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April 27, 2023

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Chair, Interagency Technical Working Group
on Race & Ethnicity Standards
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Via: http://www.regulations.gov

Re: Feedback on Initial Proposals for Updating OMB's Race and Ethnicity Statistical Standards: OMB-2023-0001

Dear Mr. Sivinski, Ms. Young and Dr. Orvis:

On behalf of the California Pan-Ethnic Health Network and the undersigned groups, we appreciate the opportunity to provide feedback on **Initial Proposals for Updating OMB's Race and Ethnicity Statistical Standards: OMB-2023-0001.** The California Pan-Ethnic Health Network (CPEHN) is a multicultural statewide health advocacy organization that aims to unite communities of color and advance racial and health equity in California. Our network of partners, the Having Our Say Coalition, the Behavioral Health Equity Collaborative, CA-OPEN and the Public Health Collaborative are comprised of over forty racially and ethnically diverse community-based organizations (CBOs) across the state, dedicated to improving the health and well-being of the state's vulnerable populations.

Background:
In California, communities of color face persistent health disparities including higher rates of asthma, diabetes, and obesity, resulting in a shorter life span, less wealth, and less opportunity. These disparities cannot be attributed to any inherent characteristics of these communities – they are the product of structural and racist inequities that block access to resources and opportunities as evidenced by epigenetics research evidence.[i] Black Californians for example, continue to experience the highest rates of prenatal and postpartum depressive symptoms, infant and maternal mortality.[ii] Asthma prevalence among American Indians and Alaska Natives is more than 40% higher than among Whites. Blacks and Latinx have twice the prevalence of type 2 diabetes and are twice as likely to die from the disease than Whites.[iii] Native Hawaiian and Pacific Islander Californians live 72.9 years on average, the second-shortest life expectancy after Native Americans.[iv]

The COVID-19 pandemic laid bare the impact of systemic racism on health. People of color who had received lower quality care and lived with chronic conditions long ignored by the health care system were more vulnerable to COVID-19, and their communities were disproportionately impacted by the

virus. Data collected from the first year of the pandemic showed Black Californians made up 12% of deaths, nearly double their share of the state's population. Latinx aged 18-34 comprised more than two-thirds of all deaths in that age bracket, an age range otherwise considered to be "low-risk". Disaggregated data in Los Angeles County showed that COVID-19 infected Pacific Islanders at a rate more than twice that of the state as a whole – and killed them at a rate 2.6 times higher, the highest rates of any racial or ethnic group.[v] As a result, COVID-19 has resulted in a well-documented widening gap in Californian's life expectancy with Latinx, Black, and Asian populations experiencing a larger decrease in life expectancy in 2020 and 2021 compared to Whites.[vi] An additional study on the impact of COVID found that Native Americans' average lifespan is 67 years, a decrease of more than 7 years since 2012.[vii] Importantly, it is well-documented that deaths among Native American people are known to be undercounted in many contexts (by a margin of =30% in some cases), due to misclassification of race or ethnicity in death certificates.[viii] The term data genocide has been used by researchers at the Urban Indian Health Institute and other organizations to describe the erasure of data attesting to deleterious health outcomes for Native American communities.

The collection of self-reported, comprehensive, disaggregated, and granular demographic data is a necessary first step to identifying and then reducing disparities. This is particularly critical in California, the nation's most diverse state, where communities of color make up over half (63%) of the state's population.[ix] Additionally, California represents a wide array of communities made up of diverse races and ethnicities who speak over 200 languages. Forty-six percent of Californians speak a language other than English at home; 18.1% of Californians over age 5 have limited English proficiency.[x] The ability to self-identify is critical for ensuring an accurate count of the state's diverse Tribal populations. As several large sample studies (N>600 in total) show, Native Americans frequently report multiple Tribal affiliations and/or self-identify as both Native American and another race/ethnicity.

California has made great strides in requiring the collection of granular race/ethnicity data by health plans and providers. For example, California's two major public purchasers, Medi-Cal and Covered California now require health plans to stratify and report quality performance measures by race and ethnicity. Additionally, Covered California requires plans to have self-reported race and ethnicity data from at least 80 percent of their members, which is based on the CMS requirement for documentation of demographic data for 80% of beneficiaries in electronic health records by providers and hospitals. **However, despite these gains, when payers and providers collect race and ethnicity data, the data is often rolled up to the minimum 1997 OMB categories**. This is insufficient to support meaningful disparities reduction and has harmed California's efforts to identify and address disparities. For this reason, we strongly support revisiting the OMB race/ethnicity standards now to ensure race/ethnicity categories are representative of the diverse populations in our state.

We are supportive of the Working Groups proposals to combine the race and ethnicity category which allows individuals to identify with as many race and/or ethnicity categories as they choose, create a Middle Eastern and North African (MENA) category and include additional granular categories for all race and ethnicity categories. These revisions will strengthen efforts to identify and reduce disparities in health outcomes. However, for these changes to be truly meaningful, OMB must account for the varied and specific needs of California's diverse communities, ensuring no one is left behind. This includes:

- **Requiring the collection of detailed race and ethnicity categories by default.** We strongly support OMBs recommendations to update the OMB 15 to include additional more granular race/ethnicity categories. These categories should be required not voluntary and additional granularity should be strongly encouraged and incentivized even in cases where the data may not be published or may require combining multiple years of data due to small sample sizes. The U.S. history of erasure of data (e.g. data genocide) for smaller populations, including American

Indian/Alaska Native as referenced above, must end now. We urge OMB to issue guidelines that make it clear these are minimum standards, encourage federal agencies to include groups with significant state or regional representation that may otherwise be overlooked by NCT standards, and incentivize the collection and reporting of more granular data for smaller, racially/ethnically diverse populations whenever possible.

- **Strengthening community engagement to ensure the voices of all communities are considered and heard when recommending proposed changes to race/ethnicity categories.** This includes hearing from smaller racially and ethnically diverse and geographically dispersed populations including American Indian and Alaska Natives, Indigenous Latinx, Native Hawaiian and Pacific Islanders and Black or African-American populations who have been historically and systematically erased, omitted and/or undercounted. As part of this consultation, there may be a need to differentiate between the "urban multi-tribal" Native community/population and the more singular tribal characteristics of an On Reservation community. There are distinctively different cultures and with Native Americans, Culture is a significant determinant of health.
- **Convening a permanent Working Group in order to ensure that race/ethnicity classifications and terminology are reflective and responsive to evolving norms**: While we applaud the Interagency Technical Working Group on Race & Ethnicity Standards for updating the OMB standards now, we cannot wait another 25 years to update these standards again. The U.S. population is much more multiracial and diverse than it was in 1997. We agree with the OMB that race and ethnicity categories are a fluid construct that is influenced by current social and political thinking. At the same time, our systems of measurement are also evolving. COVID-19 laid bare the impact of health disparities on communities of color and necessitated the need for more robust, real-time and granular collection and reporting of data on COVID infections, treatment, hospitalizations and death rates by race and ethnicity in order to not mask disparities by smaller racially/ethnically and geographically dispersed communities.
- **Facilitate a robust discussion of the additional data collection needs in Black/African American populations, American Indian/Alaska Native and other Indigenous populations, and Asian and Pacific Islander populations** where multiple categories are necessary to counter the continued diluting and undercounting of these populations. This is particularly urgent in the context of COVID-19 where lack of granular data collection masked disparities, particularly for smaller racially/ethnically diverse communities, as well as in the context of a renewed public reckoning since the murder of George Floyd where discussions of how best to capture adequate data by lineage for example, is critical to acknowledging the history of our government institutions as a system of oppression, and the impact of that history on health outcomes today. Structural racism is the reinforcement of centuries of racist rhetoric, public policies, laws, rules, and practices sanctioned and even implemented by various levels of government. Thus the ability to properly identify and address disparities continues to be paramount.

In short, the Task Force must properly engage and communicate with all groups to ensure these and future changes are informed by and reflective of the communities they are intended to address.

Our detailed comments and recommendations to the Interagency Taskforce's questions are below:

1. Collect race and ethnicity information using one combined question.

Comment: We support one combined question for race and ethnicity because it will reduce confusion and optimize response rates, especially among Latinx/Hispanics. This is critical for ensuring an accurate count of California's Latinx/Hispanic population, which comprise 39.4% of the state. In 2013, California adopted the OMB's separate race and ethnicity categories as part of its single streamlined application for health coverage.[xi] The application's two separate questions on race/ethnicity resulted in confusion for

many Californians, who simply left the race category blank. This in turn was a challenge for California's state purchasers, Medi-Cal and Covered California, who had to adopt their own internal protocols for classifying and imputing race and ethnicity data for the millions of enrollees in our public health care system. The lack of self-reported race/ethnicity data and the subsequent imputation of this data runs counter to the research on best practices for collecting this data.[xii]

We appreciate the additional research conducted by the U.S. Census Bureau on the impact of a combined race/ethnicity question which found that the separate question format does not reflect the way that many Latino individuals self-identify. Since many Latinos do not see themselves in any of the race categories under the current standards, a large proportion (nearly 44 percent) select "Some Other Race" or skip the race question entirely.[xiii] As a result, the Census Bureau must "assign" these individuals a race for many datasets. Per the U.S. Census Bureau, under the current standards, many Latinos end up being categorized as White if they do not self-select a race in addition to identifying an ethnicity[xiv], and all individuals who identify as Middle Eastern or North African are categorized as White by definition.[xv] This ends up inflating the apparent size of the White population and hindering our ability to look critically at racial and ethnic disparities.

In reviewing the research, we were also encouraged by the fact that the combined question with detailed checkboxes resulted in increased use of OMB standard categories, decreased nonresponse, and improved accuracy, for additional racially/ethnically diverse populations. For example, while concerns have been raised about the potential effects of a combined question on reporting for Afro-Latino communities, research shows that it would actually *improve* reporting for this group. A slightly *higher* percentage of respondents identifying as Hispanic also identified as Black in a combined question with detailed checkboxes (1.8 percent) compared with the current separate question format (1.5 percent). This increase was even more pronounced when looking at paper form responses alone (3.2 percent vs. 1.7 percent).[4] This approach would also provide benefit to AIAN data: per Brookings Institute analysis of Census data, one of the more common definitions of Native Americans as single-race, non-Hispanic AIAN (using the two-question format) excludes more than three-quarters of the total Native population, including those who are Indigenous from South/Central America (who are considering AIAN per OMB's own definition).[xvi]

It is important as OMB moves forward to consider the additional data collection needs in the Black/African American populations where multiple categories are necessary to block the continued diluting and undercounting of Black/AA populations who are Black/North African, Black/Middle Eastern, Black/Latino, Black/Caribbean, etc. We urge the Interagency Working Group to engage with these communities to ensure their concerns are addressed, while also making this research more readily available on its website and through additional town halls and other community engagement activities.

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

Comment: There are currently more than 5 million Middle East North African (MENA) Americans living all over the U.S., with the largest concentration of MENA populations living in California, Michigan and New York. Currently California's Middle East and North African (MENA) population is vast and diverse with roughly 732,262 Californians.

The U.S. government's classification of Middle Eastern and North African (MENA) Americans as White means there is no direct way to numerically count members of this group in official statistics. Therefore, any potential disparities and inequalities faced by MENA Americans remain hidden. This is particularly troubling given that many MENA groups don't consider themselves "White" as they are currently categorized.[xvii] For these reasons, we support the new category of Middle Eastern and North African

(MENA), while at the same we also note concerns raised by some of our partners that the term MENA which combines North Africa with Middle East is a divisive issue in the African continent. *Moving forward we urge the OMB to address these concerns and we would appreciate additional information on the rationale for adopting particular terms, and combining geographic regions such as the Middle East and North Africa.*

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

Comment: California has made great strides in requiring the collection of granular race/ethnicity data by health plans and providers, since the last update to the OMB race/ethnicity standards. However, when payers and providers do collect race and ethnicity data, they are generally rolled up to the minimum 1997 OMB categories. The OMB is considered the ceiling rather than the floor. This is insufficient to support meaningful disparities reduction in California and nationally.

For this reason, we strongly support a more explicit and unequivocal requirement for detailed, disaggregated data by the six most numerous subcategories with additional write-in examples, based on the 2015 U.S. Census Bureau National Content Test Race and Ethnicity Analysis Report, with the option for territorial, state, and local additional categories, e.g,, adding additional Asian and Latino/Hispanic subcategories in California [note that Covered California currently collects disaggregated data for the following Asian subcategories]:

- Asian Indian
- Cambodian
- Chinese
- Filipinx/a/o
- Hmong
- Japanese
- Korean
- Laotian
- Vietnamese
- Other Asian

and for the following Latino/Hispanic subcategories:

- Mexican, Mexican American, Chicano
- Cuban
- Guatemalan
- Puerto Rican
- Salvadorian
- Other Hispanic, Latino, or Spanish origin

and for the following Native Hawaiian and Pacific Islander subcategories:

- Native Hawaiian
- Samoan
- Guamanian or Chamorro
- Other Pacific Islander

Using the six most numerous subcategories as the minimum required disaggregation allows for changes to subcategories as populations change. 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[xviii] as well as recommendations of the President's Advisory Commission on Asian Americans, Native Hawaiians, and Pacific Islanders[xix].

We urge OMB to clarify that these categories are the floor, as opposed to the ceiling. In cases were these minimum categories are not met, OMB should require agencies to specifically state whether any data in the minimum categories is not reported because the data 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. We note there is often no explanation for why data is not reported out in the minimum categories.

OMB must make it clear that additional granularity for smaller, racially/ethnically diverse populations, including Black, American Indian/Alaska Native and other Indigenous populations is strongly encouraged and expected. We would also argue for example, that a simple category of American Indian/Alaska Native is not sufficient given the over 400 Tribes and cultures in North American. We would support, for example, referring to Tribal Epidemiology Center guidance (including Urban Indian Health Institute) for collecting and reporting tribal affiliation data, which allows for more granular understanding of tribal identity than an AIAN category alone. In instances where populations are excluded,

We also urge OMB to require all federal information collections use open-ended write-in fields for each detailed sub-group to collect detailed race and ethnicity responses. Only through self-identification are we able to get complete disaggregated data. The ability to write in a response is critical towards the realization of that goal and should be the standard. In addition, we strongly recommend that agencies collecting these detailed race/ethnicity identification report that important data in a timely way to the public and to inform federal efforts to promote equity in health and well-being.

4. Update Terminology in SPD 15.

Comment: We support use of terms "multi-racial" and "multi-ethnic" (rather than "mixed race"), or alternatively, "individuals identifying as more than one race", or "individuals identifying as more than one ethnicity." Multi-racial should be used only when there is the opportunity to identify specific races.

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

Comment: Indirect estimations for race and ethnicity (using zip code/census tract/address data and/or surnames) should never be used to assign a race and/or ethnicity to individuals and should be strictly limited to applications at a population or community level to add estimations to fill in missing or unknown data. Indirect estimations based on zip code/census tract/address data and/or surnames are challenged by consequences of historic and persistent systemic racism like redlining. For example, indirect estimation may miss smaller communities or dispersed communities, including American Indian, Alaska Native, Native Hawaiians, Pacific Islanders, and some Asian American subgroups, people with disabilities, and LGBTQ+ people. These types of indirect estimations, due to various limitations in their creation and use, should never be a replacement for the gold standard of self-reported data collection and reporting.

6. Comments On Any Additional Topics and Future Research.

Comments: We urge OMB to take into account additional data collection needs in the Black/African American population. California is at the forefront of discussions on how data on Black/African Americans could better reflect evolving race/ethnicity categories by including lineage, a critical step as

states and localities grapple with critical questions about the negative impact of the U.S' historic anti-black racism on health outcomes and the myriad of solutions to address these impacts including discussions about reparations.[xx]

Despite California entering the Union in 1850 as a free state, its early state government supported slavery. Pro-slavery White southerners held a great deal of power in the state legislature, the court system, and among California's representatives in the U.S. Congress. The ability to properly classify an individual's lineage is critical to countering these policies and ensuring economic equity for all Californians.
In July 2022 for example, California became the first state to require two state agencies, the State Controller's Office and the Department of Human Resources to present a separate demographic category for descendants of enslaved people when collecting state employee data beginning January 1, 2024. The new categories will include African Americans who are descendants of people who were enslaved in the United States and Black employees who are not descendants of people who were enslaved in the United States. The data collected will be included in a public state report on or after Jan. 1, 2025.[xxi]

Conclusion: We appreciate the opportunity to comment on these important proposed revisions to the OMB's race/ethnicity standards, and look forward to continued discussions and opportunities for community engagement. If you have any questions please contact: Cary Sanders/Senior Policy Director/CPEHN at: csanders@cpehn.org.

Sincerely,

ABC Alliance for a Better Community
ACCESS Reproductive Justice
California Black Health Network
California Rural Legal Assistance Foundation
California Pan-Ethnic Health Network
Central Valley Urban Institute
Centro Binacional del Desarollo Indígena Oaxaqueño
Connecting for Better Health
Healthy House Merced
Hmong Cultural Center
Korean Community Center of the East Bay
Manifest MedEx
Mixteco Indigena Community Organizing Project/Proyecto Mixteco Indigena
PALS for Health
PARS Equality Center
Ram, Inc.
Street Level Health Project
The Children's Partnership
Vision y Compromiso
Western Center On Law & Poverty
Dr. Paul Masotti, Director of Research and Evaluation, Native American Health Center, signing as an individual

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[ii] "2021 Edition Health Disparities Race/Ethnicity California," https://www.chcf.org/publication/2021-edition-health-disparities-race-ethnicity-california/.

[iii] "California 2020-21 Health Disparities Report," https://www.dhcs.ca.gov/Documents/MCQMD/CA2020-21-Health-Disparities-Report.pdf

[iv] "A portrait of California 2021-22," https://ssrc- static.s3.amazonaws.com/moa/APortraitofCalifornia2021-2022.pdf

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[x] U.S. Census Bureau, American Community Survey: https://data.census.gov/table?q=ACSDP1Y2019.DP02&g=040XX00US06&tid=ACSDP1Y2019.DP02&hidePreview=true

[xi] Covered California Application for Health Insurance: https://www.dhcs.ca.gov/services/medi-cal/eligibility/Documents/2014_CoveredCA_Applications/ENG-CASingleStreamApp.pdf

[xii] Explanation of Data Standards for Race, Ethnicity, Sex, Primary Language and Disability, U.S. Department of Health and Human Services Office of Minority Health: https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=54

[xiii] Racial Identification for the Self-Reported Hispanic or Latino Population: 2010 and 2020 Census. U.S. Census Bureau. March 27, 2023.

[xiv] Race Reporting Among Hispanics: 2010. U.S. Census Bureau. March 2014.

[xv] 2015 National Content Test Race and Ethnicity Analysis Report. U.S. Census Bureau. February 28, 2017.

[xvi] "Why the federal government needs to change hot it collects data on Native Americans," Robert Maxim, Gabriel R. Sanchez, and Kimberly R. Huyser, March 30, 2023. https://www.brookings.edu/research/why-the-federal-government-needs-to-change-how-it-collects-data-on-native-americans/

[xvii] ""Middle Eastern and North African Americans may not be perceived, nor perceive themselves, to be White," February 7, 2022. Neda Maghbouleh https://orcid.org/0000-0001-8541-2079 neda.maghbouleh@utoronto.ca, Ariela Schachter https://orcid.org/0000-0002-7404-4140, and René D. Flores https://orcid.org/0000-0002-9137-3261Authors Info & Affiliations https://www.pnas.org/doi/abs/10.1073/pnas.2117940119

[xviii] 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"

[xix] President's Advisory Commission on Asian Americans, Native Hawaiians, and Pacific Islanders Recommendations, September 2022

[xx] "California becomes the first state to break down black employee data by lineage," August 18, 2022: https://www.npr.org/2022/08/16/1117631210/california-becomes-the-first-state-to-break-down-black-employee-data-by-lineage

[xxi] SB 189: https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=202120220SB189