michigan University, related this experience: In Michigan, when I first started to study cancer screening practices among the Asian Pacific American community, I wanted to know which groups are more at risk. The data we had at that time from the Michigan Department of Community Health only contained Asian Americans as in one group. They were claiming that we had too small of the sample so they cannot separate into subgroups. Asian Americans are the only groups (along with Latino) in the 2010 census have "increased" in population. So our Healthy Asian Americans Project ended up collecting our own data during health fairs. Although we're making small incremental progress, it's time consuming and also costly for us to take on this tremendous task.

In Illinois, the Asian Health Coalition found the lack of disaggregated data masks the diversity of health outcomes, disease burdens, and health disparities within and across the Asian American and Pacific Islander (AAPI) population. In their words, "Having information on the health status and needs of specific subgroups would allow policymakers, health planners, and community-based organizations (CBOs) to develop more effective and targeted health programs and policies, thereby improving health outcomes and reducing disparities within each distinct AAPI community." In response, they conducted a comprehensive assessment of the health needs, determinants of morbidity and mortality, and health care access patterns of three AAPI communities in Chicago. The survey found public health programs were not tailored to meet the cultural and linguistic needs of many AAPI communities.[37] The survey consumed around $100,000 in resources and the equivalent of two dedicated full time employees.

InterIm CDA works with AAPI populations in Seattle and had been frustrated in trying to relay their client's concerns about public safety to city and county officials, who often assumed model minority stereotypes about the conditions of AAPI neighborhoods. Because they lacked any disaggregated government data, InterIm CDA put significant resources into conducting a qualitative and quantitative survey of residents, which showed the diverse concerns from different ethnicities and language speakers.[38] These results convinced public safety officials to focus on more culturally competent practices, such as addressing concerns about calling 911 and sanitation improvements[39]. In addition, InterIm CDA received funding to conduct additional surveys in future years.

Shahana Hanif, testifying in favor of the New York City data standards bill on behalf of CAAAV: Organizing Asian Communities stated that in order to identify trends and needs in the city's Asian population in housing developments. Because the data did not exist, they

[37] Asian Health Coalition of Illinois. Chicago Asian Community Surveys: A Comprehensive Report. (2010), . https://www.dropbox.com/s/4fpr9ym7i6wh8c9/AHC_CACS_2010.pdf?dl=0
[38] Public Safety Matters 2016 Chinatown-International District Public Safety Survey. Interim CDA. 2016. https://drive.google.com/file/d/0BzjJ87bZaDLQRjlzNDlYLXlwMW8/view
[39] Mayor's Chinatown/International District Public Safety Action Plan. City of Seattle. July 2016. http://murray.seattle.gov/wp-content/uploads/2016/07/C-ID-Public-Safety-Mayors-Action-Plan-07-01-2016.pdf

used last names in voter files and door knocking, to assess trends. Hanif testified that disaggregated data would have enabled them to better serve the community.[40]

Community groups that provide health services, such as clinics, will also benefit from the enhanced standards. Many health centers that provide services to diverse populations already track detailed origin, race, and ethnicity data during their client intake process. For example, when Asian Health Services in Oakland, CA started tracking their clients' health outcomes by detailed race, because information was not otherwise available on local health trends at that level, they found higher smoking rates for Korean and Vietnamese immigrant men, higher hepatitis B rates for Chinese and Vietnamese patients, and high levels of diabetes among their overall Chinese population. However, health centers do not have a standardized set of detailed checkboxes or guidelines for guidance and therefore different health centers may not collect race and ethnicity data the same way. While the OMB standards do not apply to the type of data that federally qualified health centers report, they will, along with guidance, provide a resource for these centers.

Reduction in burden on survey tabulation and analysis

We acknowledge that adding additional check boxes may lead to some initial upfront costs in system upgrades and new paper in non-digital data collection. Yet, there is reason to believe the federal government will save money in the long term by avoiding the costs already associated with the current standards and lack of detailed data collection.

Some surveys have fill-in-the-blanks options for race and ethnicity. Adding check boxes not only encourages more self-identification, as found in the Census National Contest Test, but it reduces the costs in determining the intent and correct categorization of potentially unclear or illegible write in responses. More check boxes that increase the likelihood that respondents will see categories that they identify with, such as the top six Asian and NHPI populations that we recommend OMB adopt, reduce the likelihood that they will use write-in answers. For example, Ninez Ponce, PhD, MPP, Principal Investigator, California Health Interview Survey (CHIS), University of California Los Angeles Center for Health Policy Research, told APIAHF the following, "for a diverse state as California, expanding racial/ethnic categories in surveys acknowledges a greater range of cultural identities, increases the quality of representation in surveys, AND facilitates data processing savings. For CHIS, it actually costs more to code open-ended 'Other specify' responses than to create pre-specified response categories for race and ethnicity."

Furthermore, standardizing the collection of detailed race and ethnicity data will provide consistency across federal data collection, reducing costs and complexities in comparing responses across programs and surveys. Currently, there is no standard format for which detailed checkboxes agencies should utilize, adding complications to researchers using multiple datasets in studies. Requiring a minimum six checkboxes, along with a write-in with consistent examples, will increase reliability of federal race and ethnicity data. For national standardization and consistency, we also encourage OMB to issue guidance to state and local agencies that are not subject to federal government standards (such as state agencies administering vital records) recommending they follow the new standards.

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[40] Hanif,S. Testimony before the New York City Council - Joint Hearing of the Governmental Operations and General Welfare Committees. May 11, 2015, http://legistar.council.nyc.gov/View.ashx?M=F&ID=3754113&GUID=2543CD89-617C-4695-87B1-B7CEC8D73225

Federal agencies and OMB have the potential to consider methods of tabulating survey and other data collections in ways that further reduce any burdens. For example, New York City is implementing its standards by using one standardized race and ethnicity data collection form, both for written and digital data collections. This form is processed by the mayor's office as a way to centralize reporting processes and reduce the implementation costs for agencies required to collect detailed data. Because there is one form with one method of processing data, costs are less. The city plans to have its standards fully implemented within a year. While this method may be difficult to replicate for the entire federal government, it demonstrates that there are creative processes OMB can consider when evaluating any burdens of requiring collection of disaggregated data.

Data collection supports compliance with federal civil rights laws.

In addition, we echo the comments of the Leadership Conference on Civil and Human Rights that our nation must have the most effective and updated tools to investigate and enforce civil rights laws. Discrimination takes an uncountable toll on human lives in everything from housing to voting rights to health care. By collecting detailed data, federal agencies will be better equipped to protect the civil rights of our increasing diverse country.

In summary, 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 data for Asian groups and for Native Hawaiian and Pacific Islander groups using the U.S. Census Bureau 2015 National Content Testing optimal question format for disaggregated classifications.

Combined Question to Collect Race and Ethnicity Data

The Census Bureau's 2015 National Content Test provides evidence for maximizing the response rates to race and ethnicity questions through changes in phrasing. Asians and NHPIs self-identified more often when they were posed a question that presented combined race and ethnicity.[41] Based on the results of the 2015 National Content Test, we support the combined race and ethnicity question because it increases the rates of Asian and NHPI participation and self-identification. We also support the combined question because it appears to, broadly, better align with people's preferences and concepts of identity.

However, we urge OMB to also issue complementary guidance on the wording and instructions accompanying the race and ethnicity question. Respondents should clearly understand they may check as many boxes as they feel they personally identify with. OMB should also consider advising agencies that different people may interpret the words "race" and "ethnicity" differently and that question wording should be as inclusive as possible.

A Distinct Middle Eastern and North African Classification

We echo the comments of the National Network for Arab American Communities in favor of establishing a new Middle Eastern and North African (MENA) group and reporting category.

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[41] U.S. Census Bureau, 2015 National Content Test Preliminary Results on Race and Ethnicity (2016), http://www2.census.gov/cac/nac/meetings/2016-10/2016-nac-jones.pdf

Currently, people from this population must select one of the current five race categories, regardless of their how they self-identify. The MENA population has a distinguishable community and background that warrants identification in federal surveys. As the 2015 Census National Content Test showed, many people who are of MENA origins select the category when given the option, suggesting a significant population that has not been able to identify itself. 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 identify instances of discrimination, better address hate crimes, and prioritize health and social services programs. **Therefore, we urge OMB to establish the new MENA category in revising the standards.**

Updates to Terminology Used for Race and Ethnicity Classifications

We strongly urge OMB to change the terminology for Native Hawaiian and Pacific Islander populations. We strongly urge changing the terminology in the standards to "Native Hawaiian and Pacific Islanders" rather than the current "Native Hawaiian and Other Pacific Islander." We developed this position with the Native Hawaiian & Pacific Islander Alliance.[42] This terminology reflects the common wording used by the NHPI community. We also support ending the use of the term "Guamanian" and using "Chamorro".

We support the removal of the term "Far East" from the standards. This term is not in common use, many consider it offensive and it should not be used in any federal data collection.

We support the proposal to end the use of a "principal minority race" as a designation in the standards. As the diversity of the U.S. population continues to increase, agencies must adopt standards of reporting out at least all the OMB minimum categories, unless unable to for statistical significance or privacy and confidentiality reasons, in which case agencies should clearly and publically justify such exclusions. When combined, Asians and NHPI are the "majority" populations in the state of Hawaii. Communities of color are the majority populations in the state of California. Demographics have significantly changed over the past twenty years. Asians are the fastest growing race group in the United States, with 43% growth between the 2000 and 2010 Censuses. [43] The difference in changes over time among Asian groups illustrates both the need for disaggregated data and the need for reconsideration of terminology. For example, between the two Censuses, the Bhutanese population experienced a nearly 1000% increase while the Japanese population decreased. The NHPI population also grew rapidly between 2000 and 2010 at 35%, more than three times faster than the U.S. population as a whole.[44]

Best Practices in Collecting Race and Ethnicity Data
In addition to collecting higher quality data, we urge OMB and all agencies involved in data collection to continue to follow best practices in stakeholder engagement and confidentiality and privacy. When collecting this data, agencies would be best served to partner with community

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[42] Native Hawaiian & Pacific Islander Alliance and the Asian & Pacific Islander American Health Forum, Guidance on the Classification of Native Hawaiian and Pacific Islanders (2008),
http://www.apiahf.org/sites/default/files/NHPI_Healthbrief0131_2008.pdf
[43] U.S. Census Bureau, 2010 Census Briefs, The Asian Population: 2010 (2012),
https://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf
[44] U.S. Census Bureau, 2010 Census Briefs, The Native Hawaiian and Other Pacific Islander Population: 2010 (2012),
http://www.census.gov/prod/cen2010/briefs/c2010br-12.pdf

groups with connections to diverse populations in order to ensure respondents understand the purpose of the data collection. Community groups are able to explain the importance of race and ethnicity data. In addition, data collections should have clear information on the purpose and uses for which the data will be used, as well as descriptions of the steps agencies take to protect respondent privacy and confidentiality.

Thank you again for the opportunity to provide comments on the proposed changes to the standards. Please direct any questions about our comments to Amina Ferati, Senior Director of Government Relations & Policy (aferati@apiahf.org) or Ben D'Avanzo, Senior Policy Analyst, at bdavanzo@apiahf.org.

Sincerely,

Kathy Ko Chin
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