

**Executive Summary of Responses  
to  
Request for Information Seeking Stakeholder Actionable Input to  
Improve Research on Health and Well-Being for Asians, Native  
Hawaiians, and Pacific Islanders**

NIH request for information (RFI) ([NOT-CA-22-047](#)) titled “Seeking Stakeholder Actionable Input to Improve Research on Health and Well-Being for Asians, Native Hawaiians, and Pacific Islanders”

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## Executive Summary

In 2021, the NIH Asian American, Native Hawaiian, and Pacific Islander Health Scientific Interest Group (AANHPI-HSIG) initiated an strategic effort to better understand and improve health-related research tailored toward the needs of Asian Americans (AA), Native Hawaiians (NH), and Pacific Islanders (PI) in support of the White House Initiative on Asian Americans, Native Hawaiians, and Pacific Islanders (WHIAANHPI) and [Executive Order 14031](#) of May 28, 2021. As part of this effort, an NIH-wide working group led by NCI developed and published a groundbreaking Request for Information (RFI), titled "Seeking Stakeholder Actionable Input to Improve Research on Health and Well-Being for Asians, Native Hawaiians, and Pacific Islanders." ([NOT-CA-22-047](#)), open from February 14 to April 22, 2022. This RFI marked the first NIH request aimed explicitly at gathering disaggregated insights including subpopulations across eight research fields pertinent to the health of AA and NHPI communities in the United States. A comprehensive analysis was subsequently conducted on the inputs and opinions of RFI respondents. This report summarizes the results of this analysis to help inform NIH's research efforts toward addressing and reducing existing health disparities within AA and NHPI communities.

### Summary of Five Major Priority Themes for Recommendations

In response to the RFI, 43 unique responses were received from various US organizations, scientific societies and foundations, health professional and physician groups, academic university hospitals, companies, and local, state, and regional government entities. There were 8 responses specific for AA health, 11 for NHPI health, and 23 for AA and NHPI health, in which each response was further verified or reviewed for coding agreement. This executive summary aims to encapsulate the major findings and recommendations from the above-referenced RFI. These responses are grouped into five research priority themes (in no particular order): (1) Disparities and Research Needs in Health Conditions, Risk Factors, and Health Care Access, (2) Research Infrastructure, Methodology, Data and Biological Resources, and Technology, (3) NIH Grant Review, Research Funding, and Reporting, (4) Community Engagement and Community-Centric Research, and (5) Workforce and Leadership.

#### **1. *Disparities and Research Needs in Health Conditions, Risk Factors, and Health Care Access***

Ongoing research needs and opportunities identified from RFI responses include significant disparities in chronic or non-communicable diseases, and in understanding the specific multilevel risk factors (such as genetic predispositions, lifestyle, and social determinants of health) that contribute to them, including both physical and mental health outcomes. Cultural and language barriers potentially act as significant factors affecting healthcare access and utilization, especially among first-generation AANHPI immigrants.

Recommendations to address these challenges emphasize the importance of ensuring optimally inclusive research approaches, building community trust for research participation and clinical trials, improving genetic and genomic research directed toward understanding the nature of health disparities, advocating for optimal disaggregated data collection and utility among AA and NHPI subpopulations, and establishing consortiums for health screening programs. Addressing these challenges may require implementing multi-faceted, culturally informed research approaches in a network or center setting. Expanding research on the effects of discrimination on AA and NHPI populations and ensuring the meaningful, intentional, and culturally appropriate engagement of AA and NHPI communities in the research enterprise will contribute to better understanding and achieving more equitable health outcomes.

## **2. *Research Infrastructure, Methodology, Data and Biological Resources, and Technology***

Significant challenges were identified in data to better understand AA and NHPI health disparities, including underrepresentation of AA and NHPI in existing health and health research data sets (lack of sufficient data/small sample sizes), race classification issues, and database structural barriers. These challenges are exacerbated by a general lack of active engagement and participation by non-English speaking AA and NHPI populations and multiracial individuals, thereby impeding the quality, quantity, and accessibility of health-related data.

Recommendations for addressing these challenges include enhancing AA and NHPI representation in research efforts by overcoming language barriers, building trust when working with the AA and NHPI community, expanding datasets to include standardized and disaggregated data collection from AA and NHPI populations if appropriate, establishing centralized data management systems, and advancing technology for efficient data handling of small sample sizes. Considering cultural sensitivity in data interpretation and leveraging AI and machine learning for language translation services is crucial for improving the quality, accessibility, and delivery of health services for Limited English Proficiency (LEP) AA and NHPI populations.

## **3. *NIH Grant Review, Research Funding, and Reporting***

The majority of responders to this RFI suggested that careful consideration be given to supporting meritorious grant proposals focused on AA and NHPI health disparities research, because only 0.18% of NIH's budget from 1992 to 2018 was allocated to AA and NHPI health research (Đoàn, L. N., et al. 2019. JAMA Network Open, 2(7)). Limited grant funding durations makes it harder to accommodate the necessary depth of community engagement, and a critical gap exists in disaggregated NIH funding data for AA and NHPI health research.

Recommendations provided through the RFI to address these challenges include establishing a dedicated NIH priority plan for AA and NHPI research with increased funding and dedicated research centers or networks, enhancing research training and support, promoting community trust and engagement, revising underrepresentation in research criteria to include AA and NHPI groups, and improving data reporting for subpopulations. Addressing potential biases in grant review through

potential specialized review groups with proper cultural competency training and implicit bias mitigation strategies is equally critical to ensuring equitable research funding for both AA and NHPI, and other communities experiencing disparities.

#### **4. *Community Engagement and Community-Centric Research***

Significant challenges were reported through the RFI, including a community-based participatory research model biased towards academic interests over community needs, cultural and contextual barriers, and a deep mistrust of participation in research.

Recommendations to address these challenges include emphasizing a shift towards community-centric engagement, including the expansion of community involvement and participation in appropriate research phases, and improving overall trust. Culturally informed methodologies, communication and dissemination strategies are critical toward achieving these aims. Enhancing funding by adapting flexible approaches to accommodate the diverse needs of AA and NHPI populations was mentioned.

#### **5. *Workforce and Leadership***

RFI respondents reported a critical need for enhancing cultural competency, greater involvement of community leaders in decision-making processes, and improved representation in leadership roles for biomedical research fields at NIH and other agencies external of NIH.

Corresponding recommendations to address these needs include prioritizing the development of a culturally competent research workforce, increasing funding support for Career Development Awards, and establishing a network of mentors to connect researchers with minority-serving institutions to foster collaborative partnerships to enhance the representation of AA and NHPI communities in health research and address the unique health disparities facing these populations.

### **Conclusions and Next Steps**

The feedback received through the RFI process underscores a feeling or impression by respondents of the urgent need to further address the multifaceted health disparities facing AA and NHPI communities caused by interplay of complex factors, such as genetic predisposition, lifestyle and behavior, environmental factors, social determinants of health, and language barriers to research participation and healthcare access. Similarly, a corresponding feeling among respondents is that significant strides can be made towards improving the health outcomes for AA and NHPI by (1) supporting multi-level and multifaceted preclinical and clinical disparities research on diseases with a high incidence and/or mortality among AA and NHPI populations and subpopulations, (2) enhancing trust and therefore intentional community engagement in research planning and implementation to ensure cultural relevance and effectiveness, (3) improving the ability to communicate or report on disaggregated data for major subpopulations with innovative methodology and technology in overcoming the challenges such as small sample size or widely geographically distributed living, (4) developing culturally sensitive

interventions that help improve access to quality health care, especially for immigrants with language barriers, and (5) establishing a culturally competent research workforce with increased leadership opportunities.

Collaborative efforts between NIH, academic researchers, community organizations, and healthcare providers were suggested as essential to drive meaningful change and ensure increased NIH research dedicated to improving AA and NHPI health outcomes and reducing health disparities.

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