

AAPI community data needed to assess better health outcomes

EXECUTIVE SUMMARY

This report lays out an historical overview of the politicizing of the AAPI community for the purpose of distributing federal resources based on need as determined by federal data collection efforts. This report also outlines what current federal, state, local, as well as private and non-government associated data efforts entail, and the limitations associated with current efforts. Finally, this report re-emphasizes the need for continued surveillance of data collection initiatives, and greater granularity of data collection, pertaining to AAPI communities in the U.S. and its territories. and greater granularity of data collection, pertaining to AAPI communities in the U.S. and its territories.

BACKGROUND

At the height of the Vietnam War in 1968, a young Japanese graduate student at the University of California at Berkeley, Yuji Ichioka, banded with other students in an attempt to shut down the university in collective protest against the conflict. The demonstration was not only successful for five months, but Ichioka and his student colleagues also successfully initiated a self-determination campaign against the derogatory term, “Oriental,” then reserved for all persons of Asian descent, birthing the distinction, “Asian American,”¹ which we use to this day.

The United States Census Bureau’s “Asian” racial category refers to “a person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent...,” while “Native Hawaiian or other Pacific Islander” refers to “a person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.”² Asian Americans and Pacific Islanders (AAPI) collectively comprise the largest and fastest growing racial group in the U.S. Having ancestry from over 20 countries, they emigrated to the U.S. for myriad life opportunity and/or geo-political reasons, which are outlined in greater detail in the following sections below. Their health experiences in the U.S. are as diverse as their backgrounds and socio-political statuses within the U.S, yet our data systems infrastructure do not fully illustrate the rich complexity of their different experiences.

Prior to the 1997 Clinton Administration, the White House Office of Management and Budget (OMB) operationalized all public data according to its long-standing “Standards for the Classification of Federal Data on Race and Ethnicity.” After signing Executive Order (EO) 13125, which intended to “improve the quality of life for Asian Americans and Pacific Islanders through increased participation in Federal programs where they may be underserved...,”³ President Clinton established the White House Initiative in June 1999. The grouping of AAPIs should therefore be understood as a socio-political construct, born from the Clinton White House Initiative in order to bring greater attention to the disparate life experiences that different Asian subgroups experience in the U.S.⁴ The following year, the Clinton Administration revised the OMB standards, and declared:

OMB is accepting the recommendations of the Interagency Committee for the Review of the Racial and Ethnic Standards with the following two modifications: (1) the Asian or Pacific Islander category will be separated into two categories— “Asian” and “Native Hawaiian or Other Pacific Islander,” and (2) the term “Hispanic” will be changed to “Hispanic or Latino.”

The revised standards will have five minimum categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. There will be two categories for data on ethnicity: “Hispanic or Latino” and “Not Hispanic or Latino.”⁵

Since then, the Bush⁶ and Obama⁷ Administrations have also amended and/or extended the original EO, creating national statutes meant to recognize and redress the health and social inequities which AAPIs have historically experienced. President Trump re-established the White House Initiative on AAPIs in May 2019, during Asian Pacific American Heritage month⁸.

Through these EOs, the previous Administrations also maintained a webpage, which featured AAPI health data, along with other considerable data points. The webpage operated under the purview of the Department of Education but has since come under the directorship of the Department of Commerce. On October 10, 2019, our AMA sent a letter to Secretary of Commerce, Wilbur Ross, advocating for the restoration of webpages on the Asian American and Pacific Islander initiative that specifically address disaggregation of health outcomes related to AAPI data. On December 17, 2019, our AMA received notice from Secretary Ross's office indicating that they are working on web page restoration. At the completion of this report, however, the web page had not yet been restored to the Department of Commerce website.

The dearth of racially and ethnically disaggregated data reflecting the health of AAPI persons and families underlies the struggles of the physician community to fully attend to, and be attuned to, the unique needs of their AAPI patients. Beyond the clinical setting, given that federal designations and distinctions yield variances in terms of resource distribution (i.e., public health programs supports, public benefits, etc.), it is imperative to hasten all efforts that disaggregate Asian American and Pacific Islander health outcomes and overall social needs. Without such granularity, clinical providers and researchers risk misunderstanding the unique characteristics that impact AAPI health behaviors, beliefs, uses of medical spaces, and the components that lead to their distinct health outcomes. The remainder of this report will focus on the current state of data disaggregation regarding AAPI health outcomes and representation in medicine.

Asian American and Pacific Islanders (AAPIs) in the U.S.

Historical Considerations

The Asian and Pacific Islander presence, in the land that would become the United States, dates back to the 1850s. Life opportunity, economic promise, war, and/or colonialism and other cultural conflict, either pulled or pushed many individuals and families from their homelands to a new land. The first groups to arrive were Chinese and Japanese men to work in California gold mines, or on the Transcontinental Railroad, or to cultivate new frontier lands. Over the course of almost a century, newly emigrated Asians in America faced severe economic hardship and social exclusion from mainstream society through racialized policies, including the Chinese Exclusion Act (1882), the Immigration Act (1917), the National Origins Act (1924), and the imprisonment of Japanese Americans at the start of World War II⁹ (for which they received reparations in the form of restored property rights, \$20,000, and a Presidential apology)¹⁰. Consequently, Asian communities were relegated to service industries-level occupations and de jure segregated ghettos. While Asians generally value work ethic and entrepreneurship, it was the seeds of social discrimination across generations that bred a practice of business ownership in America. This trend remains today: most major American cities with a large Asian-American population retain a Chinatown, an enclave of small, Asian-American owned restaurants, laundries, groceries, salons, and other such service-oriented businesses¹¹.

Current State of AAPI Community

Today, approximately 20 million Asian Americans hail from about 20 sovereign or American colonized countries across East Asia, South Asia, and Southeast Asia: more specifically, most are from China, India, or the Philippines¹². Vietnamese, Korean, and Japanese descendants are also strongly represented in the U.S. To a lesser extent, there are American residents with ethnic roots to Pakistan, Cambodia, Thailand, Laos, Bangladesh, Burma, Nepal, Indonesia, Sri Lanka, Bhutan, Malaysia, and Mongolia. The Hmong people are technically country-less; many who are refugees (or mere generations removed) from the Laos region¹³, also now call the U.S. home. Collectively, Asian Americans comprise the largest and fastest growing racial group in the U.S., burgeoning from 11.9 million to 20.4 million between 2000 and 2015¹⁴. They are slated to account for 11 percent of the

U.S. population by 2050¹⁵ and “by 2065, the Asian American population alone is projected to almost triple to 62 million.¹⁶” Asian Americans make up almost 60% of the Hawaiian population. About half (45%) of the Asian American population in the U.S. live on the West Coast between California, Nevada, and Washington State. A quarter of Asian Americans live in the U.S. South, about the same proportion reside in the Northeast corridor, and about 12 percent live in the Midwest. Almost a third of Asians in America reside in multi-generational homes¹⁷.

Altogether, the Asian American community represents well over 100 spoken languages, an aspect that lends astutely to the growing globalization rationale that all but necessitates that American-born citizens learn at least one Asian language, namely Mandarin Chinese¹⁸. About half of Asian American adults possess a bachelor’s degree or higher, surpassing higher education rates of White Americans, and most are gainfully employed. More recent immigrants from South Asia are doctors and nurses, engineers, and financiers with greater means to come to the US¹⁹. Such high performance along socioeconomic indicators perpetuate the Asian “minority model” myth, where ostensibly, unlike other minoritized groups, Asians are lauded for having improved their collective status and social standing through hard work and exceptional educational performance, without asking for special considerations, or without reliance on public benefits²⁰. This trope erringly gives the impression that AAPIs do not have needs to which governments, researchers, and physician bodies must pay especial attention. In fact, Asian Americans experience the highest language barriers compared to other racial and ethnic groups with Limited English Proficiency (LEP), and more than a third reside in linguistically isolated homes. Among a number of Asian American communities, Limited English Proficiency is highly correlated with medication non-compliance²¹ and inconsistent engagement with Western health systems. Islamophobia, and other experiences of discrimination against non-Christian practicing Asians (many of whom practice Buddhism, Hinduism, Sikhism, Taoism, animism, or other religions) are harmful to the health of AAPIs. Furthermore, racial profiling of AAPIs—especially since 9/11—is associated with poorer health outcomes²². Subsets of the Asian community have been hit hard by anti-immigrant rhetoric and U.S. Immigration and Customs Enforcement (ICE) raids in their communities, creating fear and isolation. Understanding their health and engendering their trust is critical for our public health. More recent xenophobia against Asians, spurred by the coronavirus outbreak and misinformation on the pandemic, only exacerbate these stressors.

Moreover, while they are collectively economically strong, existing data suppresses the wide education, economic, and overall health outcomes, in between ethnically Asian subgroups. For instance, Indian Americans, on average, have more education, and enjoy higher salaries²³ on account of attaining more lucrative occupations as physicians and scientists, compared to Laotian or Cambodian Americans, who historically work within service industries.

Clearly, due to wide sub-ethnic group representation, Asian America is by no means monolithic and is in fact comprised of the most diverse of minoritized populations.²⁴ This rich diversity is attributable to myriad languages spoken, religions practiced, and other cultural distinctions that set Indonesians apart from Indians, who are very different from Japanese and Koreans, and so on. Consequently, their health behaviors, beliefs, and challenges deserve distinct attention. Given the unique social positions they occupy—spanning from the “model minority” to the war-trauma refugee—documenting differences among such highly segmented communities is an essential starting point for implementing a wide array of policies and interventions to give credence to the potentially vastly different interventions needed to improve overall Asian American health.

AAPI Health Status & Public Health Implications

Before the implementation of the Patient Protection and Affordable Care Act (ACA) tenets mandating insurance coverage for all, and especially the protections afforded special populations under Section 1557²⁵, AAPI health research already cited the deep healthcare access barriers AAPIs faced²⁶, but existing data are limited for the reasons outlined below.

AAPIs experience tremendous health disparities among Asian and Pacific Islander groups and inequities compared to the non-AAPI or non-Hispanic White population. AAPIs are the sole group in which cancer—especially of the stomach and the liver²⁷—is still the leading cause of death²⁸, and where rates of tuberculosis

and Hepatitis B²⁹ are still exceedingly high (almost 30 times higher than non-Hispanic Whites). AAPIs experience higher rates of diabetes and obesity, as well as cardiovascular diseases compared to non-Hispanic Whites. Health screening (for HIV/AIDS, for example) and preventive health-seeking behaviors are also lower among AAPIs compared to non-Hispanic Whites.³⁰

Under the auspices of the ACA, all federally funded health surveys must collect data disaggregated by seven Asian American categories: Chinese, Indian, Filipino, Vietnamese, Korean, Japanese, and 'other Asian'³¹. This 'other Asian' delineation collapses a more complex story. On the other hand, since the ACA, there has been an increase of insurance coverage among AAPIs; their insurance coverage rates are now similar to those of White Americans³². Yet, overall, AAPIs still experience difficulties with Medicaid enrollment due to language inaccessibility, although there is very little research that demonstrates the extent of this. The ACA has done much to advance data disaggregation efforts of the AAPI health experience, but more needs to be done. Extended and disaggregated data collection of these challenges would lend well toward creating a fuller and more accurate story and interventions to correct these issues.

Existing Collection Efforts of AAPI Race & Ethnicity Data: Strengths & Limitations

Data Collection: Existing Federal Efforts

Much of what we know about the health of the U.S. population comes from national surveys conducted by the federal government, such as the National Health and Nutrition Examination Survey (NHANES) and the National Health Interview Survey (NHIS). The significant role these scientific data repositories play in determining how national funds are appropriated in support of one program, often at the behest of another, or sets of others, cannot be overstated. Each year, Members of Congress on the Appropriations Committee assign monies to critical programs through a more or less objective process wherein they depend on existing data to rank programmatic, and thus, population need, for programs. The greater the severity of the issue that impacts a community, and/or the larger the community itself, the greater the odds that programming or resources supporting that issue and/or community's needs will be funded and funded well. Gone are the days of Congressional earmarking—Members no longer have the power to set aside specific monies for their constituent communities that may be in the direst of need. For these reasons, it is even more necessary that national data with respect to the health and social progress of Asian Americans and Pacific Islanders be distinguished and narratives clearly demonstrate the great inter-disparities between ethnic groups.

With Census 2020 upon us, reaching AAPI communities at the disaggregated level is crucial not only for determining accurate counts, but also for demonstrating the social strengths and, perhaps most importantly, the social vulnerabilities AAPI communities face and will face in this new decade. Without deriving adequately representative data of such special communities, it is likely that smaller AAPI communities will be counted out and their medical needs, unaccounted. For those most marginalized and socially isolated, the lack of data is also a lack of control, which often hinders communities from developing their narratives, health or otherwise, for which they can contend in current social structures, including both the right to have and analyze collected data.

Each national source provides a baseline sense of specific AAPI populations' health status. For instance, *Healthy People 2010* and *Healthy People 2020* both highlight the unique needs of Asian Americans by establishing baseline health outcomes data for AAPIs in infant mortality, cancer, heart diseases, HIV/AIDS, diabetes, and immunization rates³³. However, neither fully encapsulates and conveys the heterogeneity of AAPIs, thus suppressing fundamental cultural differences between communities, as well as the health behaviors, beliefs, and outcomes differences that arise as a consequence of these inherent variances.³⁴ In processes of determining distribution of limited and critical monies for programs and policies that support health of highly diverse communities, there is limited utility associated with high-overview data.

Essentially, there are major limitations to the use of existing survey data, particularly for studying small populations such as AAPI subcommunities. In addition to the problems associated with smaller sample sizes, there are other weaknesses associated with federal race and ethnicity data. Federal data tend to be cross-sectional and do not capture more temporal sensitive phenomena that bear on health outcomes, such as stress associated with racial or ethnic discrimination. Federal data are dependent upon self-report, which may not always be corroborated with more objective methods, such as health records, and the like. There is also a lack of consistent race/ethnicity categories used in data collection.

The greatest of these data threats stem from the size of AAPI population segments relative to the total Asian population; there is a small likelihood that the data sets will adequately capture or achieve robust representation of unique life experiences across the AAPI community. Apart from highly specialized studies, surveys generally obtain data from too few people to break out separate results for small populations. Even when these data are available, other unique characteristics, such as immigration status, confound outcomes and those groups need to be weighed comparably to U.S. born AAPIs. As a result, even valid inferences drawn about the population (or major segments thereof) based on well-designed survey samples may not apply to small populations. Challenges exist in obtaining sufficient sample sizes to conduct powerful analysis of Asian Americans overall, and even more for subpopulations. Researchers often attempt to correct for this by oversampling certain communities, but often, these segments are difficult to identify, hard-to-reach, and therefore hard-to-count, or may outright be less likely to participate in federal survey research for myriad reasons, including mistrust of American government and fear of retaliation from authority figures³⁵.

Data Collection: Existing State & Local Efforts

It is not surprising that the states and locales comprised of the largest AAPI populations are leading the force in disaggregated data collection. For this, we can look at efforts in California (at the state level), New York City, and Chicago.

The State of California is, by far, the most advanced state in disaggregated collection of data pertinent to the Asian American experience, delineated by AAPI ethnic community. Dating back to the mid-1990s, the state has required its agencies, boards and commissions to collect and disaggregate its public-facing data by race and ethnicity, specifically for AAPIs. More recently, under the auspices of 2016 state Assembly Bill No. 1726 (AB-1726), the decree is extended beyond the earlier law. It will take full effect in 2022, and will track major disease and mortality trends, pregnancy rates, and housing-related phenomena. More specifically,

Existing law **requires any state agency, board, or commission that directly or by contract collects demographic data as to the ancestry or ethnic origin of Californians to use separate collection categories and tabulations for specified Asian groups and Pacific Islander groups**, and requires a state agency, board, or commission to include data on specified collection categories and tabulations in every demographic report on ancestry or ethnic origins of California residents that it publishes or releases. Existing law requires specified agencies to use additional separate collection categories and other tabulations for major Asian groups and Native Hawaiian and other Pacific Islander groups, and also requires those agencies to take additional actions, including, among other things, posting, and annually updating, the demographic data collected on their Internet Web sites, and updating the reporting categories to reflect these Asian and Pacific Islander groups as they are reported for the 2020 decennial census.³⁶

However, even this measure is funding-dependent. So, while the edict is authorized, its lack of appropriated funds threatens the potential scope of the effort.

In March 2018, the New York City Department of Health and Mental Hygiene put forth a comprehensive data brief on the state of "Health Disparities Among Asian New Yorkers"³⁷. Using Community Health Survey (CHS) data, the report highlighted health behaviors, health conditions, and healthcare utilization rates of the city's Chinese, Indian, Filipino, and Korean residents. It provides a sharp view of challenges the city is and will face without pointed public health interventions by racial/ethnic subgroup. So, it is disconcerting to also report that, in December 2019, New York Governor Andrew Cuomo vetoed a State Assembly Bill 677, citing budgetary

constraints and implementation impediments as threats to the bill's longevity. Designed in a spirit similar to California's Assembly Bill No. 1726, the New York equivalent, "would have required state agencies to collect demographic data for a wide number of Asian American ethnicities".³⁸

Outside of formal data collection, local forums and community-based organizations have a major role to play with respect to supporting data collection of AAPI community residents. Due to the rapport and trust they have inculcated with AAPI communities over time, these organizations tend to have greater accessibility and entree into more esoteric or sacred spaces occupied by AAPIs than do government representatives. They often head up health-oriented interventionist programs. In Chicago, for example, the organization Cook County CARES (Cancer Alliance to Reignite and Enhance Screening), works with community-based organizations and with hospitals, and other health systems, to increase colorectal screening rates among low income residents, including Asian men aged 50 and older. In other cities throughout the U.S., the Asian Pacific Islander American Health Forum, the Association of Asian Pacific Community Health Organizations, and the National Asian Women's Health Organization are all examples of organizations pulling hefty weight to spread critical health messages to AAPI constituents, indirectly, yet substantially supporting the very purpose that disaggregated data sets out to achieve: telling a fuller story.

Data Collection: Academia & Private Institutional Initiatives

Countless researchers have shed light on the distinctions between AAPI communities and have used their research to call for granularity in data in order to identify medically underserved AAPI communities (MUACs)³⁹. In 2009, the Institute of Medicine (IOM) released a report, titled "Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement"⁴⁰, which called for standardization for health care quality improvements, centered around training health care providers and implementing best practices for assessing patient race, ethnicity, and language proficiencies. Private grant-conferring institutions also rely on national data to help determine their grantee applications. Private philanthropy often relies on national data trends to determine funding allocations, and also uses data to prioritize and qualify applications. Applications that rely on AAPI data are arguably, then, at a disadvantage if they cannot demonstrate health phenomena at the subgroup level.

AAPI Representation in Medical Pathways Programming & Leadership

The desire and/or inspiration to pursue a pathway to medical service and leadership often begins early in life. Yet the pathways are often uneven for minoritized populations for reasons outside of their individual control. In their 2001 study, Luzzo and McWhirter astutely noted, "for many ethnic minority adolescents, career decisions are not based on personal choice and interests but are instead bound to socioeconomic needs and cultural obligations."⁴¹ Other historical issues, such as de facto segregation, and inequitable school resource distribution renders medical education unattainable for many minoritized students who would otherwise strive to become physicians⁴². AAPI students, who tend to value and are reared in households where interdependence and family obligations are paramount over self-aspirations⁴³, are underrepresented in medicine. This is particularly the case for lower-income AAPI adolescents, such as Laotians and Cambodians, compared to adolescents of higher socioeconomic standing, such as those of Japanese or Indian descent. Between 2002-2012, there was a surge of Asian applicants to American medical schools, but the data do not distinguish by subgroup⁴⁴, and in fact creates the impression that Asians as a bloc are overrepresented in medicine, where in fact the lack of data disaggregation contort the picture that certain Asian groups are more represented than others, who are not highly represented at all.

One current pathway for Asian physicians seeking to secure permanent residency or citizenship in the U.S., as well as guaranteed job placement, is through the Conrad 30 J-1 Visa Waiver Program. Conrad 30 "allows J-1 medical doctors to apply for a waiver for the 2-year residence requirement upon completion of the J-1 exchange visitor program."⁴⁵ To qualify for the waiver, these physicians must deliver care in health professional shortage areas (HPSAs), or among patient populations that are deemed a part of a medically underserved

populations (MUP). The implications of maintaining this program are significant: given the U.S. is already experiencing a physician shortage, especially in rural and underserved areas, these physicians cover crucial care delivery gaps. The program has yet to be extended, although several U.S. Senators have presented Congressional legislation—the Conrad State 30 and Physician Access Reauthorization Act⁴⁶—to extend the program through 2021. Our AMA supports this legislation.

Research has shown that “demographic representation... improves health care access for underserved populations, improves the cultural effectiveness of the physician workforce as a whole, and improves medical research and innovation for all populations.⁴⁷” As the racial and ethnic demographics of our nation shift, there is greater need for pathways and workforce opportunity programming that encourages a more representative physician workforce.

Conclusion

Beyond data disaggregation, our AMA will actively review existing AMA policy on disaggregated racial and ethnic data collection, and better coordinate existing efforts to standardize data production on the state of AAPI medical leadership and by ethnic community health outcomes. Undoubtedly, there is great need for both national as well as community-level disaggregated AAPI health data collection delineated by race and ethnicity, and also offered in languages native to the AAPI community. What is measured is what is valued; what is undercounted tends to be counted out. Precise investigative research disaggregated by ethnic subgroups is needed to yield accurate health outcomes trends for Asian Americans and Pacific Islanders. Current efforts are not robust enough to close the lid on this case. Surely, quantitative research will help researchers to visualize trends, but qualitative reports will add a density to the data that is currently missing. Without individual groups information, the physician community stands mired in serious knowledge gaps and may risk unintentionally perpetuating harms.

Moving forward, intentional efforts to support collection and evaluation of AAPI data as a whole and by subgroup will be a part of our AMA mission. The effort underscores each of our AMA Strategic Arc purviews in that supporting disaggregated AAPI data will (1) help create a clearer picture of medical education and ongoing training needs of AAPI student-physicians, current physicians, and aspiring doctors; (2) shed light on the prevalence of chronic conditions from which certain AAPI sub-populations suffer compared to others; and, (3) provide insight on how physicians may tailor their practices to better serve their AAPI patients from a culturally competent standpoint.

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