

Data Equity for Asian American and Native Hawaiian and Other Pacific Islander People in Reproductive Health Research

Katrina J. Heyrana, MD, PhD, Bliss Kaneshiro, MD, MPH, Reni Soon, MD, MPH, Brian T. Nguyen, MD, MSc, and Melissa F. Natavio, MD, MPH

Though racial and ethnic disparities in sexual and reproductive health outcomes are receiving greater interest and research funding, the experiences of Asian American and Native Hawaiian and Other Pacific Islander (NHPI) people are often combined with those of other racial and ethnic minority groups or excluded from data collection altogether. Such treatment is often rationalized because Asian American and NHPI groups comprise a smaller demographic proportion than other racial or ethnic groups, and the model minority stereotype assumes that these groups have minimal sexual and reproductive health needs. However, Asian American and NHPI people represent the fastest-growing racial-ethnic groups in the United States, and they face disparities in sexual and reproductive health access,

quality of care, and outcomes compared with those of other races and ethnicities. Disaggregating further by ethnicity, people from certain Asian American and NHPI subgroups face disproportionately poor reproductive health outcomes that suggest the need for culturally targeted exploration of the unique drivers of these inequities. This commentary highlights the evidence for sexual and reproductive health disparities both in and between Asian American and NHPI groups. We also examine the failures of national data sets and clinical studies to recruit Asian American and NHPI people in proportion to their share of the U.S. population or to consider how the cultural and experiential diversity of Asian American and NHPI people influence sexual and reproductive health. Lastly, we provide recommendations for the equitable inclusion of Asian American and NHPI people to promote and systematize the study and reporting of sexual and reproductive health behaviors and outcomes in these culturally, religiously, and historically diverse groups.

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From the Department of Obstetrics & Gynecology, Cedars Sinai Medical Center, and the Department of Obstetrics & Gynecology, Keck School of Medicine, University of Southern California, Los Angeles, California; and the Department of Obstetrics, Gynecology & Women's Health, John A. Burns School of Medicine, University of Hawaii, Honolulu, Hawaii.

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Corresponding author: Katrina J. Heyrana, MD, PhD, Department of Obstetrics & Gynecology, Cedars Sinai Medical Center, Los Angeles, CA; katrina.heyrana@cshs.org.

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In 1985, the Department of Health and Human Services (DHHS) published the “Report of the Secretary’s Task Force on Black & Minority Health,” the first U.S. government report to call attention to health disparities in people from racial and ethnic minority groups.¹ This led to a proliferation of research identifying disproportionately poor outcomes for Black, Indigenous, and People of Color (BIPOC) and their structural drivers.² However, policymakers and researchers often exclude Asian American and Native Hawaiian and Other Pacific Islander (NHPI) people, who comprise 6.0% and 0.2% of the U.S. population respectively, from discussions of racial, social, and health inequity. Asian American and NHPI people represent the fastest growing racial groups in the

United States.³ The Asian population grew 81% between 2000 and 2019, from 10.5 to 18.9 million, and is projected to reach 46 million by 2060.⁴ Native Hawaiian and Other Pacific Islander people originate from more than 30 distinct Pacific nations, are the third most rapidly expanding group, and grew by 61% during the same period.³ Despite this growth, due to relatively small individual numbers, NHPI people are often combined with Asian American populations in U.S. demographic analyses despite historical and cultural differences.

Health outcomes research frequently omits Asian American and NHPI populations for several reasons. Asian American and NHPI people are concentrated in certain regions across the United States, which can make sampling logistically challenging in large national surveys. More than 50 unique cultural and linguistic subgroups fall under the U.S. Census designation of “Asian” and “NHPI,” and customizing linguistically congruent data-collection tools for these diverse populations may exceed the expertise of survey administrators and researchers. When Asian American and NHPI people are included in studies, their lower demographic proportions compared with those of other racial minority groups make it difficult to draw statistically representative conclusions about their health risks and behaviors.^{5,6}

Another prominent driver of Asian American and NHPI omission in health disparities data is the faulty assumption that these groups collectively enjoy better health outcomes than their counterparts of other races and ethnicities. The Asian model minority stereotype—that is, that Asian people achieve higher levels of academic and economic success than other racial and ethnic minority groups—perpetuates the misconception that Asian people have behaviors and patterns of health outcomes that parallel the majority White population and therefore do not require additional resources and research.^{7,8} The model minority myth is the direct result of U.S. immigration policies, beginning with the Immigration and Nationality Act in 1965, that lifted restrictive country quotas and prioritized the migration of highly trained migrants with the ability to fill U.S. labor shortages.⁸ Although large numbers of Asian professionals such as health care workers came to the United States through this legislation, relatively smaller numbers of refugees and laborers also migrated.⁹ These policy choices and resultant uneven migration patterns, rather than any extraordinary attributes on the part of Asian people, contributed to a false narrative of superior Asian industriousness compared with other minority groups. Thus, policymakers have wielded the model minority

myth to minimize the existence of structural racism by suggesting that individual effort can surmount inequitable American policies.⁸ In addition, due to the frequent demographic conflation of NHPI people with Asian American groups, this stereotype is often also implicitly extended to NHPI people despite their distinct sociopolitical histories and cultures.

Despite misconceptions about their relative privilege, Asian American and NHPI people face structural inequities that leave them vulnerable to discrimination, violence, and poor health outcomes. During the coronavirus disease 2019 (COVID-19) pandemic, BIPOC communities, including NHPI people, suffered high rates of infections, hospitalizations, and deaths.^{10,11} Even so, Asian American people and NHPI people whose distinct identities were conflated with that of Asian people were disproportionately blamed for the pandemic due to the initial identification of COVID-19 in China, leading to more than 11,500 reported instances of harassment and violent hate crimes since March 2020.^{12,13} Asian American and NHPI women experienced hate incidents, including verbal harassment, physical assault, workplace discrimination, and online harassment 2.2 times more frequently than men, exemplified most blatantly by the mass shooting of primarily Asian women across businesses in Georgia.¹⁴ These acts of violence are only the latest examples from a longstanding history of discrimination and outright aggression against Asian American and NHPI communities in the United States, including the Chinese Exclusion Act of 1882, the forced incarceration of Japanese Americans during World War II, the illegal occupation of Hawaii, and militarization and nuclear testing in U.S.-associated Pacific Island nations.¹⁵

Given the growing proportion of Asian American and NHPI people in the U.S. population, the diversity of cultures and experiences among subgroups, and their history of oppression and ongoing discrimination, Asian American and NHPI communities must be included in health disparities research to achieve reproductive justice and dismantle systemic racism. Continuing the status quo of reporting aggregated Asian American and NHPI data renders our distinct experiences invisible.

We summarize the limited research identifying sexual and reproductive health disparities in service utilization and health outcomes for Asian American and NHPI people to highlight that even the small amount of data including these populations reveal group-specific disparities that argue against the model minority myth. We also propose opportunities to improve how we collect sexual and reproductive health data for Asian American and NHPI groups.

Ultimately, we argue that the incorporation of disaggregated Asian American and NHPI data in studies examining racial and ethnic sexual and reproductive health disparities will elucidate the unique needs of this diverse group, prompting researchers, clinicians, funders, and policy makers to design, implement, and evaluate targeted, community-appropriate responses to sexual and reproductive health needs in Asian American and NHPI subgroups.

BRIEF CONTEXT ABOUT TERMINOLOGY

Throughout this publication, we acknowledge the geographical, cultural, and historical distinctions among Asian American, Native Hawaiian, and Other Pacific Islander people by separating the “AANHPI” acronym into two components: Asian American and NHPI. We recognize that even this separation is limiting, as the subgroups that comprise these divisions are culturally distinct, experience different migratory pressures that drive them to the United States (eg, armed conflicts in their home countries, U.S. occupation or annexation, economic instability, ethnic group or religious persecution), and settle in different regions of the United States where local context may also lead to divergent American experiences.

We choose to use the NHPI acronym rather than the more general “PI” acronym to underscore the fact that Native Hawaiian people, though sharing some geographic and cultural similarities to other Pacific Islander groups, did not immigrate to the United States and are instead the Indigenous people of a sovereign nation illegally occupied and made a state by the United States.¹⁶ The Native Hawaiian experience also differs from that of the Chamoru people of Guam, who live within an occupied U.S. territory but are unable to participate in electoral processes.¹⁷ However, inclusion of “Other” in the acronym acknowledges that, despite this distinct history, many Native Hawaiian people consider themselves to fall under the Pacific Islander umbrella. Additionally, the term “Native Hawaiian and Other Pacific Islander” is the official standard designation as specified by the Office of Management and Budget, the U.S. Census, and other federal agencies for the collection and reporting of race and ethnicity data.¹⁶ Whenever possible, we specify whether cited references include all members of these composite groups or only include health data from certain populations.

SEXUAL AND REPRODUCTIVE HEALTH DISPARITIES WITHIN THE ASIAN AMERICAN AND NHPI COLLECTIVE

Asian American and NHPI people are less likely to seek out regular sexual and reproductive health care

compared with people of other races or ethnicities. Asian American adults often avoid preventative sexual and reproductive health care due to language barriers, lack of cultural congruence with health care professionals, limited health literacy, and financial concerns.¹⁸ They are the least likely of all ethnicities to have a personal doctor, undergo routine Pap tests, or obtain mammograms.^{19–21} When they do engage in sexual and reproductive health care, Asian American people are the least likely to use highly effective forms of contraception even though they are the most likely of any racial or ethnic group to be interested in long-acting reversible contraception, suggesting a disconnect between methods that Asian American people want to use and methods that they are offered.^{22,23} Asian American adolescents are less likely to consistently use condoms or other forms of contraception, be knowledgeable about human immunodeficiency virus (HIV) transmission, and feel comfortable disclosing health needs to health care professionals than their White peers.^{24–26}

Pregnant Asian American and NHPI people also face distinct challenges. “Listening to Mothers in California,” a statewide population-based survey on the pregnancy experiences of Californians, revealed that Asian American and NHPI women were least likely to receive counseling or medication for anxiety or depression, seek midwife care, or use a doula, and were most likely to perceive biased care related to the languages they spoke.²⁷ In childbirth, Asian American people experience similar rates of unplanned, vertex, singleton cesarean deliveries as Black people for reasons including labor dystocia and nonreassuring fetal status.^{28–30} They are more likely than White people to experience severe perineal laceration, postpartum hemorrhage, or peripartum infection.³¹ Asian American and NHPI people in composite also have an increased risk of inpatient maternal mortality compared with White people (adjusted odds ratio [aOR] 1.72), even when adjusting for age, median household income, payer status, mode of delivery, and postpartum hemorrhage.³² Additionally, they experience the highest rates of stroke among pregnant women with chronic hypertension (adjusted risk ratio 3.62 vs 1.71 for Black women and 1.75 for Hispanic women vs a referent White group).³³

SEXUAL AND REPRODUCTIVE HEALTH DISPARITIES AMONG ASIAN AMERICAN AND NHPI SUBGROUPS

Analyses of available Asian American and NHPI subgroup data provide further insights into the sexual

and reproductive health needs of Asian American and NHPI ethnic groups that can be obscured when data are aggregated. However, even these data tend to be limited in either geographical scope or subgroup granularity. We present existing data with as much granularity as is currently available, acknowledging that the lack of subgroup data, especially for NHPI and smaller Asian American subgroups, incompletely characterizes the extent of Asian American and NHPI sexual and reproductive health disparities.

Although Asian American people in aggregate are the least likely to engage in preventative care such as Pap tests and mammograms, data from the California Health Interview Survey showed that Vietnamese women undergo Pap screening at the lowest rates of all Asian American women (61%) and Korean women have the lowest rates of mammography (53%), putting these groups at higher risk of delayed cervical and breast cancer detection.³⁴ Delays in detection may also translate to increases in mortality in some Asian American and NHPI groups. In a California epidemiologic analysis, NHPI people suffer a 41% higher overall cancer mortality rate, with particularly increased risk for breast and endometrial cancers.³⁵ Similarly, Filipinx people who are younger than 50 years old are more likely to die from uterine cancer than their White counterparts (HR 1.41).³⁶

From an obstetric standpoint, a cohort study using U.S. vital statistics data from 2014 to 2017 to examine adverse maternal outcomes in Asian American and NHPI birthing people showed how widely subgroup outcomes can vary.³⁷ Asian Indian people were most likely to have pregnancies affected by gestational diabetes (11.7% vs 4.9% of non-Hispanic White people) and undergo cesarean delivery (18.1% vs 11.1%).³⁷ People from all Asian American subgroups were more likely than White people to experience a composite maternal morbidity outcome, including admission to an intensive care unit, blood transfusion, unplanned hysterectomy, and uterine rupture, with the aOR highest for NHPI (1.46), Filipinx (1.35), and other Asian people (1.44; all Asian American people excluding those of Asian Indian, Chinese, Filipinx, Vietnamese, Korean, and Japanese heritage).³⁷ A Hawaiian study on peripartum intensive care unit admissions supported these findings, with Filipinx (aOR 1.45) and NHPI (aOR 1.39) people more likely to be admitted to the intensive care unit than White people.³⁸

An earlier analysis of U.S. birth certificate data as well as smaller retrospective studies revealed high rates of gestational hypertension or preeclampsia and preterm birth in Filipinx and NHPI people.^{39–41} In

fact, Filipinx women in San Diego, California have preterm birth rates (10.7–10.8%) nearly equivalent to U.S.-born Black women (10.9%).⁴² Preterm birth rates notably remained high for both immigrant and U.S.-born Filipinx women, whereas White, Hispanic, Black, and other Asian women experienced fewer preterm births in their immigrant subpopulations.⁴² Subgroup disparities persist even after delivery: NHPI infants experience mortality rates at twice that of White infants.⁴³

LIMITATIONS OF ASIAN AMERICAN AND NATIVE HAWAIIAN AND OTHER PACIFIC ISLANDER INCLUSION IN NATIONAL DATA SETS

The highlighted examples of disparities affecting Asian American and NHPI people are by no means comprehensive. Yet the methods that researchers, public health officials, and policymakers use to collect and analyze health care data limits our ability to research, publicize, and effectively intervene on these disparities. National surveys sponsored by the DHHS provide much of our understanding of racial and ethnic differences in the health of the U.S. population. In the past, many population surveys have omitted Asian American and NHPI data, citing an inability to recruit enough Asian respondents to draw reliable conclusions.⁵ However, omitting Asian American and NHPI health data not only overlooks the unique health risks of Asian American and NHPI individuals, but indirectly suggests that Asian American and NHPI groups may not experience the risks or pathologies incurred by other racial or ethnic groups, thereby reinforcing the model minority myth. Findings from analyses that focus on a single major or easily accessible Asian American and NHPI subgroup are additionally problematic, because these data may be extrapolated to represent the health of all Asian American and NHPI people.⁸

As of 2011, Section 4302 of the Affordable Care Act requires that all DHHS-funded population-based health surveys include standardized information on race and ethnicity, with specific guidance on the collection of Asian American and NHPI subgroup data.⁴⁴ These surveys include the National Vital Statistics System, National Health Interview Survey, and the National Health and Nutrition Examination Survey, which now oversample Asian American and NHPI people and assign survey weights to individual data to provide nationally representative health estimates.⁴⁵ These surveys are additionally offered in Asian languages. However, all existing surveys still limit their subgroup health-data collection to

the minimum federal categories of collection—that is, Indian, Chinese, Filipinx, Japanese, Korean, Vietnamese, Hawaiian, Guamanian/Chamorro, and Samoan subgroups.

In contrast, the National Survey of Family Growth, which is one of the most commonly used sources of representative data on sexual and reproductive attitudes and behaviors, has yet to adopt procedures to oversample from and accommodate the low English proficiency or low socioeconomic status of some individuals in Asian American and NHPI subgroups.⁴⁶ Although the National Survey of Family Growth collects Asian American and NHPI subgroup data, it does not oversample Asian American or NHPI populations and is, therefore, less likely than other federally-funded health surveys to collect sufficient subgroup data to make nationally representative estimates of health behaviors. Furthermore, researchers can only access findings on these subgroups if they submit a proposal to the National Science Foundation's Restricted-Access Research Data Centers. Given these restrictions and the lack of attention to the diversity among Asian American and NHPI subgroups, health research continues to omit Asian American and NHPI data from analyses or, at best, report health data in aggregate. Data disaggregation is crucial to identify and target inequities that exist among Asian American and NHPI subgroups, because risk profiles and health outcomes can vary widely among subgroups. This visibility is essential for policymakers to address the intersectional health care needs of these populations. Further research must prioritize the analyses of these population-based data, with attention to the diversity and disparities in sexual and reproductive health among Asian American and NHPI subgroups.

LIMITATIONS OF ASIAN AMERICAN AND NATIVE HAWAIIAN AND OTHER PACIFIC ISLANDER INCLUSION IN CLINICAL STUDIES

In 1993, the National Institutes of Health Revitalization Act established guidelines for including women and racial and ethnic minorities in clinical research, with specific inclusion of Asian American, NHPI, and other minority subpopulations. As a result, studies that included Asian American and NHPI people in clinical trials have resulted in unique insights into steroid hormone metabolism.^{47,48} However, recruiting Asian American and NHPI people into clinical trials and cohort studies remains challenging. Medical mistrust due to our profession's history of mistreating BIPOC communities, language and cultural differences, and limited health care access reduces recruit-

ment into research studies. Recent migration further complicates these challenges: Asian and NHPI newcomers to the United States may be unfamiliar with the research process, fear deportation because of interactions with medical institutions, and may be insulted by financial incentives for research participation.⁴⁹

Cultural or religious stigmas regarding sexual and reproductive health additionally hinder research into sexual and reproductive health attitudes, behaviors, and outcomes in Asian American and NHPI subgroups.⁵⁰ Discomfort around sexual and reproductive health care limits health care access and is a barrier to clinical research participation. Thus, researchers seeking proportional Asian American and NHPI representation in their studies should create culturally congruent recruitment materials in a variety of languages to intentionally recruit prospective Asian American and NHPI research participants. Community-based participatory approaches, where community members play an equal role to academic researchers in the design and execution of a research project, improves Asian American and NHPI community investment in the research and increases the chances that results of the study are relevant to the groups being studied.⁴⁹

CONCLUSIONS AND RECOMMENDATIONS

The model minority stereotype and smaller demographic proportion of Asian American and NHPI people in the United States have historically limited their inclusion in research about sexual and reproductive health disparities and led to the assumption that this community experiences few, if any, adverse sexual and reproductive health outcomes. However, this assumption is insupportable by even the small number of studies that have interrogated the sexual and reproductive health experiences of these diverse populations. Asian American and NHPI people encounter significant and often subgroup-specific disparities in sexual and reproductive health service utilization, reproductive cancer outcomes, and obstetric and peripartum care. To combat the perpetuation of inequitable sexual and reproductive health research that continues to erase the needs of Asian American and NHPI communities, we make the following recommendations in alignment with our Asian American and NHPI colleagues in other health fields.^{8,16,51}

First, the routine collection of disaggregated race and ethnicity health data must become standard practice. At a minimum, researchers should include DHHS-mandated subgroups when collecting information about participant race and ethnicity—specifically, Indian, Chinese, Filipinx, Japanese, Korean,

Vietnamese, Native Hawaiian, Guamanian/Chamoru, and Samoan subgroups. Researchers or demographers could also adopt the more expansive approach for race and origin reporting devised by the Asian and Pacific Islander American Health Forum, ACCESS, Unidos US, National Urban League, and National Congress of American Indians, which allows respondents to specify their race or origin from a list of standard options while providing a free text option to designate their subgroup identity (see page 11 at <https://www.apiahf.org/wp-content/uploads/2021/02/APIAHF-Policy-Recommendation-as-Health-Equity.pdf>).⁵¹ Collecting race and ethnicity data at this level of granularity not only benefits Asian American and NHPI people but also other small subgroups who frequently find themselves rendered invisible in research, such as Middle Eastern or North African people with various countries of origin who are often subsumed into the “White” category in DHHS standardization.

Secondly, involving community stakeholders in research prioritization and recruitment is critical in ensuring that sexual and reproductive health research is appropriately individualized for different Asian American and NHPI subgroups. Organizations that serve their own communities best understand the values and priorities of those communities, and this context is especially pertinent in sexual and reproductive health research where history, culture, and religiosity can intersect to generate stigma in some Asian American and NHPI subgroups.

As the proportion of Asian American and NHPI people residing in the United States continues to rise, their continued exclusion from sexual and reproductive health research represents a form of structural violence that will deepen health inequities for the most vulnerable people in these groups. Working toward *data justice*—high-quality racial and ethnic data collection, routine data disaggregation, and community-driven approaches to subgroup research—is the first step in understanding and addressing the sexual and reproductive health needs of Asian American and NHPI communities.

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