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

April 22, 2022

The Honorable Lawrence A. Tabak  
Office of The Director  
National Institutes of Health  
United States Department of Health and Human Services  
9000 Rockville Pike  
Bethesda, Maryland 20892  
Submitted via Email to [NIHAANHPIRFI@nih.gov](mailto:NIHAANHPIRFI@nih.gov)

**RE: Request for Information (RFI): Seeking Stakeholder Actionable Input to Improve Research on Health and Well-being for Asians, Native Hawaiians, and Pacific Islanders (Notice No. NOT-CA-22-047)**

Dear Director Tabak:

The Asian & Pacific Islander American Health Forum (APIAHF) and the 39 undersigned organizations respectfully submit this response to the National Institute of Health's (NIH) Office of the Director's Notice No. NOT-CA-22-047, Request for Information (RFI): *Seeking Stakeholder Actionable Input to Improve Research on Health and Well-being for Asians, Native Hawaiians, and Pacific Islanders*. (Feb. 14, 2022) (hereinafter, RFI).

The organizations represented here work to advance the health and well-being of over 25 million Asian Americans, Native Hawaiians and Pacific Islanders (AA and NHPI) across the U.S. and territories. We aim to improve access to and the quality of care for communities who are predominantly immigrant, many of whom are limited English proficient (LEP), and may be new to the U.S. healthcare system. We draw upon this extensive experience in addressing health inequities in AA and NHPI communities to respond to this RFI.

**NIH Must Invest in Research on AA and NHPI Communities**

AA and NHPI communities are the fastest growing and most diverse racial groups in the U.S. With such a robust and diverse population, also comes a diversity of needs and challenges that are unique to each respective AA and NHPI subgroup. However, in examining clinical research projects funded by the NIH, a cross-sectional study found that 529 research projects focused on AA and NHPI participants between 1992 and 2018, **composing only 0.17% of the total NIH budget**.<sup>1</sup> According to the same study, the proportion of the NIH budget has only increased from 0.12% before 2000 to 0.18% after 2000.<sup>2</sup> These alarming figures are reflective of the overall lack of resources and prioritization on the health and wellbeing of AA and NHPI communities. Thus, the best way to improve research on AA and NHPI communities is to invest more on research in these communities.

<sup>1</sup> Lan N. Đoàn, Yumie Takata, Kari-Lyn K. Sakuma, "Trends in Clinical Research Including Asian American, Native Hawaiian, and Pacific Islander Participants Funded by the US National Institutes of Health, 1992 to 2018," JAMA Network Open (July 24, 2019) available at: <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2738623>.

<sup>2</sup> Ibid.

While there is some data available on health disparities and chronic diseases that disproportionately affect AAs and NHPs, they only scratch the surface of the disparities in our communities.<sup>3</sup> Such data is also conflated with the often inconsistent collection and reporting of data on AAs and NHPs. As illustrated in federal and local data collection and reporting on AAs and NHPs during the COVID-19 pandemic, many states and locales did not collect COVID-19 infection data on AAs and NHPs or failed to disaggregate from AA and NHP, which directly impacts national data reported to federal entities. The pattern of incomplete and inaccurate data on AAs and NHPs often creates misleading narratives and conclusions that complements the lack of available research. Although reported data often portrays AA and NHP communities faring well during the pandemic when compared to other racial groups, the reality is that COVID-19 has become one of the top three leading causes of death in AA and NHP communities.<sup>4</sup>

## **Recommendations**

In order to address research gaps and barriers for AA and NHP communities, NIH must proactively invest in more targeted research for AA and NHP communities and ensure that all research that includes racial and ethnic data is inclusive of AA and NHP communities. We provide the following recommendations for NIH to take appropriate measures to address research gaps and barriers in AA and NHP communities.

1. **Funding for research targeting AA and NHP communities must be increased and explicitly benchmarked on an annual basis, immediately and going forward.** The low percentage of NIH funded research projects on AA and NHP communities can be alleviated by investments in research projects in these communities, including specific AA and NHP subgroups. Such research can better identify and paint a more accurate picture of the health of AA and NHP communities.
2. **All research must include AA and NHP communities.** All clinical research and trials should have protocols that provide a clear data collection and reporting plan, recruitment plan, and present evidence of the degree to which racial and ethnic minority participants are being recruited and included in the study. This can include the targeted education to diverse physicians to encourage AAs and NHPs and other racial and ethnic minorities to participate in research and clinical trials. Further, collected data on AA and NHP communities shall be disaggregated, at minimum, by the Office of Management and Budget standard and in compliance with Section 4302 of the Affordable Care Act.
3. **All research must consider language accessibility and cultural competency.** With 1 in 3 AAs and NHPs being LEP and nearly 60% of the AA and NHP population being immigrants, it is critical that meaningful efforts are made to outreach to and learn about the needs of LEP and immigrant populations. While all research should develop culturally and linguistically appropriate communication and information specific to the research, NIH can also play a critical role in ensuring public outreach and education about the importance of research.
4. **Researchers should build and nurture sustained partnerships with community based organizations.** All research should build partnerships with trusted community leaders and organizations as part of their protocols for recruitment. This is critical to overcoming barriers that are common across racial and ethnic minorities to participation around the issues of mistrust, lack of comfort with the research or clinical trial process, lack of information and lack of awareness. For example, community recruiters (trained members of the community) can assist with education about the research or clinical trial.

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<sup>3</sup> See APIAHF, "Snapshot: Asian American, Native Hawaiian, and Pacific Islander Health" (August 2019) available at: [https://www.apiahf.org/wp-content/uploads/2017/09/August2019\\_SnapshotAANH/PIHealth\\_Factsheet-3.pdf](https://www.apiahf.org/wp-content/uploads/2017/09/August2019_SnapshotAANH/PIHealth_Factsheet-3.pdf).

<sup>4</sup> CDC/National Center for Health Statistics, "Leading causes of death for Asian or Pacific Islander non-Hispanic population" (last reviewed Feb. 2022) available at: <https://www.cdc.gov/nchs/fastats/asian-health.htm>.

## **Conclusion**

Thank you for this opportunity to submit comments and suggestions on improving research on the health and well-being of AAs and NHPs. The NIH efforts to address research gaps and barriers is an encouraging and a welcomed sign of change. Although we could not address every health disparity that is prevalent in AA and NHP communities, we hope that this is an invitation to continue regular discussions and dialogue between NIH and AA and NHP communities. Please do not hesitate to contact APIAHF policy manager, Azizah Ahmad, at [policy@apiahf.org](mailto:policy@apiahf.org) for further information.

Sincerely,

Asian & Pacific Islander American Health Forum (APIAHF)  
Act To Change  
American Public Health Association, Asian Pacific Islander Caucus  
Asian American Research Center on Health  
Asian Americans Advancing Justice | AAJC  
Asian and Pacific Islander American Vote (APIAVote)  
Asian and Pacific Islander Caucus for Public Health (APIC)  
Asian Pacific American Labor Alliance, AFL-CIO  
Asian Pacific American Medical Student Association  
Asian Pacific Partners for Empowerment, Advocacy and Leadership (APPEAL)  
Asian Services in Action, Inc. (ASIA)  
California Pan-Ethnic Health Network  
Center for Pan Asian Community Services  
Disability Rights Education and Defense Fund (DREDF)  
Empowering Pacific Islander Communities (EPIC)  
Hmong National Development  
Japanese American Citizens League  
Justice in Aging  
Kamehameha Schools  
Karen Society of Nebraska  
Micronesian Islander Community  
Monsoon Asians & Pacific Islanders in Solidarity  
National Asian Pacific American Families Against Substance Abuse  
National Asian Pacific American Women's Forum  
National CAPACD- National Coalition for Asian Pacific American Community Development  
National Council of Asian Pacific Americans (NCAPA)  
National Federation of Filipino American Associations  
National Japanese American Memorial Foundation (NJAMF)  
National Organization of API Ending Sexual Violence  
National Partnership for Women & Families  
National Tongan American Society  
NYU Center for the Study of Asian American Health (CSAAH)  
OCA-Asian Pacific American Advocates  
Orange County Asian and Pacific Islander Community Alliance (OCAPICA)  
Pacific Islander Community Association of Washington  
SHK Global Health  
Sikh American Legal Defense and Education Fund (SALDEF)  
South Asian Public Health Association (SAPHA)  
Southeast Asia Resource Action Center (SEARAC)  
University of Hawaii System - Office of Strategic Health Initiatives