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Asian American and Native Hawaiian and Pacific Islander Visibility and Data Equity: Insights From NIH RADx-UP

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The COVID-19 pandemic disproportionately affected the health and well-being of more than 24 million Asian Americans and 1.6 million Native Hawaiian and Pacific Islanders (NHPIs)

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CONFLICTS OF INTEREST

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in the United States.^{1,2} Among the combined population (AANHPIs), specific subgroups like Native Hawaiians, Pacific Islanders, Filipinos, and Cambodians faced significantly higher rates of exposure and death from COVID-19 compared with other Asian American groups.¹ At the height of the pandemic in mid-2020, the proportion of COVID-19 cases among Asian Americans exceeded their population representation in 17 states.³

Despite missingness and reporting delays, Hawaii—the only state that collected and reported subethnic COVID-19 information on AANHPIs—reported that 21% of Native Hawaiians and 4% of other Pacific Islanders accounted for 43% and 25% of the state’s COVID-19 cases,⁴ respectively. Furthermore, in California, second to Hawaii for the highest proportion of Asian Americans, Asian Americans represent 17% of the population and accounted for 13% of COVID-19-related deaths, 6% of cases, and 18% of vaccinations.⁵ High rates of COVID-19 among AANHPIs, many of whom have preexisting conditions (e.g., obesity and hypertension) and increased risk of exposure (i.e., overrepresented in health care and essential work settings), highlight the large disparities that predated the pandemic and point to gaps in income, education, access to good health care, community programs, and social integration.⁶

In addition, the pandemic escalated racism and violence against AANHPIs; Asian American elderly and women were particularly vulnerable.⁷ For AANHPIs, the pandemic and the research funding opportunities at community and institutional levels that resulted from the pandemic provided timely opportunities to collectively advocate health and data equity.⁷ Socioecological determinants and health outcomes among AANHPI communities in the United States are heterogeneous, requiring representation of diverse subethnic groups in research. However, clinical, behavioral, and epidemiological research often lacks adequate and timely AANHPI representation, leading to poor data quality.⁶⁻⁸ Efforts to advance knowledge on AANHPIs are often underprioritized and misunderstood. AANHPI data are referenced as an aggregated ethnic/racial group or miscategorized as “other race,” which inappropriately obscures and dilutes crucial and unique differences among AANHPI subgroups—information that may be essential to addressing subethnic disparities. Although aggregate data may have benefits, like “power in numbers,” which can be advantageous in policy-making, practices that aggregate all AANHPIs as one ethnicity/race are forms of structural racism, making smaller groups and their needs invisible by collapsing them into one ethnic/racial group.⁶⁻⁹

The National Institutes of Health’s (NIH’s) Rapid Acceleration of Diagnostics-Underserved Populations (RADx-UP) initiative is a consortium of 137 research projects studying COVID-19 behavioral (vaccine and testing) patterns in communities across the United States, its territories, and Tribal Nations.¹⁰ Most NIH RADx-UP projects were built upon well-established, trusting relationships between academic researchers and community partners. Community collaborators representing AANHPIs span the country and US-affiliated Pacific Islands, such as Guam and Republic of the Marshall Islands. In the consortium, we represent 7 RADx-UP Asian American and NHPI projects with similar and diverse data from our respective communities, many of which have historically been hard to reach, demonstrating our deep connection and commitment to advocate for Asian American and NHPI issues during the COVID-19 pandemic. Our projects are not without

community advocates, who serve as trusted collaborators who liaise their connections to uncover critical health and other needs of the minoritized groups. This editorial describes a collective process of validating community-based work that actively highlights AANHPI-led partnerships with community leaders and other stakeholders. We describe collaborations that have enabled true insider community experts to access, explore, and interpret sensitive and often misunderstood topics with AANHPI community members, such as poor mental health and discrimination within the health care system.

ASIAN AMERICAN, NATIVE HAWAIIAN AND PACIFIC ISLANDER DATA STANDARDS

AANHPI subgroups have varied histories and political and immigration contexts, which uniquely impact their socioeconomic circumstances, health, and well-being. Existing societal backdrops like the model minority myth, perpetual foreigner syndrome, colonial mentality, racism, and proximity to Whiteness exacerbate poor health outcomes.^{3,11} In addition, intergenerational survival behavior, which encourages compliance with authority figures and subservience, masks challenges faced by many.¹¹ Survivors of World War II Japanese internment camps and their children were often encouraged to stay silent and be model Americans.¹² Many AANHPIs, like other immigrants, often delay seeking assistance for their health because of fear that bringing attention to themselves will jeopardize their immigration status.^{3,7,8} AANHPI health needs are thus overlooked, resulting in higher rates of chronic health conditions such as cancer and diabetes—highly prevalent issues among specific AANHPI subgroups (e.g., Filipinos, Koreans, Samoans, Tongans).¹³⁻¹⁵ Over the life course, AANHPI health care access issues persist, ranging from poorer quality of health care services to low utilization of preventive care.¹³

Not all national or big data sets assemble, provide access to, or report subethnic group information.¹ Most data sets aggregate AANHPI as one ethnic/racial category, because it is small compared with other US ethnic groups.^{16,17} Although there are growing federal efforts to disaggregate data and information on AANHPI subethnic groups, access to such disaggregated data to document and address health disparities has been challenging because, by default, subethnic AANHPI data are aggregated within the larger AANHPI ethnic/racial category.¹⁷ AANHPI data are often not reported at all or are deemed missing, and if collected, are then aggregated.¹⁸ In addition, federal guidelines to obtain such granular ethnic/racial information often do not follow the Office of Management and Budget standards,¹⁹ which distinguish NHPIs from Asians and which provide standards for data management and presentation of race data, as well as Office of Minority Health,²⁰ which sets data criteria for race classifications. Another issue of AANHPI data quality is that enhanced methods such as oversampling are ignored.^{11,16-18}

RADX-UP AND ASIAN AMERICANS, NATIVE HAWAIIANS AND PACIFIC ISLANDERS

Measurements and questionnaires used to assess health and mental health status have mainly been empirically studied among majority White samples.⁷ It is widely documented that

ethnic minorities are underrepresented in clinical and translational research. Data on ethnic minorities and, more specifically, AANHPIs, rarely drive the development of widely used community public health tools and interventions.¹⁹ Researchers working with AANHPIs often assess validity and reliability of these tools post hoc.²¹ Research and data collection practices were created by the majority group, with little or no regard to monitor systemized biases and racialized practices resulting in AANHPI invisibility.²² To work around these widely used but often insensitive instruments, the research projects represented in this editorial completed additional work to improve and revise survey items to better align with the needs and priorities of diverse AANHPI communities. Outlined below are some of our efforts:

Survey Measures

All RADx-UP-funded projects are required to collect the same variables using standardized survey questions known as common data elements (CDEs).¹⁰ Although well established and utilized by many other research groups, these CDEs are not inclusive or reflective of the “underserved populations” in our RADx-UP projects. The required CDEs consisted of more than 100 questions, ranging from demographics to COVID-19 behaviors, and were deemed lengthy and confusing by study participants, leaving little room for additional survey questions that could better align with priorities of the AANHPI community and address more culturally relevant information (i.e., experiences of discrimination, historical trauma, fiscal or housing insecurity)^{3,7,9}

Culturally Aligned and Inclusive Efforts

The CDEs did not offer options for other major Asian languages like Tagalog, Vietnamese, Khmer, Thai, or Hmong. For our RADx-UP projects, considerable efforts were made during the development and implementation stages to create more language-appropriate surveys. We invested resources to translate and provide interpretation of the CDE survey instruments for six different Pacific Islander languages (i.e., Native Hawaiian, Marshallese, Samoan, Tongan, Chuukese, and Pohnpeian) and seven Asian languages (i.e., Chinese, Tagalog, Vietnamese, Korean, Khmer, Thai, and Hmong) across our RADx-UP projects. In the field, survey administration typically required up to 30 minutes online or 1 hour on paper to complete, regardless of whether it was facilitated by trained staff or community health workers, and whether it was conducted in the native language or in English, using paper or online formats. These time-consuming processes place a significant burden on both researchers and community-based partners. Capacity building involved iterative protocols and feedback with community partners, AANHPI translations by native speakers, and culturally relevant examples. These investments in community-engaged research align with collectivist approaches, fostering harmony among AANHPI communities.

Community-Driven Approaches for Recruitment

The RADx-UP efforts, led by large academic institutions, have been enriched by strong partnerships with community leaders and stakeholders who possess expertise in accessing sensitive and preexisting health topics, such as mental health challenges, barriers to health resources, and quality health care.^{11,22} Trust between participants and researchers was fostered, especially through the advocacy and connections of community

representatives who carry the community's weight.²³ During the COVID-19 pandemic, our academic-community collaborations highlighted the essential importance of trust in public health information to engage AANHPI participants effectively. By leveraging Hawaii's and California's diverse AANHPI population, we identified how trust and information consumption influenced participation in COVID-19 mitigation strategies. Notably, NHPs and Filipinos exhibited greater distrust in official sources, significantly hindering their engagement. Our successful academic-community collaborations, community-based strategies, and cultural expertise effectively engaged and enrolled participants in our research studies.

Community Experts

Although large academic institutions are leading the RADx-UP efforts, the approach relies on the partnership of community leaders and stakeholders, who are content experts on accessing data on sensitive undiscussed topics predating the pandemic, like poor mental health, systemic barriers to health resources, and quality health care. The ability to obtain information from the community shows trust by both participants and researchers.^{18,24} Not all ethnic subgroups benefit from designated community health workers, but all communities have trusted stakeholders, elders, religious leaders, and convening spaces (e.g., churches, restaurants, grocery establishments) that are vital to building community trust for research as well as grounds for recruitment, retention, and dissemination.²²⁻²⁴ We need further investment to fortify and maintain these dynamic relationships and to build new ones.

Adapting to Communities in Real Time

RADx-UP projects faced challenges because of changes in community-based organizations during the pandemic, but they adapted with additional resources, flexibility, and consistent communication to include diverse voices. Flexibility was required for every community interaction, from research planning to data collection and data dissemination. Meaningful AANHPI research meets the community members where they are. RADx-UP research protocols for AANHPI communities supported various ways of interaction, including different preferences for engagement and communication across the community. For example, in one RADx-UP project with Pacific Islanders, some community members preferred answering survey questions online, while others preferred one-on-one surveys administered in their native language. In addition, with dissemination, some community groups preferred a presentation of results in a community gathering (e.g., church) delivered in PowerPoint while others preferred "low tech" data walks at community events with poster boards of results.

Collective Advocacy for a Paradigm Shift

As we move into the postpandemic era, the collaborations and partnerships formed by these funded projects provide a strong foundation for addressing AANHPI issues. However, it is crucial that Asian American and NHPI issues receive greater recognition and sustained federal support. To maximize the momentum built by community progress and success of these diverse, community-focused projects, additional investment will allow new partnerships and fortification of dynamic relationships with AANHPI communities throughout the United States.

Understanding Discrimination and Anti-Asian Hate

The experiences and perceptions of discrimination among AANHPI groups vary greatly, and these experiences have deepened during the pandemic,²¹ with limited data collected before it. The intersectionalities of AANHPI characteristics—such as age, gender, time from immigration, socioeconomic status, geographic location, and expressive phenotypes—moderate the perception of racism. Identifying discrimination ranges from recognizing structural racism to reporting specific discriminatory events. Furthermore, dismissing discrimination and racism events as not being significant enough to notify authorities or speak about are common occurrences in AANHPI communities.⁷ Questions for AANHPI participants about discrimination can be ambiguous or misinterpreted, requiring further explanation or assistance so that they can accurately identify relevant experiences from their past.^{7,9}

Changes to Current Data Infrastructure

Data on Asian American and NHPI health determinants and outcomes are delayed by three to five years.^{3,6,18} This further postpones community response and allocation of resources by those who often decide these dissemination efforts. Democratizing AANHPI data and providing meaningful reports through data access and accountable data practices may lead to a culture that collects and disseminates information about AANHPI subethnic groups.¹⁶⁻¹⁸ Coincidentally, research practices of single, mutually exclusive race reporting dilute the narratives of the roughly 17% and 56% multiracial Asian Americans and NHPIs residing in the United States,²⁵ respectively. Research decisions to report only on racial hierarchies codify the historical attempts to divide and minimize AANHPI lives and experiences. The collection of disaggregated data must be a standard practice, and small sample sizes (although not statistically robust) should still be collected, disaggregated, and reported on.^{18,19} Only then will research and data practices be trustworthy by respecting the distinct contexts of AANHPI subgroups, cultures, and national origins, making visible the various unique narratives and demonstrating that statistics (or positivist and deficit research) is not the only driver of inquiry.

Funding and Timeline Considerations

There is a strong need to invest both structurally and financially in Asian American and NHPI health-related content, warranting AANHPI surveillance and cohort studies as well as larger data samples that are truly representative of Asian American and NHPI heterogeneity. Furthermore, it is crucial to address severe limitations in the review process by training a diverse group of reviewers to understand the diversity within the AANHPI population. Funding AANHPI initiatives requires intentional and equitable resource allocation by decision-makers and institutions to not stifle AANHPI access and progress. Communities are bound by timely funding that allows programs to actively run and support further grant funding.

Significant amounts of personnel and time are often required to address barriers to minority participation in research studies, which may include lengthy consent forms, translation of nonexistent terms within certain cultures, and survey fatigue. Funding institutions must consider the timelines of community-based partners, which may not align with academic or

federal cycles. Sponsoring institutions should avoid imposing specific research protocols on communities without adequate support. Instead, they should involve communities early in the development of funding opportunities and include AANHPI representation in the review processes. Grants should not only state the need for community-based partnership but also foster academic-community collaboration throughout the process.

CONCLUSION

This editorial offers a glimpse into the nationwide efforts to better understand the impacts of COVID-19 on AANHPIs and provide specific research methods used to work in the communities. It also serves as an advocacy tool, pushing to improve data disaggregation, data collection procedures, and data analysis, and to prioritize funding opportunities that address community needs and impact in AANHPI communities.

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