AAPCHO
ASSOCIATION OF ASIAN PACIFIC
COMMUNITY HEALTH ORGANIZATIONS

April 15, 2023

Shalanda Young, Director
Office of Management and Budget
725 17th Street NW
Washington, DC 20503

Bob Sivinski, Chair
Interagency Technical Working Group on
Race and Ethnicity Standards
1650 17th Street NW
Washington, DC 20500

RE: Initial Proposals For Updating OMB's Race and Ethnicity Statistical Standards (OMB-2023-0001)

Dear Director Young and Chair Sivinski,

On behalf of the Association of Asian Pacific Community Health Organizations (AAPCHO), thank you for the opportunity to comment on the *Initial Proposals For Updating OMB's Race and Ethnicity Statistical Standards* as published in the Federal Register on Friday, January 27, 2023. We strongly support the steps OMB and the Interagency Technical Working Group on Race and Ethnicity Standards (Working Group) are taking to better understand the nation's diverse communities, which includes expanding race and ethnicity data collection standards and requirements to get a true picture of the needs and challenges they face. We support the Initial Proposal and have recommended improvements that are outlined below on how to improve final updates to OMB Statistical Policy Directive 15 for the communities AAPCHO's members serve.

AAPCHO represents 34 community-based health organizations, 29 of which are Federally Qualified Health Centers (FQHCs), that provide care to more than 630,000 patients annually. Our members are dedicated to promoting the health status of medically underserved Asian Americans (AAs), Native Hawaiians, and Pacific Islanders (NH/PIs) in the United States, the U.S. territories, and the Freely Associated States. The primarily low-income AA and NH/PI patients and communities our members serve rely on a number of supports to maintain their health and well-being and to live as critical members of our communities and economies.

As you are aware, data disaggregation has long been a top issue for the broad AA and NH/PI civil rights advocacy networks across every issue area, including AAPCHO and our member community health centers. The proposed changes to government-wide data collection and reporting standards in the Initial Proposal, along with the recommendations we make below, will have significant positive outcomes for AA and NH/PI communities as well as federal, state, and local government agencies and non-government organizations who work in them.

AAPCHO urges the OMB Working Group to design their revision to Directive 15 to permit for full recognition of underserved and hard-to-count communities and to implement the new rule alongside guidance that enables agencies to quickly and substantially utilize data disaggregated by racial and ethnic subgroups to fulfill their civil rights responsibilities and produce more detailed demographic reports.

AAPCHO's specific recommendations include:

- Require the collection of detailed race and ethnicity categories, including the proposed inclusion of Asian (Chinese, Vietnamese, Filipino, Korean, Asian Indian and Japanese), Native Hawaiian and Pacific Islander (Native Hawaiian, Tongan, Samoan, Fijian, Chamorro, and Marshallese) individuals.
- Collection of disaggregated data must be mandatory, and provide a minimum floor against which agencies are required to collect data.
- Create robust guardrails to ensure that agencies do not opt out of detailed collection of the race and ethnicity categories.
- Prioritize the inclusion of a "write in" option over using a checkbox to designate "another group".
- Ensure data equity for the U.S. territories.
- Middle Eastern or North African (MENA) must be added as a new minimum category.

C.3. Require the collection of detailed race and ethnicity categories by default

AAPCHO supports the mandatory collection of detailed race and ethnicity data. Asian American, Native Hawaiian, and Pacific Islander communities are incredibly diverse, having origins in more than 30 countries, comprising more than 50 ethnic groups, and speaking more than 100 different languages; each with their own complex histories and experiences. This diversity–and the starkly different experiences in nearly every aspect of social and economic life, from health and mental health, immigration, English language proficiency, income, poverty, employment, housing, and education–cannot be captured under the current minimum standard framework that only provides for broad categories of "Asian" and "Native Hawaiian" and "Other Pacific Islander." This aggregated data framework has had real and negative implications for our communities, often masking or completely erasing disparities within ethnic subgroups and perpetuating a "model minority" myth that harms our ability to receive the resources and services we need and are entitled to.

In a health care setting, collection of and access to comprehensive, standardized, and disaggregated demographic data is essential for health care professionals, policymakers, and other stakeholders to identify, monitor, and develop targeted strategies for addressing and mitigating health disparities. This is especially important for diverse AA and NH/PI communities. AAPCHO member community health centers have been collecting detailed race and ethnicity data for years and have demonstrated the cost effectiveness, improved health outcomes, and improved patient satisfaction that come with providing tailored services that are culturally appropriate and in the language their patients can understand, which would not be possible without access to disaggregated data.

Requiring all government programs to collect and report detailed race and ethnicity data allows for individuals to identify their full identity and recognizes the dignity and humanity of lived experiences behind the data. The Initial Proposal's "Example for Self Response Data Collections: Combined Question with Minimum and Detailed Categories" (detailed form) is consistent with the Working Group's finding that this approach performed the best of the options tested by the Census Bureau and is consistent with AAPCHO's goals of comprehensive data collection and disaggregation. The detailed form is also consistent with President Biden's stated goals to Advancing Racial Equity and Support for Underserved Communities Through the Federal Government[1] as well as recommendations of the President's Advisory Commission on Asian Americans, Native Hawaiians, and Pacific Islanders[2]. We applaud the Initial Proposal for carrying forward these goals.

Consistency is a primary goal. We also believe that federal agencies should use consistent methods of data collection to the fullest extent possible. In proposing a combined question for race and ethnicity data, the working group suggests "flexibilities" for agencies that depend on aggregate data, observer-reported data, or data from non-federal providers. We are concerned that inconsistent practices could lead to data that are not comparable in quality or measurement.

We are also deeply concerned that the Initial Proposal does not set a sufficiently high bar for agencies to set aside requirements to collect race and ethnicity at the detailed category levels and leaves such decisions to the agencies' discretion. Given a choice, and as we have seen under the current Directive 15 requirements, agencies may find is "easier" or simpler" to collect race and ethnicity under the Initial Proposal's Figure 3 minimum categories–or worse, wrongfully interpret these minimum categories as the most they are required to do–and opt to only do that. We strongly recommend that any final directive must ensure that agencies collect

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[1] See President Biden's "Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government" and "Executive Order on Further Advancing Racial Equity and Support for Underserved Communities Through The Federal Government"

[2] https://www.hhs.gov/sites/default/files/whiaanhpi-september-2022-commission-report.pdf

race and ethnicity at least at the Proposed detailed categories level, unless there are extraordinary, justifiable, and approved (more below) reasons not to do so.

We acknowledge that there may be initial startup costs for building the systems to collect these data, such as the building and deployment of updates to electronic health systems, as well as the hiring and training of staff to appropriately administer question sets. However, with the robust application of federal data standards across all government agencies, as well as the likely adoption of these standards by state and local governments and private and nongovernmental entities, the costs of these updates would be diffused across all agencies, technologies, and products, reducing individual expenditures.

Additionally, the benefits of collecting the data far outweigh any implementation challenges or costs or costs. The SPD 15's minimum categories—by design—are inadequate to capture the full measure of the diversity of our nation's rich communities and will result in short- and long-term gaps in our understanding of the population. Collecting only aggregated data will perpetuate health disparities and inequities–exactly in opposition of the Working Group's goals.

If the Working Group does decide to move forward with a SPD 15 minimum categories form (Figure 3), it must be implemented with strong criteria for the limited circumstances in which it can be used by an agency. AAPCHO recommends that anytime an agency wants to collect less race and ethnicity than the detailed categories (Figure 2),it must first propose that change through a formal public comment period. The agency must be able to provide clear justification for why it proposes to collect less detailed data, why it cannot use the detailed categories levels, and why aggregated categories are required or more favorable. The agency should be required to solicit and respond to public comments on the proposal. OMB must expediently review and approve/deny these requests and have clear guidelines against which to measure these requests. Unless the agency has sufficiently cleared the criteria for using the minimum categories and is granted approval to collect less data than the detailed categories level, the agency must use the detailed categories. Only in this way can agencies be held accountable for robust and uniform data collection across all agencies.

AAPCHO further recommends that the detailed form (Figure 2) be positioned as the federal minimum standard. In the case of a state or service area, a racial or ethnic group reaches a certain percentage of the population, programs or surveys collecting state or regional data should add additional check boxes of groups that have larger representation in those states or regions. For example, states like Hawaii and Oregon have large groups of people residing under the Compacts 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. Collecting information from regions with high COFA populations should add these categories as options under Native Hawaiian and Pacific Islander as such data can assist federal agencies in tailoring their programs to the target populations served.

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

AAPCHO supports the detailed categories included in Figure 2. It is consistent with feedback that AAPCHO provided in 2017 and makes a meaningful step forward in collecting disaggregated data on Asian, Native Hawaiian, and Pacific Islander individuals. We do, however, encourage OMB to establish a process for adding additional categories and provide agencies and agency grantees with clear guidelines to collect race and ethnicity data beyond the detailed categories where appropriate.

There are 24.5 million Asian Americans[3] and 1.6 million Native Hawaiian and Pacific Islanders[4], alone or in combination with other races and ethnicities, living in the US, together making up 7.8% of the American population[5]. Within these aggregated elements, there is tremendous diversity of the populations[6]. These categories includes more than 30 countries of origin, 50 ethnic groups, and speaking over 100 languages from Southeast Asia, South Asia, and East Asia, and diasporas[7]. Asian Americans are also the fastest growing major racial and ethnic group of the last two decades[8], with eight national origin groups doubling in population (Bangladeshi, Indian, Indonesian, Malaysian, Mongolian, Pakistani, Sri Lankan, Thai), and three growing ten times or more (Bhutanese, Burmese, and Nepalese) in that period; this growth is expected to continue, with Asian Americans projected to become the largest immigrant group in the US in three decades, by 2065[9].

Similarly NH/PI groups comprise at least 20 communities in the US[10]. While a majority of NH/PI are Native Hawaiian, more than half of all NH/PI identify as multiracial. NH/PI are also one of the fastest growing racial groups, growing 40% from 2000-2010, doubling or more in population in Arkansas (151%), Nevada (102%), and Alaska (102%) in that same period, and growing by 87% in Arizona and Alabama. Broad categories like 'AANHPI' and 'API' that roll together NH/PI groups

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[3] https://data.census.gov/table?q=asian+groups&tid=ACSDT1Y2021.B02018

[4] https://data.census.gov/table?q=Native+Hawaiian+and+Pacific+Islander&tid=ACSDT1Y2021.B02019

[5] https://data.census.gov/table?q=population&g=0100000US&tid=DECENNIALPL2020.P1

[6] https://www.census.gov/library/stories/2022/05/aanhpi-population-diverse-geographically-dispersed.html

[7] https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-americans

[8] https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-origin-groups-in-the-u-s

[9] https://www.commonwealthfund.org/publications/issue-briefs/2020/jul/gap-closed-aca-impact-asian-american-coverage

[10] https://www.empoweredpi.org/s/NHPI-Demogrpahic-Profile-National.pdf

with AAs erase significant differences in identity, socioeconomic outcomes, history, and immigration patterns both between NH/PI and AA and among NH/PI.

The required collection of race and ethnicity at the detailed category level as depicted in the Initial Proposal's Figure 2 will dramatically improve data collection and allow individuals from these communities to self-identify on the forms. However, it is important to acknowledge that the addition of these six check boxes under each broader category do not capture the totality of the diverse backgrounds and identities of AA and NH/PI individuals in this country. More categories are preferable to fully capture the identities and the intersections of individual races and ethnicities, and we recommend OMB direct and provide clear guidelines to agencies, as well as for agencies to encourage their grantees, to collect additional race and ethnicity data where possible, especially when service areas and program administration in smaller geographic areas would benefit from more detailed information.

Furthermore, recognizing the growth in the Asian American population anticipated in the next decades, as well as changing geopolitical migration patterns, it is important to routinely and regularly update the race and ethnicities list on the detailed data collection form. We recommend updating the detailed form at least every 5 years to reflect changing population patterns. We urge OMB and the Working Group to submit a final Directive that reflects that the total number of checkboxes under Asian and the total number of checkboxes for Native Hawaiian and Pacific Islander would not necessarily remain at 6 each; additional subcategories could be added as additional new checkboxes.

It is important that OMB and the Working Group develop specific criteria (e.g., the specific percentage of total population) by which additional racial or ethnic groups would be added to the detailed form. This threshold must be grounded in research and evenly applicable. In order to be ready for the first 5-year update, the threshold must be established by the Working Group and OMB no later than 18 months after the publication of the final Directive.

3c. Some Federal information collections are able to use open-ended write-in fields to collect detailed racial and ethnic responses, while some collections must use a residual closed- ended category (e.g., "Another Asian Group"). What are the impacts of using a closed-ended category without collecting further detail through open- ended written responses?

It is imperative that all federal information collections use open-ended write-in fields to collect detailed race and ethnicity responses. Only through self-identification are we able to get complete disaggregated data, and enabling individuals the ability to self identify recognizes their humanity and self-determination. The ability to write in a response is critical towards the realization of that goal and should be the standard.

Currently 3.5% of Asian Americans are counted under ‘Other Asian’ and 1.4% of all Asian Americans wrote-in their identity after choosing ‘Other Asian[11].’ Additionally 22.7% of Native Hawaiians and Pacific Islanders are counted in one of the ‘Other Pacific Islander’ categories and 7.9% of all NH/PIs wrote-in their identity after choosing ‘Other Pacific Islander[12].” As the “write in” option becomes more common, and in the absence of additional check boxes, the percentage of write-in self-identifications will grow. Removing the write-in option altogether would erase the identity of at least 800,000 Asian Americans and 350,000 Pacific Islanders.

We recognize, however, that not all agencies may have the technological advancement to collect write-in responses when the final Directive is issued, and we encourage that all agencies dedicate the necessary resources to upgrade these systems. If technology does prohibit the collection of write-in responses, it is vital that agencies still be required to collect race and ethnicity data at the detailed level with the addition of a seventh checkbox under each major population group. As proposed, this would include a seventh checkbox “Other Asian” under the “Asian” category and a seventh checkbox “Other Pacific Islander” under the “Native Hawaiian and Pacific Islander” category. These check boxes would nest as a seventh check box of similar shape and size under each of the broader categories.

If the Working Group does move forward with allowing agencies to add an additional “other” checkbox in lieu of collecting write-in responses, the policy and process to do so must be implemented with strong criteria and guidelines by which the agency demonstrates it does not have the ability to collect write-in responses. Similar to our recommendation regarding collecting data at less than the detailed categories, an agency seeking an exemption to not provide a write-in option must first be noticed for public comment and approved by OMB. The agency must provide clear justification for why it cannot provide an option for write-in responses, and that justification must be consistent with all other agency data collection efforts and programs. The agency should also be required to solicit and respond to public comments on the agency's request to not provide an option for write-in responses. OMB must be designated to expediently review and approve/deny these requests and have clear guidelines against which to measure these requests. The agency must receive approval from OMB before the “another group” checkbox is permitted.

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[11] https://data.census.gov/table?q=asian+groups&tid=ACSDT1Y2021.B02018
[12] https://data.census.gov/table?q=Native+Hawaiian+and+Pacific+Islander&tid=ACSDT1Y2021.B02019

3d. What should agencies consider when weighing the benefits and burdens of collecting or providing more granular data than the minimum categories?

Significant and consistent disparities among AA and NH/PI communities are masked by aggregating data and the lack of granular data is a barrier to equity. For example, aggregated data suggest that Asian Americans have the lowest health insurance uninsurance rate of any racial or ethnic group.[13] But that statistic does not tell the full picture. While in aggregate, Asian Americans have the lowest rate of uninsurance, in 2015, of the top 10 highest uninsured groups in the US, 5 are Asian Americans (Pakistanis at 20.9%, Koreans at 20.5%, Cambodians at 18.9%, Vietnamese at 18.5%, Bangladeshis at 18.2%) and 2 are Native Hawaiian and Pacific Islanders (Micronesians at 18.3% and Samoans at 16.7%)[14]. Being uninsured is significantly associated with poor health outcomes and has a dramatic impact on an individual's decision to seek and maintain care. Without access to the nuances in the disaggregated data, it is possible to overlook the critical need for tailored strategies to do outreach and enrollment in certain communities.

Moreover, as the COVID-19 pandemic made abundantly clear, access to disaggregated data can have immediate implications to understanding and addressing health crises and providing meaningful care to diverse populations—and without it negatively mask the harm to specific patient populations. For example, Santa Clara County in California collected disaggregated data on COVID-19 vaccination rates and found that in May 2021, while case rates among Asian Americans overall were the lowest second only to whites, case rates among Vietnamese and Filipino residents were significantly higher than average and exceeded or were comparable to that of African American residents.

Similarly, in Alameda County, one of our member health centers saw that the Vietnamese and South Asian residents had nearly twice the case rates of the aggregated Asian American group. The identified disparities from the disaggregated data, which otherwise were masked, allowed health centers to stand up mobile vaccine units in specific geographical areas where these populations were located and ensure that multilingual staff and in-language materials were on hand for these specific populations.

Additionally, early in the pandemic NH/PI communities were consistently aggregated within the broad "Asian" or "other" category, making the pain and suffering experienced by these communities invisible when allocating targeted responses and resources. NH/PI data was available separate from the Asian category in only 19 states, despite NH/PIs having among the

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[13] https://www.commonwealthfund.org/publications/issue-briefs/2020/jul/gap-closed-aca-impact-asian-american-coverage

[14] https://www.searac.org/wp-content/uploads/2018/04/2015_ACA_policy_brief_v13_final.pdf

highest death rates from COVID-19 when disaggregated of any population group, in some cases higher than African Americans and Latino communities.

The lack of data delayed care, affected the allocation of resources, and made these communities largely invisible. We hope that with the transition to disaggregated Asian and NH/PI categories, health centers, other health care providers, federal health agencies, and government agencies generally will have additional tools to ensure they can address the unique needs of the diverse communities they serve.

As discussed above, many AAPCHO member health centers have been collecting detailed race and ethnicity data for years and have built these categories into their systems and processes. HRSA is already moving to require all health centers to submit disaggregated race and ethnicity data to the Unified Data System beginning in 2024. Mandating similar requirements across government will ensure that data collected at health centers will be consistent and comparable with other public programs and will allow comparability across government.

Additionally, as we have discussed, we acknowledge that there may be startup costs for building the systems to collect these data, such as the building and deployment of updates to electronic health systems. But with the robust application of federal data standards, the costs of these updates would be diffused across all agencies, technologies, and products, rendering the costs negligible.

But above all, it is important to highlight that the benefits of collecting the data far outweigh any implementation challenges or costs or costs. The SPD 15's minimum categories—by design—are inadequate to capture the full measure of the diversity of our nation's rich communities and will result in short- and long-term gaps in our understanding of the population.

3e. Is it appropriate for agencies to collect detailed data even though those data may not be published or may require combining multiple years of data due to small sample sizes?

AAPCHO supports the collection of detailed data even if the data may not be published in order to build longitudinal data sources and to build an understanding and trust in the data collection. Agencies have demonstrated the success of this approach and have reported such data in more recent years with the help of innovative statistical techniques, in order to meet the needs of communities. The Census Bureau, for example, has reported such data from the American Community Survey by minimally aggregating them as necessary and introducing statistical noise to protect privacy in the case of smaller sample sizes. While these data are less accurate when treated in this way, they are indispensable to advocates in identifying the needs of the community by providing more actionable data rather than no data at all. Additionally, as more new statistical methods are innovated, having longitudinal data on our rapidly growing communities that can be reported even retrospectively would be invaluable for policy-making, research, and advocacy purposes.

We urge OMB to revise the standards to favor more clearly the presentation of data for all standard (major) race and ethnicity categories, as well as more detailed data, whenever statistically possible. We believe the designation of an “All Other Races” category is no longer appropriate, as it renders many people “invisible” for important policy and programmatic purposes. Instead, the standards should direct agencies that are unable to report data for specific race or ethnicity categories due to unacceptable quality or statistical reliability, confidentiality concerns, or absence of legal requirements, to note clearly (with the use of an asterisk or footnote, for example) the reason(s) why data are not included for those groups. Further, and particularly important if a new combined question is used, the standards should require agencies to publish data for the largest race and/or ethnicity combinations, noting that those combinations might be different for different geographies. Those combinations could include, but are not limited to, Black/African American and Hispanic/Latino, White and Hispanic/Latino, Black/African American and MENA, American Indian and Alaska Native and Hispanic/Latino, Native Hawaiian and Pacific Islander and Asian, and White and Asian.

Agencies should be required to include specific commentary when any data in the minimum categories is not reported because it was not collected, not analyzed, or found not to be statistically significant. For example, if a survey’s sample size made it impossible to report out data on all the minimum categories, the agency should explicitly state that in reports and presentations.

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 conditions are met?

Detailed data collection must be required in all cases unless a strong justification against specific criteria is provided by an agency. There is no circumstance in which the SPD-15 should allow a voluntary approach to the collection of disaggregated data. And, in fact, a “default” structure as proposed in the Initial Proposal—as opposed to a requirement—allows for the possibility of an agency opting out. As recommended above, OMB should make clear that disaggregated data at the detailed categories level is the requirement with very few exceptions.

Clear and rigorous guidelines must be established under which any agency or program would be permitted an exemption from mandatory disaggregated data collection. OMB should review applications against these strict guidelines before any agency is permitted to reduce their data collection obligations.

AAPCHO further recommends that the Working Group release clear guidelines for how agencies may voluntarily collect additional data on top of what is already required by the detailed form.

4. Update Terminology in SPD 15.

AAPCHO applauds the Working Groups efforts to update language to remove racists, misleading and/or vague terminologies and categorizations from the SPD 15. Consistent with the goals of this proposal, terminology should ensure that all people are able to self-identify with one or more of the categories in a way that is respectful, consistent, and clear.

The draft definitions included in the proposal are comprehensive in coverage of many racial and ethnic identities. We appreciate that the proposal includes separate categories so that individuals can identify as Asian or Native Hawaiian and Pacific Islander, and that the proposal expands the definitions within each category to include additional self-identification of where communities are from. However, it is important to acknowledge the fluidity of racial and ethnic identities and the importance of frequently updating these forms.

We believe that the updated detailed form is reflective of meaningful distinctions and respectful of how many people refer to themselves. However, it is important to maintain and prioritize options that allow individuals to both “choose all that apply” and allow a write-in to fully capture self-identifications.

4.a. What term (such as “transnational”) should be used to describe people who identify with groups that cross national borders (e.g., “Bantu,” “Hmong,” or “Roma”)?

AAPCHO supports the recommendations of the National Council of Asian Pacific Americans and the Southeast Asia Resource Action Center (SEARAC) regarding individuals who identify with groups that cross national borders. Specifically, we support the need for further research on better ways to count several transnational groups who are counted among Asian American and Pacific Islander populations; better ways to count these groups are needed than including them in ‘Other’ categories, where their identities and numbers are erased. Hmong, Montagnard, Okinawan, Indo-Fijian, Malay, Urdu, Indo-Caribbean, and several diasporic groups are some of the populations whose complex histories defy counting under a single – or sometimes any – national origin category. To avoid having these groups be lost under the ‘Other’ categories, and the resulting undercounting and erasure, more research on better ways to count these populations is needed.

At the same time, community input on these and other questions on identity and self-identification should be regularly and frequently incorporated into the research and testing process. Ultimately, both national origin and ethnic identity are important aspects of immigrant identity, and neither is universally more significant than the other. A more accurate approach would see data collected on both national origin and ethnic identity for all immigrants, so that depending on the particular analysis or application, one or both can be used. Finally, the conflation of race with national origin in data collection is of great concern and community input should be solicited on more appropriate framing of these interlinked identities in the data collection process.

However, we do not believe that the need for additional research should delay or otherwise prevent OMB and the Working Group from finalizing a new Directive 15 consistent with areas of agreement as soon as possible. As we have noted above, the structure and inclusion of additional subgroups should be reviewed at least every 5 years with necessary updates as research and new understanding becomes available.

4b. As seen in Figure 2, based on the Working Group's initial proposal, the question stem asks "What is your race or ethnicity?" Do you prefer a different question stem such as: "What is your race and/or ethnicity?", "What is your race/ethnicity?", "How do you identify?", etc.? If so, please explain.

AAPCHO supports recommendations to revise this question to read "What is your race/ethnicity" OR "What is your race and/or ethnicity?" AND add "How do you identify?" We believe this question structure is more inclusive and allows individuals to self-identify in the manner most appropriate for them. It is our experience that many people often confuse race and ethnicity and use them interchangeably. The terminology should allow respondents to choose the option they most identify with regardless if they consider the category(ies) their race and/or ethnicity and clarify that they are not limited to two, or worry about the difference between the two terms.

5. Guidance is necessary to implement SPD 15 revisions on Federal information collections.

Strong guidance is needed to implement the SPD 15 revisions. Part of the guidance must include support for individuals with limited English proficiency (LEP).

Health centers serve nearly 30 million patients each year, including more than 1.6 million AAs and NH/PIs. For AA and NH/PI communities, health centers are a medical lifeline, communicating accurate, scientific information and providing holistic, high quality, coordinated services in ways that are culturally and linguistically appropriate. AA and NH/PI-serving health centers provide care to disproportionately more limited English proficient (LEP) patients than the average health facility, recognizing that effective care requires reducing language barriers. Among AAPCHO members, nearly half—47 percent—of patients served are LEP and nearly 90 percent are low income, falling below 200 percent of the poverty line. Further, our collaborative partners at NACHC reports that nearly 1 in 4 patients served by health centers was LEP and 95% of health center patients surveyed reported that their clinicians spoke their language. AA and NH/PI-serving health centers employ multilingual staff and may serve as high as 99% LEP.

Our experiences as health centers serving individuals who have LEP underscore the importance of strong guidance and clear messages about the importance of data collection and full self-identification. Without in-language support, some individuals will not be able to appropriately fill out the forms or understand the options available. But with in-language support, our health centers are able to collect race and ethnicity data as part of our data collection efforts.

Partnerships with community providers, including health centers and other community-facing organizations will be key to full implementation of the detailed data form.

In addition, it is critical that any guidance addresses how to talk about the limits of the confidentiality of these data. Some individuals will have concerns about how their data will be identified and what personally identifiable data could be attributed back to them. Fear of reporting to immigration officials or other law enforcement may have a chilling impact on participation. Strong guidance and partnerships with community providers can support this work as well.

C.2. Add “Middle Eastern or North African” (MENA) as a new minimum category

AAPCHO strongly supports the Working Group’s proposal that MENA be added to SPD 15 as a new minimum reporting category. Individuals who identify as MENA have had their data aggregated under the “White” reference category since the OMB issued its 1977 standards. As a result, these individuals have not been able to fully access equal protection or equal opportunity, and policy and program makers have not been able to track issues unique to their populations.

By disaggregating MENA data from that of non-Hispanic White populations and enabling agencies to report more detailed population data, agencies would be able to better assess underserved communities needs and identify coverage gaps for federal programs.

Evidence suggests that members of the MENA community suffer from poorer health outcomes at a greater rate and face unique cultural and linguistic barriers to accessing high-quality healthcare services. Congress has authorized the Department of Health and Human Services (HHS) to research and develop programs to eliminate health disparities through the National Institute on Minority Health and Health Disparities (NIMHHD) and Office of Minority Health (OMH). However, by aggregating MENA data under the White category, Directive 15 currently obscures the reality of health disparities and impedes the work of the HHS, NIMHHD, and OMH. By disaggregating MENA data, agencies would develop a more accurate picture of racial and ethnic disparities, particularly in areas such as healthcare. The establishment of a MENA category as part of a combined race and ethnicity question would provide a stronger evidence-base for these agencies to collectively eliminate health disparities, ultimately to the benefit of all communities.

The proposed rule asks the question if the term "Middle Eastern or North African" (MENA) is likely to continue to be understood and accepted by those in this community? AAPCHO supports the comment letters by National Network for Arab American Communities (NNAAC) and Arab Community Center for Economic and Social Services (ACCESS) who, as leaders in the MENA community, suggest that the MENA designation is understood and accepted by the community. What is more, the MENA definition would allow the collection of the statistics necessary to track the experiences of the MENA community. This change is long overdue—and is enthusiastically welcomed by leaders in the MENA community.

6. Comments On Any Additional Topics and Future Research.

AAPCHO strongly encourages OMB to 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 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.

Additionally, while this proposal does not provide guidelines for where or from whom the agencies should administer federal data collection initiatives, AAPCHO continues to encourage all agencies to collect data from the U.S. territories. It is unacceptable that many federal data sets do not include any information from the territories, or when they do, the territories are relegated to footnotes indicating that information is unavailable. This makes the experiences and challenges of U.S. citizens, nationals, and immigrants who reside in the territories completely invisible, and it disproportionately disenfranchises communities of color, the majority of which residents of the territories are Hispanic or Latino, Pacific Islander, and Asian. We strongly encourage OMB to consider establishing guidelines and requirements for all federal agencies to include the territories in their data collection program.

Conclusion

AAPCHO applauds OMB and the Working Group’s commitment to updating race and ethnicity standards across the federal government. Many communities for too long have been unrecognized and left out of federal data, which has exacerbated inequities and made it more difficult for government and non-government agencies to target resources and support where they are most needed. We look forward to the final revisions to Statistical Policy Directive 15, and are committed to working with the agencies to implement these guidelines in support for AA, NH/PI, and all communities.

Sincerely,

Adam P. Carbullido

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Director of Policy and Advocacy