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### Authors

Chen, Moon S  
Lee, Richard J  
Madan, Ravi A  
et al.

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## Charting a Path Towards Asian American Cancer Health Equity: A Way Forward

Moon S. Chen, PhD, MPH Jr <sup>1,\*</sup> Richard J. Lee, MD, PhD <sup>2</sup> Ravi A. Madan, MD <sup>3</sup> Van Ta Park, PhD, MPH <sup>4</sup>  
Susan M. Shinagawa, MPH <sup>5</sup> Tracy Sun, MPH <sup>6</sup> Scarlett L. Gomez, PhD, MPH <sup>7</sup>

<sup>1</sup>Department of Internal Medicine, UC Davis School of Medicine, Sacramento, CA, USA; <sup>2</sup>Massachusetts General Hospital Cancer Center and Harvard Medical School, Boston, MA, USA; <sup>3</sup>Genitourinary Malignancies Branch, Center for Cancer Research, National Cancer Institute, Bethesda, MD, USA; <sup>4</sup>Department of Community Health Systems, School of Nursing, University of California, San Francisco, CA, USA; <sup>5</sup>Asian and Pacific Islander National Cancer Survivors Network, Spring Valley, CA, USA; <sup>6</sup>Asian and Pacific Islander American Health Forum, Washington, DC, USA; and <sup>7</sup>Department of Epidemiology and Biostatistics, UC San Francisco School of Medicine and the Helen Diller Family Comprehensive Cancer Center, San Francisco, CA, USA

\*Correspondence to: Moon S. Chen Jr, PhD, MPH, University of California Davis, 4501 X St, Suite 3016, Sacramento, CA 95817, USA (e-mail: mschenjr@ucdavis.edu).

### Abstract

On July 29, 2021, the US Food and Drug Administration's Oncology Center of Excellence convened Conversations on Cancer. This conversation, the first ever by the US Food and Drug Administration, focused on Asian Americans and served as the platform for this Commentary. Panelists elaborated on topics ranging from heterogeneity in Asian American demographics to racism through a path to health equity and supplemented this Commentary with literature citations. Asian Americans are the fastest-growing US race group, yet data aggregation obscures distinctions and cancer disparities within the more than 24 million Asians living in the United States with harmful impacts on communities and patients, as illustrated by breast cancer survivor Susan Shinagawa's patient-to-advocate journey. Bigotry against Asian Americans has been pervasive since the 19th century, but especially during the COVID-19 pandemic. Asian Americans are unique as the first US population to experience cancer as the leading cause of death. Asian Americans are disproportionately affected by cancers because of infectious origins and have the highest rates of lung cancer among never-smoking women. The infinitesimal proportion of the National Institutes of Health's budget compared with experiencing the highest percentage increases of any US racial population more than 3 decades highlights the dearth of focused research among Asian Americans. Recognizing the heterogeneity of Asian Americans and that disaggregated data are critical for accurately characterizing distinct ethnic groups, focusing on the impact of racism and COVID-19 on cancer disparities, and focusing and prioritizing funding resources are necessary steps forward for achieving health equity for Asian Americans.

On July 29, 2021, the US Food and Drug Administration's (FDA's) Oncology Center of Excellence convened Conversations on Cancer to discuss racism and injustice encountered by Asian American and Pacific Islander communities in the United States. More than 400 individuals virtually attended the 90-minute panel discussion entitled "Advancing Equity in Asian American and Pacific Islander Communities: Racism and Injustice," which covered topics spanning from existing Asian American health-care disparities, barriers, and challenges to achieving health equity, to anti-Asian bigotry and hate crimes (especially since the COVID-19 pandemic began), to advancing health and health equity for Asian Americans. The panelists' first agreement was focusing the Commentary only on Asian Americans, because Pacific Islanders are a separate census category (1). Prior to Census 2000,

the aggregated "Asian and Pacific Islander" census category obscured the greater health burden and disparate health status of Pacific Islanders (2,3). In 2000, the Census Bureau began using 2 distinct categories: Asians, and Native Hawaiians and Other Pacific Islanders. As FDA Conversation panelists, we understand the importance for Native Hawaiians and Other Pacific Islanders to present their own health issues, and advocated the FDA sponsor a Conversation for Native Hawaiians and Other Pacific Islanders to address health inequities, racism, and injustice in their communities. To address Native Hawaiians and Other Pacific Islanders in this article would require 2 distinct sections, essentially doubling this Commentary's length.

The July 2021 Conversations on Cancer was important for several reasons. It was the first FDA panel focused on Asian

Americans, the fastest-growing US race group in percentage increase. Discussions linked the nation's history of anti-Asian racism and recent pandemic-related anti-Asian hysteria with Asian Americans' unique (one of a kind), unusual (different from the majority of Americans), and unnecessary cancer burden. Challenges and recommended solutions to achieving health equity were discussed and are highlighted in this Commentary.

## Asian American Population Definition and Demographics

Asian American populations have been the fastest-growing US racial population over the past 3 decades, from 1990 to 2020 (Supplementary Figure 1, available online). The federal Office of Management and Budget defines "Asian" as "a person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam" (4).

Population counts for all census categories have become more nuanced, with data reported as single race alone (eg, "Asian alone") and "Asian alone or in combination" (with another race) (5). Hispanic ethnicity is determined separately but is not mutually exclusive from race (6). Selecting "Asian alone" as the defining parameter, the percentage of population increase from 2010 to 2020 is 35.5%, and 38.6% for "Asian alone or in combination" (7,8), compared with the 15.4% US population increase (7). More than 24 million people self-identified as Asian alone or in combination in the 2020 Census, comprising 7% of the total US population (5,6), with Asian American's growth rate outpacing all other US racial and ethnic groups for more the 3 decades (1990-2020) (7,8).

Another 3.5 million Asian Americans identify as mixed race (8). Asian American populations are projected to increase to 46 million by 2060 (8,9). In addition to deriving from more than 20 Asian countries of origin, Asian Americans also vary by nativity (foreign-born vs US-born), acculturation levels, language or dialects spoken (more than 200), geographic and neighborhood context, and educational and economic attainment (8-11), all factors that determine cancer risk and prognostic factors. The heterogeneity of Asian American populations is reflected in the broad distribution of socioeconomic characteristics (8-10). Among Asian Americans, Asian Indians have the overall highest (79%) college graduation attainment and median household income (\$123 700) compared with Bhutanese Americans with the overall lowest educational attainment (16% college graduates) and median household income (\$49 854) (8-10). These 2 Asian American subgroups also fall within the highest and lowest levels (for stated characteristics) among the total US population (10). Asian American limited English proficiency rates range from 22% among Asian Indian and Filipino Americans to 53% among Vietnamese Americans (8,10,11), with implications for health-care access and outcomes (9).

## Racist History Affects Today's Cancer Inequities

Racism was well known to the earliest US immigrants from Asia (12,13). The Page Act of 1875 denied entry of Asian women into the United States to marry Asian men who entered the United States in the 1850s or earlier (12,13). The Page Act and the 1882 Chinese Exclusion Act were the first US anti-immigration laws

(12,13). Congress repealed the Chinese Exclusion Act in 1943, in part because China became a US ally in the war against Japan. One year earlier, following Japan's attack on Pearl Harbor, 120 000 Japanese immigrants and their US-born or US-citizen Japanese American children were forcibly removed and incarcerated in US prison camps (13) without due process. Fifty years later, the experiences of camp descendant and 3-time cancer survivor Susan Shinagawa bring to question the link between institutional racism and cancer care.

## An Advocate's Story: "Asian Women Don't Get Cancer"

In January 1991, Susan Shinagawa, a 34-year-old third-generation Japanese American, attended an American Cancer Society workshop on Breast Self-Examination, though she had previously never thought about breast cancer. In June 1991, Shinagawa palpated a firm, painful, pea-sized lump in the upper-inner quadrant of her right breast. As taught, she monitored the persistent lump, then sought medical advice. Following clinical evaluation with 3 breast specialists and a diagnostic ultrasound revealing the lump was a solid mass, Shinagawa was told, "You're too young to have breast cancer, you have no family history of cancer, and, besides, Asian women don't get breast cancer" (14-16). When Shinagawa requested a biopsy, she was denied and admonished by the surgical breast oncologist. She sought a second opinion, this time insisting on a biopsy, which revealed invasive ductal carcinoma. Shinagawa turned her experience with a dismissive surgical oncologist into action, becoming one of the nation's leading advocates for cancer education, health equity, and research (16). Her experience broadly reflects those of women from other Asian American ethnicities, though Shinagawa acknowledges her English language fluency and cultural perspectives greatly influenced the extent of articulating her needs and insisting on a second opinion. Shinagawa's advocacy on the importance of data disaggregation has been supported by studies using ethnically disaggregated studies of Asian Americans (17-24).

## COVID-19: Impact on Asian Americans

The COVID-19 pandemic has profoundly influenced Asian Americans in ways that likely will have enduring impacts on exacerbating cancer health disparities within their communities (25). The restrictions the pandemic has imposed on health-care access and a shift towards increasing use of telehealth, the documented effect on delayed diagnoses and treatments (26,27), and restrictions to health-care access because of technology and/or language barriers may differentially affect Asian Americans across the cancer continuum. Another consequence of the pandemic is increased anti-Asian sentiment and associated targeted crimes in the United States resulting from racist national rhetoric (28,29), which in turn has adversely affected confidence in health-care-seeking behaviors among Asian Americans, especially elders (30). FBI data revealed that hate incidents targeting Asian Americans increased 70% from 2019 to 2020 (31). In the year between the first quarters of 2020 and 2021, the Center for the Study of Hate and Extremism found a 189% increase in the number of hate crime reports from persons of Asian ancestry (32).

The pandemic also elucidated the vulnerability of Asian Americans on a broad spectrum from COVID-19-related anti-Asian violence to the inability (or unwillingness) of people to

acknowledge the COVID-19 burden on Asian Americans. In September 2020, Kaiser Family Foundation and Epic Health Research Network reported their joint study conclusion: Asian Americans and Pacific Islanders had the highest US COVID-19 hospitalization and mortality rates (33-35). In their analysis of 50 million patients, Asian Americans were 57% more likely to be hospitalized and 49% more likely to die of COVID-19 than their White American counterparts with similar socioeconomic status and underlying conditions (33).

Asian Americans also lead the nation in long-term COVID-19-related unemployment (48%). The pandemic's disproportionate impact on Asian American populations is in large part reflected by the overrepresentation of essential workers at both ends of the socioeconomic or occupational spectrum: 17% to 20% (36) of US health professionals on one end and a high percentage of low-wage, no-benefits essential workers in food production, transportation, and other frontline jobs as well as small family-owned businesses (eg, convenience stores and restaurants) on the other end (33,36-39). Heightened fears of anti-Asian racism and assaults may have led to lower COVID-19 test rates and delays in seeking health and cancer care after COVID-19 symptoms arose (35). Multigenerational households and close living quarters of many Asian American immigrant families may explain rapid COVID-19 transmission within such households. Institutional racism manifested through the exclusion of Asian Americans from discussions of COVID-19 disparities by governmental and quasi-governmental organizations and as clinical research participants as well as the paucity of health research focused on Asian Americans all contribute to Asian American COVID-19 disparities (33,35-39). We would thus expect the pandemic to exert pervasive and enduring impacts across the cancer continuum among Asian Americans.

### Model Minority Myth and Asian Americans' Cancer Burden: Unique, Unusual, and Unnecessary

First introduced in the 1960s and popularized by the mainstream media, the model minority myth as it relates to Asian Americans is the depiction that Asian Americans—through their educational achievements, financial success, and overcoming adversities—also excel as models of good minority health. Providers' assumptions of the model minority myth can lead to neglect of appropriate health screenings and recommendations on diet and physical activity. Among Asian Americans, there can be negative effects on mental and physical health (40,41). When health statistics are disaggregated by Asian subgroups and differences in cancer burden are described (42,43), the evidence points to considerable health disparities (44-46). The consequences perpetuated by aggregated data (which masks the within-group differences) and societal indifference lead to "invisibilization" or the intentional omission of Asian Americans (37) and especially the exclusions of Asian Americans in biomedical, behavioral, psychosocial, or other health research and funding (47,48). For instance, between 1992 and 2018, only 0.17% of the budget of the NIH funded the aggregated group of Asian Americans, Native Hawaiians, and Other Pacific Islanders (47,48), and only 5 cancer clinical trials in January 2013 recorded on ClinicalTrials.gov focused on Asian Americans (49). The model minority myth is also the driving force behind the NIH (50) not recognizing Asian Americans as an "underrepresented minority" (46). Being the fastest growing racial and ethnic US population in percentage terms and the

first US racial population to experience cancer as the leading cause of death should be considered as reasons for needing to include Asian Americans as an underrepresented minority.

From 1935 to 2010, heart disease was the leading cause of deaths for all US population groups (51). In 1987, "Asian or Pacific Islander" women became the first US race population to experience cancer as the leading cause of death (52), followed by Asian American men in 2004 (53). In 2007 and 2008, cancer became the leading cause of death for American Indian or Alaska Native women (54) and Hispanics or Latina women (55), respectively. Hence, the cancer burden for Asian Americans is unique in being the first (women) and only US racial group to experience cancer as the leading cause of death for both men and women (56).

The Asian American cancer burden is unusual in that Asian Americans are disproportionately affected by cancers infectious in origin (57). Korean Americans experience the highest rates of stomach cancer, presumably attributed to *H. pylori* and high pickled vegetable (eg, kimchi) consumption (58). Chinese Americans experience the highest US rate of nasopharyngeal cancers, linked to high consumption of Cantonese salted fish (59). Vietnamese American women experience the highest US rates of cervical cancer, possibly linked to a high prevalence of the human papillomavirus (42).

Asian immigrants born in East Asia (China, Korea, Philippines, but not Japan) and Southeast Asia (Cambodia, Laos, and Vietnam) and Hmong experience the highest rates of hepatocellular carcinoma (primary liver cancer) among all US racial and ethnic groups due to elevated chronic hepatitis B virus (HBV) infection rates (60). Asian Americans experience the highest chronic HBV incidence rates, 3.41 in 100 000 (95% confidence interval [CI] = 2.64 to 4.39), compared with the overall US population with a rate of 0.35 in 100 000 (95% CI = 0.28 to 0.45) (61). Although Asian Americans are only 7.2% of the total US population, they comprise 60% of the chronic HBV infections, with a particularly high burden among foreign-born Asian Americans (62,63).

Another unusual example of a uniquely high Asian American cancer burden is lung cancer among never smokers, particularly Asian Americans women (43). Never-smoking Chinese American women have the highest age-adjusted lung cancer incidence rate (22.8/100 000, 95% CI = 17.3 to 29.1) compared with never-smoking non-Hispanic White women (10.1/100 000, 95% CI = 9.0 to 11.6). Although the age-adjusted lung cancer incidence rate among never-smoking Asian American men is lower at 16.8 in 100 000 (95% CI = 9.3 to 26.5), it is double the rate among non-Hispanic White men at 8.2 (95% CI = 6.8 to 9.7) (43). More than one-half of Asian American women with lung cancer have never smoked, and this proportion is as high as 88% among Chinese American women with lung cancer (43).

Although the Asian American cancer burden has its unique and unusual features (64), these populations are also affected by cancers common in the United States: breast, prostate, and colon cancers. Asian Americans have been the fastest growing US race group for more than 30 years. As these populations continue their rapid growth, and the rising influence of westernization in Asia and the United States push upward trends in these cancers, a greater focus on research across the cancer continuum in Asian Americans is urgently needed.

### Culturally Competent Oncology Care

The clinical journey for Asian American cancer patients is fraught with challenges and barriers (65). For patients in need of

health care, lack of insurance and language barriers may be insurmountable roadblocks. The Affordable Care Act has largely closed the insurance coverage gap between previously uninsured Asian American adults and their White counterparts, with Asian Americans having the overall lowest uninsured rate of all US racial and ethnic groups by 2018 (65,66). Still, a wide range in insurance rates across Asian American groups exists.

Two-thirds of all Asian Americans speak a language other than English at home, and 43% of foreign-born Asian Americans are limited English proficient (9,11). For cancer patients with limited English proficiency requiring treatment, language barriers are often a major impediment to quality patient care and safety (67,68). Even when an appropriate, trained interpreter is engaged, the potential for critical physician–patient discussions being lost is a major concern. An analysis of medical interpreters suggests that only one-half of interpreters in oncology environments have sufficient knowledge of oncology or related clinical trials (69). If such obstacles are surmountable, the additional time required for interpretation will undoubtedly result in shortened physician–patient discussions about treatment options, protocols, and risk-benefit considerations, while the physician also attempts to establish a trusting relationship so the patient will feel comfortable to ask questions or share concerns (70–72). Appropriate, consistent, and effective interpretation services are critical in these settings, especially during required follow-up visits, when physicians must integrate patient communications about side effects, adverse reactions, or new symptoms into their assessment of treatment efficacy, toxicities, and potential modifications. These interactions will have a substantial impact on patients' adherence to therapy and quality of life (72–76).

It is equally important for oncology providers to consider cultural barriers that may exist even when verbal communication is not an obstacle. Cultural sensitivity and cultural competence are essential, because words such as “cancer” and “tumor” have been shown to carry more ominous connotations in some East Asian and Southeast Asian cultures (70–74). Family dynamics may also manifest differently in some Asian cultures, with implications for how they deal with a health challenge, such as a cancer diagnosis (70). A family-centric approach, in which the patient and often several family members are involved, may require extended appointments to accommodate important treatment-related discussions with the family. This tradition can persist for generations after migration to western societies in which patient autonomy is the norm. Casual disregard or resistance to greater family involvement could create detrimental effects on patients and their broader support systems, including distrust leading to decisions based on expediency rather than what is best for the patient and family (75).

Cultural stoicism can negatively affect cancer care for Asian American patients. Not wanting to burden families with a poor prognosis or the high cost of therapy may cause patients to defer care, leading to poor outcomes (74). End-of-life care decisions may also be colored by cultural perceptions; use of hospice services is lowest among Asian Americans (75).

## Underrepresentation in Clinical Trials

According to ClinicalTrials.gov, the proportion of cancer clinical trials with any racial and ethnic minority participation as its primary focus is approximately 1% of all clinical trials, with only 5 such trials focused on Asian Americans compared with 83 for African Americans and 32 for Hispanics (49). Thus, efforts to

intentionally increase the proportion of cancer clinical trials for all minorities are needed. According to the FDA (76,77), Asian Americans were consistently underrepresented in clinical trials for all types of therapeutics (2.08%) compared with their representation in the 2015 Census (5.53%). National consciousness to address Blacks and Hispanics, designated as Underrepresented Minorities, is helpful. However, the regrettable national policy excluding Asian Americans as an Underrepresented Minority, perpetuation of the model health minority myth associated with Asian Americans, and failure to consider the unique, unusual, and unnecessary cancer burden confronting rapidly-growing, distinct Asian American subgroups contribute to the lack of prioritizing Asian Americans for clinical trials. Asian Americans constituted just 2% of 102 596 US clinical trial participants, taken from 231 data snapshots of drug trials conducted between 2015 and 2019 and evaluated by the FDA (76,78). Given their low representation in clinical trials, the extent to which treatment guidelines are applicable to Asian Americans is unclear.

Eleven percent of 292 537 Pfizer global trial participants were Asian, highlighting the fact that most Asian clinical trials participants are from studies conducted outside the United States (77). Global vs US variance fails to account for potential differences in endemic infection rates or vaccination rates for viral-related cancers or for diet or lifestyle differences between Asians in their respective native countries and their Asian American counterparts. Rates of infection with cancer-associated viruses (HBV, human papillomavirus, Epstein-Barr virus) or bacteria (*H. pylori*) change as a result of migration and the availability of vaccines and health insurance; together with cancer screening and lifestyle changes, global cancer clinical trial outcomes in Asians may not apply to Asian American cancer patients.

Another barrier to quality care for Asian American cancer patients is access to novel therapies. Similar to the above-mentioned FDA data, Pfizer Pharmaceuticals evaluated their clinical trials portfolio across all therapeutic areas in the United States between 2011 and 2020 (77). Barriers to clinical trial participation for Asian American patients are many and multilayered, including (though not limited to) language assistance; assumptions by the clinical team regarding the patient's medical literacy; financial, transportation, and/or childcare resources required for more frequent clinic visits; patients' concerns associated with financial toxicity, efficacy of experimental therapies, and adverse treatment effects; the clinical team's concerns related to patient compliance to treatment protocol; and additional time and resources required to overcome these and other barriers related to delivery of quality, culturally competent care. A commitment to adequate representation and partnership between patients, community advocates, trial investigators, and pharmaceutical companies is necessary to ensure diversity of trial participants reflects the appropriate disease prevalence levels across population groups. Similar parameters that reflect disease prevalence in Asian American patients, such as enrichment for Asian American female nonsmokers for therapies designed to target epidermal growth factor receptor–mutated non-small cell lung cancer, should be undertaken.

## Underfunding Asian American Health Research and Underrepresentation of Asian Americans in Health-Care Leadership

Despite Asian Americans being the only US racial group for which cancer is the leading cause of death for both men and



women and experiencing the highest percentage increase of any US racial and ethnic population for more than 30 years, noteworthy gaps in understanding the Asian American cancer burden and health outcomes persist. As described above, unique barriers adversely impact Asian Americans across the cancer continuum, likely exacerbated by the COVID-19 pandemic. Given their unusual cancer burden, novel discoveries related to risk and prognostic factors can be achieved through focused research and clinical studies among Asian American populations.

As mentioned previously, between 1992 and 2018, only 0.17% of the total budget of the NIH funded research on Asian Americans populations (47,79,80). A portfolio analysis of grants funded by the National Cancer Institute's Division of Cancer Control and Population Sciences showed a very limited number of studies focused on Asian American populations, with none at the time addressing cancer etiology (81). Neither the NIH nor the National Science Foundation routinely considers Asian Americans to be an underserved minority group, though the evidence-based need for ethnic specificity is used.

This long-standing, disproportionate lack of investment has stifled research for Asian American populations, rendering Asian American health disparities and social inequities invisible. It further acts as a vicious cycle of discouraging and disincentivizing researchers who want to study Asian American biomedical and behavioral health issues. The lack of research funding translates to wide and deepening gaps in knowledge about the disease burden among Asian Americans, resulting in a lack of direct services and programs for Asian Americans in need.

At the same time, despite 20% representation of medical practitioners (82), the lack of proportionate Asian American representation in health-care and medical school leadership may also be a barrier to health equity. According to a 2014 American College of Healthcare Executives survey, only 5% of Asian men obtained CEO positions compared with their Black (16%), Hispanic or Latino (28%), and White (34%) (83) counterparts. Only 10% of medical school department chairs identify as Asian (84).

## Conclusions and Recommendations

Asian Americans have been the fastest growing US racial and ethnic population, in percentage terms, for more than 3 decades. The expanse of heterogeneity within Asian American populations is exemplified by the large numbers of countries of origin and spoken language(s) and dialect(s) as well as the wide range and bimodal distribution of sociocultural and socioeconomic characteristics. The lack of recognition of cancer health disparities and underinvestment of research in Asian American populations is perpetuated by the deceptively rosy picture of an overall low cancer burden based on aggregated cancer surveillance data and the myth of Asian Americans as the model health minority. Cancer survivor Shinagawa's personal story is an example of the harms exacted when a greater, unequal cancer burden is hidden behind or buried underneath aggregate cancer statistics.

To rectify these inequities, we recommend a call to action for a path forward that includes a focus on 3 areas: disaggregated data, assessment of the impact of lived experiences and historical trauma, and listening to community voices.

We should always aim to disaggregate data for Asian American subgroups. We must invest in and focus on development of statistical methodology and other approaches for

studying small populations to ensure reliable data are provided for all population groups regardless of size. We must reject the default approach of always comparing with non-Hispanic Whites as a reference group when identifying cancer health disparities, and instead we recommend applying a "health-equity conscious" approach (85) that focuses on the contributions of the unique exposures within Asian American populations, thus conducting research within Asian Americans rather than comparing Asian Americans with a referent group. To address the effects of structural racism uncovered by the COVID-19 pandemic, we must prioritize research focusing on understanding and addressing the effects of structural racism and discrimination—as the COVID-19 pandemic revealed—to improve health outcomes across the cancer continuum for Asian Americans.

Assessing the impact of lived experiences and historical trauma is important. Research to examine the impact on cancer and long-term health outcomes of the unique lived experiences and historical trauma among Asian American populations is imperative in research funding. The paucity of funding for Asian American research coupled with the vast potential for novel discoveries among this fastest-growing US population group require a greater commitment to and investment in research from public and private sectors.

The rich diversity and unique experiences within Asian American communities is best understood and appreciated by listening to and partnering with patients and community advocates. Research must ensure community representation, buy-in, and engagement.

Substantial progress in improving our understanding of cancer health disparities among these diverse and rapidly growing Asian American populations is underway, and the path forward is being forged. Collective acknowledgement, commitment, investment, and action from all stakeholders is required to achieve cancer health equity for all Asian Americans.

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## Data Availability

All of the data in this Commentary are based on the literature citations (references). There is also a link to the actual Food and Drug Administration meeting that is provided in the Notes: <https://www.fda.gov/about-fda/oncology-center-excellence/conversations-cancer>. Look for the Advancing Equity in Asian Americans and Pacific Islander (AAPI) Communities: Racism and Injustice.

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