

Medical News & Perspectives

Researchers Are Working to Disaggregate Asian American Health Data—Here's Why It's Long Overdue

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In October 2020, well into the COVID-19 pandemic, the National Academies of Sciences, Engineering, and Medicine (NASEM) published a [consensus report](#) that offered a framework for how vaccines—still in development at that time—should be distributed equitably across the US.

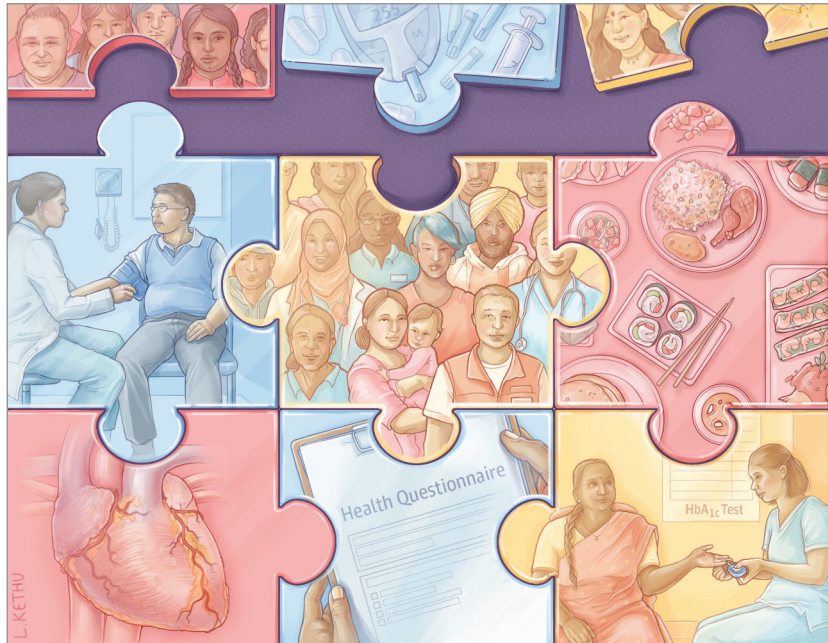
Aiming to address health disparities, the report emphasized the need to prioritize racial and ethnic groups that had been disproportionately affected by the pandemic. It mentioned American Indian and Alaska Native, Black, Hispanic or Latinx, and Native Hawaiian and Pacific Islander communities. But Asian American communities were absent in the conversation.

The report minimized the toll Asian American groups had experienced, said Stella Yi, MPH, PhD, a cardiovascular epidemiologist at the New York University School of Medicine. "It was

terrifying," Yi told *JAMA* in an interview. Community partners were trying to allocate funds to various resources based on the report. "But Asian Americans were not on it," Yi said.

The report contradicted the experiences of Yi and several other researchers who had witnessed the pandemic's effects on Asian American people, a group that includes [24 million individuals](#).

A year later, a November 2021 [review](#) would cite data from the US Centers for Disease Control and Prevention (CDC) that quantified the disparities that Yi and her colleagues had seen and experienced firsthand: in 2020, the Asian American population experienced double the percentage of deaths due to COVID-19 than the White population and as much as a 53% higher case-fatality rate. Although their smaller population meant that the absolute numbers of excess deaths were fewer among Asian American people than other groups, they experienced 37% more overall deaths than usual—an increase second only to a 53.6% jump among the Hispanic US population.



So why weren't Asian American people included in the NASEM framework for fair COVID-19 vaccine allocation?

"It's all about being invisible, being lost in aggregated data," Alka Kanaya, MD, a clinical researcher at the University of California, San Francisco, said in an interview.

For decades, US health data have been divided by demographic groups defined by the federal Office of Management and Budget (OMB), Yi explained. But grouping people into categories such as "Asian American" or "Black" masks a multitude of social, economic, and cultural circumstances that drive health outcomes, she and others say. Health data on Asian American people are often dramatically skewed by a single subcommunity that fares far better than others, perpetuating the "model minority" myth for the group as a whole. As a result, experts say researchers and policymakers have scant information on health inequities among Asian American subgroups or, critically, where resources are needed.

This data gap is not restricted to COVID-19. Across cancer, heart disease, diabetes,

and a slew of other health conditions, the way data are gathered and made available renders invisible the health risks and outcomes experienced by different Asian American subgroups, which are often lumped together as a single racial and ethnic category, Kanaya explained. What's more, information from the Native Hawaiian and Pacific Islander population is often placed in the same pool even though the [federal government recognizes](#) this as a [distinct group](#).

Experts say the aggregation obscures the [diversity](#) and health needs of Asian American people.

And although the past decade has seen advances, thanks in large part to the efforts of researchers and clinicians who belong to these communities, there's much more work to be done.

Looking for Answers

Last May, Kanaya and other researchers authored an American Heart Association [scientific statement](#) on type 2 diabetes and atherosclerotic cardiovascular disease in Asian American adults. The review noted

that all Asian American subgroups have higher rates of diabetes and deaths from stroke than the White population in the US and that, among Asian American subgroups, Filipino and South Asian adults in particular have the highest risk of developing and dying of coronary artery disease. The statement was a "call for action" to include people with different Asian ancestries in cardiovascular disease research.

"Asians make up 60% of the world and are underrepresented by a factor of 5 in clinical trials and by a factor of 6 in genetic databases," Latha Palaniappan, MD, MS, a population researcher at Stanford University and vice chair of the group that issued the statement, said in an interview. "We don't have a playbook for Asians."

Palaniappan's father died of a myocardial infarction—a heart attack—at the age of 39, when she was just 13 years old. In medical school, she began to look for data on whether heart disease disproportionately affected people of South Asian descent, the category that includes her own Asian Indian heritage. But she couldn't find South Asian people referenced in US databases, just that "the number one killer of Asians" was cancer, she recalled. Across databases from other regions, however, including Canada, Fiji, Singapore, and the UK, she found that in the early 1990s, people of South Asian origin died of heart disease more frequently than the majority demographic groups in each of those countries.

While working toward her master's degree in epidemiology at Stanford, Palaniappan looked for answers in the California Mortality Database, which disaggregated data from different Asian groups. There, she and colleagues found that Asian Indian people in the state, along with Black people, were at [particularly high risk](#) of dying from coronary heart disease in the 1990s compared with Chinese, Hispanic, Japanese, and White people.

In [subsequent research](#) published in 2016, she and her collaborators found important differences in cancer deaths between the Asian Indian, Chinese, Filipino, Japanese, Korean, and Vietnamese populations in the US—the 6 largest Asian American groups—in relation to each other and to the White population. Breast cancer, for example, was a more important cause of cancer death for Asian Indian and Filipino women than for other Asian women and White women. And stomach and liver can-

cers were a major cause of cancer death for Chinese, Korean, and Vietnamese people specifically.

Over the course of her research, Palaniappan discovered that "the story of heart disease in my family was the exact same for cancer in another Asian family, or Alzheimer's disease, or dementia," she said. "But Asians were not finding the data to improve the health of their own families because that data was not available in the United States."

To date, most of what researchers think they know about the health of Asian American people comes from studies that combine different subgroups together or focus on single subgroups. [Flawed extrapolation](#) can be a problem, Yi said. The results of a study of heart disease in Japanese men living in California, Hawaii, and Japan have been extended to different Asian American groups, for example. And because many studies are conducted only in English near large research institutions, Asian American individuals who are included are typically higher-income, English-speaking participants who don't represent the breadth of socioeconomic diversity in the community. As a result, "we are missing important differences in disease prevalence, and we're missing opportunities to prevent and treat disease," Palaniappan said.

Kanaya and colleagues recently [analyzed 7 large cohort studies](#) with Asian American participants, including the Multiethnic Study of Atherosclerosis, the Multiethnic Cohort study, and the Children of Immigrants Longitudinal Study. Each of these efforts followed up with people over time to identify factors related to health, lifestyle, and aging. But most of these cohorts comprised only a single Asian American subgroup, Kanaya said, so most remain understudied.

During the past decade, researchers have begun concerted efforts to oversample Asian-origin populations in the US. The team behind the CDC's National Health and Nutrition Examination Survey (NHANES) database was one of many that tried. But due to limited resources and small sample sizes of different subgroups, [only the aggregated data were ultimately made available](#), Palaniappan said.

Researchers therefore cannot perform meaningful statistical comparisons between Asian American subpopulations, according to Yuling Hong, MD, MSc, PhD, an

epidemiologist at the National Heart, Lung, and Blood Institute (NHLBI).

In fact, of 19 federal datasets that collect disaggregated health data for Asian American, Native Hawaiian, and Pacific Islander people, only 5 make that data public, Palaniappan and colleagues [reported](#) last year. Although researchers may be able to request access to disaggregated information, the process of doing so is expensive and onerous, she noted.

According to Namratha Kandula, MD, an epidemiologist at Northwestern University Feinberg School of Medicine, the inability to parse the health data leads to widespread clinical misconceptions, barriers to accessing preventive care, and lower rates of screening for disease.

"The clinical problem here is that when you have these aggregated data saying there's no risk in this broad group, then physicians don't look further," Kanaya added. "It perpetuates disparities. Aggregate data leads to further invisibility."

Obscured Risks

Once researchers like Kanaya began to separate out the data, the harms became evident. A 2013 [study](#) found that while 9% of all Asian and Pacific Islander patients in a Northern California health system had diabetes, low rates among the large proportion of Chinese patients and smaller Asian subgroups were obscuring much higher rates among Filipino, Pacific Islander, and South Asian patients.

In fact, the study found that "heterogeneity within these groups is more than what exists between Whites, Blacks, Latinos," Kanaya said.

Nationally representative data have since confirmed the patterns. In 2019, Kanaya and her colleagues revisited NHANES data released in 2-year cycles between 2011 and 2016, during the project's first 3 waves of oversampling Asian American communities. Their [analysis](#), published in *JAMA*, found that the prevalence of diabetes ranged from a low of 14% in the East Asian subgroup to a high of around 23% in the South Asian subgroup.

And last year, Palaniappan and other researchers reexamined data from adults in California and Hawaii, [finding](#) that the prevalence of overall cardiovascular disease varied 3-fold across the Asian and Pacific Islander subgroups they analyzed. Among the Asian groups, the Filipino population was at

highest risk while the Chinese population had the lowest risk.

Although data such as these reveal the value of disaggregation, the persistence of narratives that portray Asian communities as a monolith stymie such research, Yi said. Thus far, most initiatives to disaggregate data have been in regions with greater diversity, such as California, Hawaii, and New York, and have been led by researchers who have experienced the disproportionate health burden in their own lives. "All of us who come from these communities are looking around and saying, wait, there's something not right here," Kandula said in an interview.

Community organizers and advocacy groups play a key role in these efforts too, she said. In 2021, Yi and her colleagues were working with several Asian American organizations in New York City that wanted to know how to allocate funds to best support their various ethnic communities during the pandemic. City-wide data revealed [extremely high COVID-19 vaccination rates](#) among Asian American and Native Hawaiian and Pacific Islander people, and the researchers had little to go on to answer their questions. When they dug down, however, they found a wide range of vaccination rates, with the Chinese community at the high end and the Nepali community at the low end, Yi said.

Data such as these can help community organizers and funding agencies allocate resources more efficiently. "Equity aside, it's a matter of waste," Yi said. Without disaggregated data, "you're just wasting medicine or wasting resources towards things that people are not using or don't need."

Toward Better Data—and Better Health

The recognition of these knowledge gaps has sparked larger-scale efforts to better understand the health of Asian American subgroups, along with an influx of federal funding.

In 2021, the NHLBI, together with several other entities at the National Institutes of Health (NIH), convened [a workshop to identify research opportunities](#) for Asian American, Native Hawaiian, and Pacific Islander communities. As a result of that discussion, the NIH launched a study last year that aims to recruit 10 000 participants to understand diabetes, heart disease, stroke, and various other chronic conditions in these populations. The Fred Hutchinson Cancer

Center will act as a [coordinating center](#) for the project, which spans 5 research institutes that will each select at least 2 populations to study. In addition to measuring health using blood biomarkers, microbiome tests, and other metrics, the project will track various social determinants of health, such as immigration history and access to food.

Kandula is a principal investigator on 2 studies of cardiovascular health across different South Asian American populations—the South Asian Healthy Lifestyle Initiative, or [SAHELI](#), and the [Mediators of Atherosclerosis in South Asians Living in America](#), or [MASALA](#), study.

In the MASALA longitudinal cohort study, the team is working to identify how different ways of straddling 2 or more cultures can influence disease risk. To do so, their extensive data collection includes measures of cultural adaptation—such as fasting on specific occasions or using spices for health reasons—from people with origins in Bangladesh, India, and Pakistan.

"In doing that, we're really going to be able to show the granularity of health issues and differences between these different South Asian subgroups in risk factors for heart disease and diabetes," Kandula said. "That will allow us to more effectively address that as clinicians, as community organizations, as health and human services providers."

Kanaya, who is coprincipal investigator on the MASALA study, said its methods for understanding cultural adaptation are especially strong. Many studies of immigrants use English-language proficiency as a proxy to assess adoption of American habits and behaviors. But that's an ineffective measure for people whose countries of origin, like on the Indian subcontinent, were previously colonized by English-speaking nations. "English language proficiency is kind of a poor proxy in certain Asian groups," she said. "A fundamental gap that we have in Asian American literature is that we don't have good measures of acculturation that really draw on the richness of each cultural group. We use these proxy measures that don't work well."

Ideally, administrative datasets and large health systems should be asking more nuanced questions about people's cultural identities, immigration history, and behaviors to better understand and intervene for better health, Kanaya said. Clinicians too, should question data on health risks for ra-

cial and ethnic groups to be sure they are not inappropriately extrapolating from one group to another, Yi added.

Marshall Chin, MD, MPH, a health services researcher at the University of Chicago, says primary care clinicians must learn to move beyond textbook generalizations of Asian American people as being at low risk of various diseases. Instead, they should encompass each patient's social, cultural, and socioeconomic circumstances when guiding their health decisions.

For clinicians, these efforts are easier if health care systems can provide routes to providing culturally appropriate care, Chin added. Those routes can be direct and simple, such as making interpreters or community health workers available to help understand and bridge cultural gaps, he said. Or they can involve an analysis of policies that may make it difficult for immigrants to access necessary health care services. "It really is sort of dual—both what individual clinicians can do and what we need to do as people that work within systems," Chin said. "You have to do both."

Early last year, as part of a broader [national strategy](#) for the [White House Initiative on Asian Americans, Native Hawaiians, and Pacific Islanders](#), the Biden-Harris administration said it would act to make disaggregated data collection and reporting for these groups the norm across the federal government.

Under Health and Human Services, the [President's Advisory Commission on Asian Americans, Native Hawaiians, and Pacific Islanders](#) in consultation with community advocates has helped advance data disaggregation [across federal agencies](#) beyond the minimum OMB categories of "Asian" and "Native Hawaiian or Other Pacific Islander." Today, most national data collection systems produce data on the largest Asian American groups—Chinese, Filipino, and Indian—but data from subgroups with smaller populations are more limited.

Ultimately, experts say the work of disaggregation will benefit other racial and ethnic groups, too. People who are usually clustered together in datasets as Hispanic or Black represent a diversity of cultures, often with different health risks. For example, researchers studying Hispanic populations in California previously considered most individuals to be Mexican American, Palaniappan said. But newer analyses reveal that a significant proportion report their

origins in Central America. And, she noted, recent immigrants from Africa often have a lower risk of heart disease than Black individuals born in the US, likely because of early-life experiences of discrimination and bias in the latter group.

Capturing these nuances is critical to achieving equity. "We have to be more precise as we move on in this field," Palaniappan said. "We're not going to have precision medicine for anyone unless we have it for everyone." ■

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