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**Headquarters:**

One Kaiser Plaza Suite 850  
Oakland, CA 94612  
Main 415-954-9988  
Fax 510-419-0263  
www.apiahf.org

**Washington D.C. Office:**

1629 K Street N.W. Suite 400  
Washington, D.C. 20006  
Main 202-466-7772  
Fax 202-466-6444

*National Advocates for  
Asian American, Native Hawaiian &  
Pacific Islander Health*

October 3, 2022

National Science and Technology Council (NSTC) Subcommittee on Equitable Data  
Office of Science and Technology Policy  
Eisenhower Executive Office Building  
1650 Pennsylvania Ave, NW  
Washington, DC 20504

Submitted via email at [equitabledata@ostp.eop.gov](mailto:equitabledata@ostp.eop.gov)

**Re: Engagement and Accountability RFI**

Dear Chief Data Scientist Ross,

The Asian & Pacific Islander American Health Forum (APIAHF) sincerely appreciates the opportunity to submit comments in response to the Request for Information on Equitable Data Engagement and Accountability.

With longstanding relationships with over 150 community-based organizational partners in over 40 states and the territories, APIAHF is the nation's oldest and leading health advocacy organization dedicated to improving the health and well-being of over 25 million Asian American (AA), Native Hawaiian (NH), and Pacific Islander (PI) communities. For over 35 years, APIAHF has worked to improve access to and the quality of care for AA and NH/PI communities, many of whom are predominantly immigrant, limited English proficient (LEP), and may be new or unfamiliar with the U.S. healthcare system.

We draw upon our extensive experience in addressing the health inequities that AA and NH/PI communities face and our understanding of the needs and barriers faced by AA and NH/PI communities. Our comments primarily focus on the following questions:

- What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government related to equitable data?
- What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?
- In which agencies, programs, regions, or communities, are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

*What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government related to equitable data?*

**Prioritize short and long-term investments in data infrastructure to enable increased data sharing.** One of the main impediments to data sharing in public health stems from an outdated data infrastructure which does not allow data to be shared across

multiple platforms and sources. Without investments in the data infrastructure itself, successful data sharing is not possible. In the short term, this means investments in technology and human capabilities, while in the long-term, it entails the migration of legacy data systems to modern, equity-oriented data systems.<sup>1</sup> State and local health jurisdictions that rely on outdated and underfunded data systems need to have the resources to update data systems and to migrate existing data to newer, leaner, and more adaptable platforms. The COVID-19 pandemic especially brought to light the consequences of the underinvestment in the public health infrastructure in the U.S. and the need for sustained investments, including in health information technology.

Not only do systems need to be updated, but standards established that enable data sharing between different health care entities and public health departments at the federal, state, and local levels. This means agreed upon, transparent data-sharing and interoperability requirements that incentivize the exchange of health data across health care systems, levels of government, and public health entities in ways that promote health equity. With better quality linked data, government agencies can use the information to leverage from other sources to support and collaborate with community partners to better understand and meet community needs. For example, Health Level 7 Fast Healthcare Interoperability Resources (HL7 FHIR) are standards that are designed to allow for quick and efficient data exchanges because they adopt standards and concepts already existing and familiar to software developers.<sup>2</sup> At the same time, there must be additional standards that ensure that these data exchanges lead to ways of addressing health disparities rather than deepening them by balancing these data-sharing efforts with trust-building with communities and addressing privacy concerns.

**Increase resources dedicated to workforce training and technical assistance on data-sharing across levels of government and for community-based organizations.** Data is only as impactful as the people who collect, analyze, disseminate, and report the data. The promotion of equitable data requires training the workforce and providing technical assistance so that people understand what makes data equitable. Data sharing is more likely to occur when there is agreement on and guidelines for how the data will be used and for what purpose. For example, the Centers for Medicare and Medicaid Services (CMS) Office of Minority Health (OMH) offers health equity technical assistance resources for organizations interested in advancing health equity through data collection and analysis.<sup>3</sup> However, more resources need to be dedicated to fostering a culture that normalizes equitable data such as a plan for data equity that serves as a guide for how entities will promote equitable data through data-sharing, collection and reporting. Training a workforce to value equitable data should go beyond mandatory training on structural racism and bias in data collection, analysis and reporting to building an organizational culture that prioritizes equitable data and data practices. One way of advancing equitable data practice is through principle-aligned practices for the data life cycle, from acquisition to disposition, that protect human subjects and create a less harmful and more just data environment.<sup>4</sup>

*What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?*

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<sup>1</sup> Robert Wood Johnson Foundation, *Charting a Course for an Equity-Centered Data System: Recommendations from the National Commission to Transform Public Health Data Systems*, October 2021. Available at:

<https://www.rwjf.org/en/library/research/2021/10/charting-a-course-for-an-equity-centered-data-system.html>

<sup>2</sup> The Office of the National Coordinator for Health Information Technology, *What is HL7 FHIR?* Available at:

<https://www.healthit.gov/sites/default/files/page/2021-04/What%20Is%20FHIR%20Fact%20Sheet.pdf>

<sup>3</sup> For more information: <https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/Health-Equity-Technical-Assistance>

<sup>4</sup> Marcus Gaddy and Kassie Scott (Urban Institute), *Principles for Advancing Equitable Data Practice*, (June 2020). Available at: [https://www.urban.org/sites/default/files/publication/102346/principles-for-advancing-equitable-data-practice\\_0.pdf](https://www.urban.org/sites/default/files/publication/102346/principles-for-advancing-equitable-data-practice_0.pdf)

**Require the disaggregation of race and ethnicity data across all federal and local agencies by revising and expanding Office of Management and Budget (OMB) categories.** For decades, AA and NH/PI communities have urged for data disaggregation. However, since 1997, no changes have been made to OMB Directive No. 15, Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (OMB standards). For 25 years, these minimum standards have limited the categories by which federal agencies collect data on race and ethnicity. While we commend the current ongoing process to review the OMB Standards, without a change in the Standards, federal and state agencies as well as community-based organizations cannot be armed with the baseline tools needed to advance equitable data.

Since the OMB Standards were last re-visited, we have witnessed significant change in the population makeup within AA and NH/PI communities. AA and NH/PIs comprise the fastest growing population in the U.S., and AAs are projected to grow more than 100% between 2030 and 2060, while the NH/PI population is projected to grow by nearly 50%.<sup>5</sup> To account for these changes, APIAHF has previously urged OMB to require agencies to follow the question format used in the U.S. Census's 2015 National Content Test (NCT) Final Report, (Figure 26, page 88) which includes checkboxes for six of the largest AA as well as six of the largest NH/PI populations plus listing the next three populous populations as “for example” write-in groups.<sup>6</sup> Additionally, APIAHF has recommended that these categories not be static, but regularly updated so that when subgroup population sizes change in relative size over time, new checkbox categories are added to reflect the change in population sizes.

Some states have already taken the lead in implementing data disaggregation. In 2021, the state of New York passed data disaggregation legislation which requires all state agencies, boards and commissions that already collect demographic data to collect more granular data on AA and NH/PI groups and languages spoken. Agencies must disaggregate data for the ten most populous AA groups, along with Native Hawaiian, Guamanian, Chamorro, and Samoan groups. This legislative change would not have been possible without the decades of advocacy by AA and NH/PI community-based organizations demanding better data that reflects the diversity of our communities.

Federal, state, and local governments as well as community-based organizations depend on data to assess and distribute resources. Data that is not disaggregated cannot be equitable because it renders entire communities invisible and their needs unknown and unaddressed. Not only does the lack of disaggregated data make communities invisible, but they also fuel racist misconceptions and myths about populations- for example, the “healthy minority” misperception and “model minority” myth that Asian Americans are healthier and better off than other communities of color.<sup>7</sup>

**Increase access to equitable data for limited English proficient (LEP) populations by expanding the quantity and diversity of language services related to the collection, analysis, and reporting of federal data.** Existing federal laws and regulations, including Title VI of the Civil Rights Act of 1964, Executive Order 13166, Section 1557 of the ACA, and Language Access Plans generated by agencies, require protections for limited English proficient populations. However, in-language resources and support services are significantly lacking when it comes to data collection, analysis, and reporting. One in three Asians Americans and one in ten Native Hawaiian/Pacific Islanders are limited English proficient. In the absence of sufficient language services, many AA and NH/PI communities are unable to participate in, contribute to, or use equitable data. Considering the limited English proficiency of AA and NH/PI as well as other LEP communities, federal agencies should at minimum develop a language assistance program in data collection, analysis, and dissemination efforts.

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<sup>5</sup> U.S. Census Bureau, *Demographic Turning Points for the United States: Population Projections for 2030-2060*, (February 2020). Available at <https://www.census.gov/content/dam/Census/library/publications/2020/demo/p25-1144.pdf>

<sup>6</sup> APIAHF comment letter available at: <https://www.apiahf.org/resource/comment-letter-to-the-office-of-management-and-budget-2017/>

<sup>7</sup> Stella Yi et al, *The Mutually Reinforcing Cycle of Poor Data Quality and Racialized Stereotypes that Shapes Asian American Health*, *Health Affairs* 41:2, (February 2022). Available at: <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2021.01417>

The increased availability of language services related to the collection, analysis, and reporting of race and ethnicity data would increase opportunities for more community-based organizations to use equitable data. An example of a best practice is using interpreters to assist LEP persons in completing surveys and in-language guides/pamphlets that explain how the data that is collected will be used. These efforts to reach LEP populations should be done by recruiting and training trusted community organizers, including community health workers and patient navigators, who have cultivated strong relationships with community members.<sup>8</sup>

**Foster and strengthen partnerships with community-based organizations that are already producing and using equitable data by providing resources and support, such as grants and financial assistance.** Because of the lack of disaggregated data for the populations they serve, many community-based organizations undertake time consuming and expensive data collection for their own, including data collection utilizing in-language services. In January 2022, APIAHF in collaboration with the NYU Center for the Study of Asian American Health (NYU CSAAH) and community-based partners developed the National Covid-19 Rapid Needs Assessment survey to understand COVID-19 related needs and knowledge within AA and NH/PI communities, which was translated into Arabic and 11 Asian languages.<sup>9</sup> Federal agencies should identify and encourage such efforts by making available more resources, including financial assistance.

*In which agencies, programs, regions, or communities, are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?*

**Require state health agencies to standardize race and ethnicity categories as well as instructions on how race and ethnicity data is collected, using ACA Section 4302 as a minimum standard.** Despite guidelines such as section 4302 of the Affordable Care Act which since 2012, has required population health surveys used in federal health programs, to collect and report data on race, ethnicity, sex, primary language, and disability status, race and ethnicity data of enrollees in federal health programs, including Medicaid and Medicare, are incomplete and inaccurate. Additionally, these inaccuracies have been found to be more common for certain beneficiaries, including AA and NH/PI beneficiaries.<sup>10</sup> The lack of accurate and complete race and ethnicity data of enrollees in federal health programs impede the ability to assess and address health disparities writ large.

Data on Medicaid beneficiaries provide a key example. State Medicaid agencies vary widely in the number of categories they use to collect race and ethnicity data as well as how these variables are named and combined to create aggregated categories.<sup>11</sup> As a result, it is nearly impossible to understand the experiences of Medicaid beneficiaries as well as to understand the racial and health disparities experienced by beneficiaries at the national level. The ability to collect meaningful, reliable health data that is accurate, timely, and complete means enforcing

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<sup>8</sup> White House Initiative on Asian Americans and Pacific Islanders Interagency Working Group Data and Research Subcommittee, *Best Practices for the Disaggregation of Federal Data on Asian Americans and Pacific Islanders*, (March 2016). Available at: <https://www.hhs.gov/sites/default/files/mar2016-whiaanhpi-data-disaggregation-report.pdf>

<sup>9</sup> APIAHF, *National Multilingual COVID-19 Survey to AA & NH/PI Communities Finds Confidence in Vaccination and Widespread Misinformation*, (July 2022). Available at: <https://www.apiahf.org/press-release/national-multilingual-covid-19-survey-to-aa-nh-pi-communities-finds-confidence-in-vaccination-and-widespread-misinformation/>

<sup>10</sup> U.S. Department of Health and Human Services Office of Inspector General Data Brief, *Inaccuracies in Medicare's Race and Ethnicity Data Hinder the Ability to Assess Health Disparities*, (June 2022), OEI-02-21-00100. Available at: <https://oig.hhs.gov/oei/reports/OEI-02-21-00100.pdf>

<sup>11</sup> Heather Saunders and Priya Chidambaram (Kaiser Family Foundation), *Medicaid Administrative Data: Challenges with Race, Ethnicity, and Other Demographic Variables*, April 2022. Available at: <https://www.kff.org/medicaid/issue-brief/medicaid-administrative-data-challenges-with-race-ethnicity-and-other-demographic-variables/>

and prioritizing the standardization of categories and collection methods, such as how questions soliciting answers on health surveys are worded.

Thank you again for the opportunity to provide comments. We sincerely commend ongoing federal efforts to advance equitable data – data that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of all individuals, including those who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality – and we hope that our responses help inform the establishment of mutually beneficial collaborations between federal agencies, other levels of government, civil society and the research community. If you have any further questions or concerns, please contact us at [policy@apiahf.org](mailto:policy@apiahf.org).

Sincerely,

A handwritten signature in blue ink, appearing to read 'JKC', enclosed in a light blue rounded rectangular border.

Juliet K. Choi  
President & CEO