

Invisibility Is Killing Us:

Data aggregation and its health impact on Pacific Islanders and Asian Americans in California

A report summarizing Pacific Islander and Asian American experiences with California county public health departments' collection and reporting of public health data.

Southern California Pacific Islander and Asian American Data Equity and Health Policy Collaborative

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Key Takeaways

Background: Pacific Islanders and Asian Americans in California knew many in their communities were dying at high rates from COVID-19, from essential workers to family members, but this data and information was not being reported. These data gaps impacted distribution of resources to diagnose and mitigate COVID-19 for Pacific Islanders (PI) and Asian Americans (AA). As a response, the **Southern California Pacific Islander and Asian American Data Equity and Health Policy Collaborative** (DEHP) was formed, bringing together researchers, advocates, community-based organizations, and health departments to understand the policy challenges and opportunities to disaggregate Pacific Islander and Asian American data.

Problem:



Pacific Islanders and Asian Americans in California are invisible in health data and that invisibility is killing us. Data aggregation exacerbates health inequities and denies us the ability to be healthy.

“Despite compelling data provided to CDPH, including the fact that suicide is the leading cause of death among PI and AA ages 10-19, and the second leading cause of death among those ages 20-34, CDPH’s May 2023 “Youth Suicide Prevention Media and Outreach” request for applications (RFA) did not include the PI/AA community as a priority population to address the high rate of youth suicide.”

-Peter Gee and Erica Juhn (See Pg, 6)

1. Twenty-eight percent (11 of 39 contacted) of health departments in California abide by federal 1997 OMB-15 policy to disaggregate racial and ethnic data: Alameda, Contra Costa, Humboldt, Los Angeles, Monterey, Orange, Sacramento, San Diego, San Francisco, San Mateo, and Solano. Solano County is the only health department that goes further to disaggregate Pacific Islander and Asian American data by subgroups.

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2. Six health departments have their own standards or policy to collect and report racial and ethnic data: Long Beach, Los Angeles, Orange, San Francisco, Santa Cruz, and Solano.

Solution:



We need disaggregated data to inform the equitable distribution of resources, policies, and health outcomes for Pacific Islander and Asian American communities.

“Disaggregated Asian cancer data became publicly accessible and detected Vietnamese Americans dying at high rates from liver cancer, a result of increased risk for contracting Hepatitis B. These findings guided cancer research, health education, and organizations tailored to the Vietnamese American community.”
-Cevadne Lee (See Pg. 22)

3. The California Department of Public Health (CDPH) and each local health department should foster transparency and accountability by implementing data equity standards and building trust with the public and community.

“Pacific Islander leaders learned that if we don’t take things into our own hands and help our own community, things will never get done. The pandemic was a lesson for us all and showcased the huge need for support from our public agencies.”
-Isa Sasi (see Pg. 16)

4. Pacific Islander and Asian American community leaders and researchers have responded to the lack of disaggregated data by forming coalitions to advocate for better data and resources. Local health departments and CDPH should work with and invest in community-centered coalitions when developing and implementing policies and collecting data and sharing out health outcomes.

DATA NARRATIVE: Pacific Islanders and COVID-19 Deaths

By Melenaité Fifta

Community leaders immediately recognized there was an error in data collection and reporting when the health department for Orange County, CA, Orange County Health Care Agency (OCHCA), disclosed COVID-19 vaccination data, which purported a ~100% vaccination rate amongst Pacific Islanders (PI). Consequently, PI patient navigators and the community-based organizations they worked for realized the county's data was incorrect. The mutual concern for accurate data among community-based organizations and OCHCA led to a change in the vaccination policy. Encouraging open communication facilitated smoother collaboration amongst community leaders, county health officers, directors of local health clinics, and faith-based leaders to champion the true burden COVID-19 had on the PI population.

As the COVID-19 death toll continued to rise in the PI community, PI navigators shared Facebook photos with OCHCA officials, showing PI faith-based leaders conducting weekly funerals. The navigators made a special request to prioritize the protection of PI faith-based leaders (that did not meet the 75+ age requirement for vaccination) by vaccinating them first. The OCHCA approved the community leader's request, vaccinating 50 PI faith-based leaders at a local FQHC. The power of the partnerships expanded between the CBOs and FQHCs, to include faith-based organizations as vaccination sites. Together, the collaborative translated health materials into 5 languages, personal protective equipment was dispersed during funerals, and vaccinations were administered to community members at places they trusted. The community partners helped to share resources with the communities that trust them, advocating for better data. Strong partnerships and willingness to collaborate resulted in improved data and better health outcomes for those most affected by the pandemic when it mattered most.



Image Caption: Pacific Islander navigators prepared a table full of lei to welcome their faith-based leaders to a vaccination clinic during the COVID-19 pandemic.

Photo courtesy: Pacific Islander Health Partnership

A Road Map towards Data Equity

“Our elders were dying [from COVID-19] but there was no data telling the public this was true.”

Cevadne Lee¹

This is not just a story about data.

This is a story about individuals whose care could have been tailored to their needs, whose health care providers could have been equipped with resources to communicate more effectively with underserved patients, and whose lives could have been saved.

This is also a story about communities mobilizing, responding to the invisibility, and demanding changes in a system that does not see us. We are the communities who care. We are Pacific Islander and Asian American public health workers, researchers, community-based organizations, epidemiologists, community members, immigrants, refugees, survivors, and allies, and we care.

Through this report, we share the impact of being invisible. Pacific Islander and Asian American racial and ethnic data continues to remain either uncollected or aggregated in overly broad groups and does not allow for the needs of subgroups to be visible. These data collection deficiencies result in policy and budget decisions that are made with incomplete information, which ultimately negatively impacts the most vulnerable communities.

This is why we all want better data. We are committed to “the public” in public health and strive to ensure the collection of representative, disaggregated data that’s published in a timely manner to help as many people as possible. By highlighting stories of local health departments having participatory and meaningful engagement with communities on data disaggregation, we are building processes that are a road map towards data equity.

¹ Lee, C (2024). Belonging in data [Manuscript submitted for publication].

Our recommendations specifically for California Department of Public Health (CDPH) are:

- Create a state standard for collecting and reporting race and ethnicity data, in accordance with existing race and ethnicity data policies: federal Office of Management & Budget SPD 15, CA State Government Code 8310.5, CA State Government Code 8310.7, and CLAS standards.² Establishing a state standard is the first step in ensuring equity through a uniform process, followed by education, training, and compliance monitoring to effectively put the state standard into practice.
- Clarify the CDPH unit responsible for compliance monitoring and oversight and have it provide guidance for implementation of the state standard, particularly for local health departments with limited resources.
- Develop data collection policies and guidance for state and local health jurisdiction department staff and epidemiologists, and the communities who co-sponsored the AB 1726 (CA State Code 8310.7) legislation. Data from this report shows that the spirit of the law has not been actualized in its implementation.

Our recommendations for CDPH and local health departments are:

- Adopt accountability and transparency measures when developing and implementing data equity standards and create opportunities to share progress with the public and community members. One example of this is co-creating a privacy clause with communities when reporting granular detailed race and/or ethnicity to facilitate data accessibility.
- Consult with and facilitate communication between community-based leaders, epidemiologists, and data analysts to avoid working in silos and to build trust and opportunities for cooperation between government and communities.
- Engage with social epidemiologists that work with smaller race and ethnicity population data, languages spoken data, and geospatially dispersed populations. This can include assessing the composition and structural conditions in each health department by training epidemiologists and other data analysts on handling datasets with small population sizes.

² The National CLAS Standards are a set of 15 action steps intended to advance health equity, improve quality, and help eliminate health care disparities by implementing culturally and linguistically appropriate services. <https://thinkculturalhealth.hhs.gov/clas>

DATA NARRATIVE: Suicide Prevention Resources

By Erica Juhn and Peter Gee

The COVID-19 pandemic showed the many gaps in the public health infrastructure, from the instability to accurately assess PI/AA community needs due to lack of disaggregated data; to the lack of bicultural, bilingual staff at public agencies; as well as the lack of connection between public agencies and community organizations to quickly share information and resources. These holes in the system resulted in compounding the burden for the PI/AA communities, with increased mental illness, due to isolation, fear of contracting COVID-19, and fear of violence due to anti-Asian hate for the Asian American communities. Community partners shared that many of the older adults they serve suffered from not knowing whether they could or should leave their home, needing food but afraid to go out because they didn't want to get sick or get attacked. Yet, with the urgency of COVID-19, intra-community partnerships were forged, information was shared, resources and funding were found, to help PI/AA communities.

As the pandemic panic died down, we have unfortunately seen many of the resources and support for the PI/AA communities disappear. In the past year there have been two prominent examples of disinvestment and deprioritization of PI/AA communities by the California Department of Public Health (CDPH). Despite compelling data provided to CDPH, including the fact that suicide is the leading cause of death among PI and AA ages 10–19, and the second leading cause of death among those aged 20–34, CDPH's May 2023 "Youth Suicide Prevention Media and Outreach" request for applications (RFA) did not include the PI/AA community as a priority population to address the high rate of youth suicide. Despite a clear need, none of the \$16.3M in funds awarded to community-based providers in September 2023 went to serve PI/AA communities. CDPH's Office of Health Equity (OHE) also responded that the PI/AA community is not considered a priority population and therefore does not have nor need a designated staff specialist in their office.

These actions deepened the inequities faced by PI/AA communities. The COVID-19 pandemic showcased the strength of community partners in advocating for and supporting their communities when the systems failed.



Image Caption: Family and friends gather in solidarity to honor the life of Nick Song at Changing Tides' 3rd annual Ripple Effect: Walk for Suicide Prevention.

Photo courtesy: Little Tokyo Service Center.

Throughout this report we weave in first person stories and narratives that convey the impact of data inequities among PI and AA communities. We define data equity as data that is collected, analyzed, interpreted and distributed so that (invisible) communities have access to and can use these data.

Standards for Data Collection &/or Reporting Racial Data

From 2021 to 2022, we conducted a legal mapping study to analyze the practice of data disaggregation at counties with a population of 106,000 or more residents, as set by the California Health Equity Metric.³ Legal mapping is a specific method under legal epidemiology that analyzes the state of the law or policy concerning a particular legal topic. Our legal mapping process included analysis of federal and California state race/ethnicity data collection and reporting standards, policy practices, and policy adoption at local health departments. This process included understanding local health department standards, or a set of practices, associated with race/ethnicity data policies.

We contacted each of the local health departments identified by various means:

- Inquiry form on county health department website
- Public records requests
- Searched and emailed county epidemiologists
- Presented at statewide local health department epidemiology meeting
- Community partners reached out to county health departments

When contacting each local health department, we asked the following three questions:

- Are you using a standard of practice (policy) in place for collecting information on race/ethnicity and languages?
- If no standard of practice is in place, are state policy/standards, or OMB-15 policy standards used?
- Are certain protocols followed when it comes to collecting, coding, and reporting race/ethnicity and languages?

Each email response and/or standard of practice we received was coded and analyzed using Dedoose, a qualitative software program. NR, as shown in our table findings, denotes counties that did not respond to several requests for information. Codes were developed from the community needs assessment that was conducted in 2021 on the usage and need for disaggregated data.

³ <https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/CaliforniaHealthEquityMetric.aspx>

Summary of Our Findings

In total, 39 health departments were contacted. County health department standards of practice were analyzed to determine if federal and state policies were being used to disaggregate Pacific Islander (PI) from Asian American (AA) in data collection, analysis, or reporting. The California Department of Public Health (CDPH) does not have a racial and ethnic data collection and/or reporting standard to guide local health departments. By analyzing the local health department standards of practice, we inferred which state or federal data standards/policies were included, if any. Our qualitative analysis revealed 3 major themes:

Theme 1

Six local health departments created their own standards of practice for collecting, analyzing, and/or reporting race and ethnicity data. The standard of practice or policy documents provided by the local health departments refer to a federal or state policy when discussing their own policies.

Theme 2

The majority of the local health departments (n=24) that responded and do not have a standard of practice or policy when collecting and reporting race and/or ethnicity data, tend to use a secondary database to guide them. Common secondary data sources include: U.S. Census, CalREDIE (Infectious disease data for California), CDPH, and/or the California Health Interview Survey.

Theme 3





Local health departments may have developed a process for collecting race and ethnicity data but is not a part of a standard.

Which California Public Health Departments Count Pacific Islanders and/or Asian Americans

A summary of 36 California county and 3 city health departments' disaggregation of ethnic and racial data and their practices in collecting and/or reporting data of Pacific Islander (PI) and/or Asian American (AA) populations.

Table 1: California public health departments and their data disaggregation practices

Legend	
Blue	Reported that they follow federal 1997 OMB SPD 15 racial standards
Yellow	Reported that they use a secondary data source for collecting and reporting data (i.e., U.S. Census or CDPH)
Green	Reported that they disaggregate data further, by PI and AA subgroups
NR	No response

Local Health Department	Has standards for data collection &/ or reporting race data?	Disaggregates PI and/or AA data?	Pacific Islander Population ⁴	Asian American Population ⁴	Total Population
Alameda	No		25,525	591,439	1,628,997
Berkeley	NR	NR	834	30,428	119,607
Butte	No		1,463	14,444	207,303
Contra Costa	No		13,519	250,154	1,156,966
El Dorado	No		1,206	12,895	192,646

⁴ Source: U.S. Census Bureau. (2021). ACS DEMOGRAPHIC AND HOUSING ESTIMATES. American Community Survey, ACS 5-Year Estimates Data Profiles, Table DP05. Retrieved December 5, 2023, from <https://data.census.gov/table/ACSDP5Y2021.DP05>.

Local Health Department	Has standards for data collection &/ or reporting race data?	Disaggregates PI and/or AA data?	Pacific Islander Population ⁴	Asian American Population ⁴	Total Population
Fresno	No		4,728	123,463	1,015,190
Humboldt	No		1,072	6,902	135,010
Imperial	No		782	3,473	178,713
Kern	No		4,253	56,876	916,108
Kings	No		1,028	7,850	152,981
Long Beach	Yes		4,954	69,075	466,565
Los Angeles	Yes		57,491	1,674,783	9,721,138
Madera	NR	NR	563	4,656	160,256
Marin	No		1,119	22,946	256,018
Merced	No		1,195	24,344	290,014
Monterey	No		4,758	34,236	432,858
Napa	No		1,141	14,013	134,300
Orange	Yes		22,695	767,609	3,151,184
Pasadena	NR	NR	553	29,729	138,771
Placer	No		3,518	44,667	417,772
Riverside	No		18,517	208,062	2,473,902
Sacramento	No		29,059	315,977	1,584,169
San Bernardino	No		16,105	201,499	2,193,656
San Diego	No		33,147	495,882	3,276,208
San Francisco	Yes		6,942	333,357	808,437

Local Health Department	Has standards for data collection &/ or reporting race data?	Disaggregates PI and/or AA data?	Pacific Islander Population ⁴	Asian American Population ⁴	Total Population
San Joaquin	No		11,034	152,916	793,229
San Luis Obispo	No		1,338	15,494	282,013
San Mateo	No		14,593	256,720	729,181
Santa Barbara	No		2,401	33,437	443,837
Santa Clara	No		16,699	800,074	1,870,945
Santa Cruz	Yes		1,330	19,093	272,138
Shasta	No		990	8,451	180,930
Solano	Yes		9,122	89,783	448,747
Sonoma	No		4,400	31,625	482,650
Stanislaus	No		7,109	40,676	551,275
Tulare	No		1,533	21,862	477,544
Ventura	No		5,029	79,367	832,605
Yolo	NR	NR	2,413	39,311	216,703

- 39 out of 62 local health departments in California were contacted, excluding those in counties or cities with fewer than 106,000 people in their total population.
- Only 6 of these 39 local health departments reported that they had a standard of practice that they use for data collection and/or reporting racial data, and 4 local health departments did not provide a response.
- Of the 39 local health departments, 11 reported that they follow federal 1997 OMB SPD 15 racial standards, 24 reported that they use a secondary data source for collecting and reporting data (i.e., U.S. Census or CDPH), and only 1 reported that they disaggregate data further, by PI and AA subgroups.



Image caption: Despite calls to the local public health department to conduct COVID-19 outreach in Chinatown Los Angeles, community leaders set up a COVID-19 testing site in 2020 with assistance from the Mayor's office. Chinatown seniors were too scared to show up for testing amid fears of anti-Asian hate violence towards seniors - no data collected implies no infections to no problems.

Photo courtesy: Cevadne Lee <https://www.latimes.com/california/story/2021-04-21/chinatown-vaccine-clinic-asian-american-seniors>

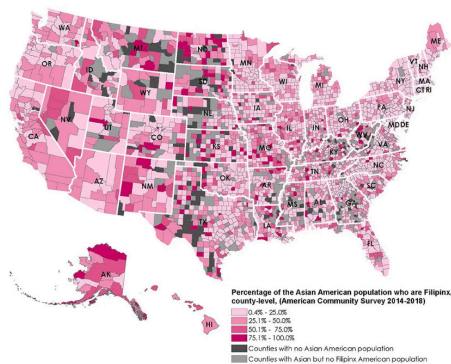


Image caption: Written by Filipina epidemiologists and public health researchers, this groundbreaking research article describes how Filipinx frontline healthcare workers contributed to a high proportion of COVID-19 mortality among Asian Americans. <https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2022.958530/full>

ORIGINAL RESEARCH
24 August 2022

Lost on the frontline, and lost in the data: COVID-19 deaths among Filipinx healthcare workers in the United States

Loraine A. Escobedo, 2 more and
Ninez A. Ponce

Centering the Pacific Islander and Asian American Communities

“Data aggregation is making us invisible, and that invisibility is killing us.”

Dr. Nadia Islam⁵

Race and ethnicity data impacts the distribution of public health resources—if it was available at all, it was only via aggregated Asian & Pacific Islander (API) data, or an undefined “other” category. Despite policies to disaggregate race and ethnicity data, the COVID-19 pandemic exposed reporting data gaps that impacted resources to diagnose and mitigate COVID-19 for Pacific Islanders (PI) and Asian Americans (AA). As a response, the **Southern California Pacific Islander and Asian American Data Equity and Health Policy Collaborative** (DEHP) was formed, bringing together researchers, advocates, community-based organizations, and health departments to understand the policy challenges and opportunities to disaggregate Pacific Islander and Asian American data.

This project was completed through four distinct phases. We conducted quantitative and qualitative research using legal epidemiology and policy planning methods. This report lays out Phases 1-3 of this project and the findings of this research.

Phase 1: Enhance existing community coalition efforts

Phase 2: Environmental scan on community usage and need for race/ethnicity data

Phase 3: Legal mapping of data collection practices at California county health departments

Phase 4: Advocate with county health departments on our findings

⁵ Islam, N. (2021, April 21). *Beyond Invisibility: Critical Steps in Disaggregated Data for AANHPIs*. National Council of Asian & Pacific Islander Physicians (NCAPIP) webinar series.

DEHP is distinguished by its focus on including Pacific Islander and Asian American communities in all aspects of this project. Almost all of our steering committee, researchers, and community partners self-identify as Pacific Islander and/or Asian American.

We align ourselves with the community-identification of Pacific Islanders residing in Southern California. The focus of our project are the diasporic communities residing in Southern California, and herein hereafter use the term “Pacific Islanders” rather than the 1997 Office of Management and Budget (OMB)’s official categorization. We were intentional on centering Pacific Islanders (residing in California) in allyship with Asian Americans, including in all references to the two populations in focus.



Image Caption: During the COVID-19 pandemic, Native Hawaiian and Pacific Islander serving organizations collaborated with Los Angeles County to develop a social media outreach toolkit. The materials featured photos of multi-generational families and were translated in five languages: Chamorro, Hawaiian, Marshallese, Samoan, and Tongan (pictured).

Photo courtesy of Southern California Pacific Islander Community Response Team.

DATA NARRATIVE: Cultural Values and COVID-19 Isolation

By Isa Sasi

As a community that values communal gatherings and is used to leaning on each other during hard times, the pandemic exposed and catapulted the issues Pacific Islanders have been facing to the forefront. Isolation became one of the hardest barriers to overcome as our community leans on each other during harder times. Our PI community comes from tight-knit households that uplift cultural values through communal spaces, family traditions, and faith. We believe in taking care of our own and take pride in being family oriented. Our elders taught us the importance of respect, love, and to always be there for each other. With these values, we choose to live in multigenerational households with our families. This is to ensure we help raise each other's children or take care of the elders when they get old.

The pandemic forced us to isolate and stay away from each other to avoid the spread of COVID-19. Coming from big families, it was almost impossible to find the space to isolate. What made it harder was not being able to be with family while battling a deadly virus and not knowing whether you would get better from it. This also meant that our cultural values were no longer allowed during this time. We no longer were able to embrace each other with hugs, cheek to cheek greetings, or take in each other's scents symbolizing taking in an elder's wisdom.

Attending funerals and participating in gift exchanges as a sign of respect and to comfort the family grieving was no longer allowed. COVID-19 took away our elders, causing waves of emotions, and it was harder for the community to grieve as their loved ones passed away in isolation. PIs being heavily rooted in the value of gathering pushed back on us, community leaders. There was no guideline on how to deal with isolation or culturally appropriate protocols for us to lean on. It was a challenge for me, us, to determine how to best advocate for our community. Telling people to stay home, isolate, or keep 6 feet apart became a burden.

Throughout this difficult time, we learned to value keeping our PI communities safe. Community leaders learned that if we don't take things into our own hands and help our own community, things will never get done. The pandemic was a lesson for us all and showcased the huge need for support from our public agencies. Our communities continue to suffer and die from disparities and we are still continuously overlooked. How much longer do Pacific Islanders need to suffer until they get the help they need? And, how much longer will these public agencies continue to use insufficient data to justify including our communities as a priority population?



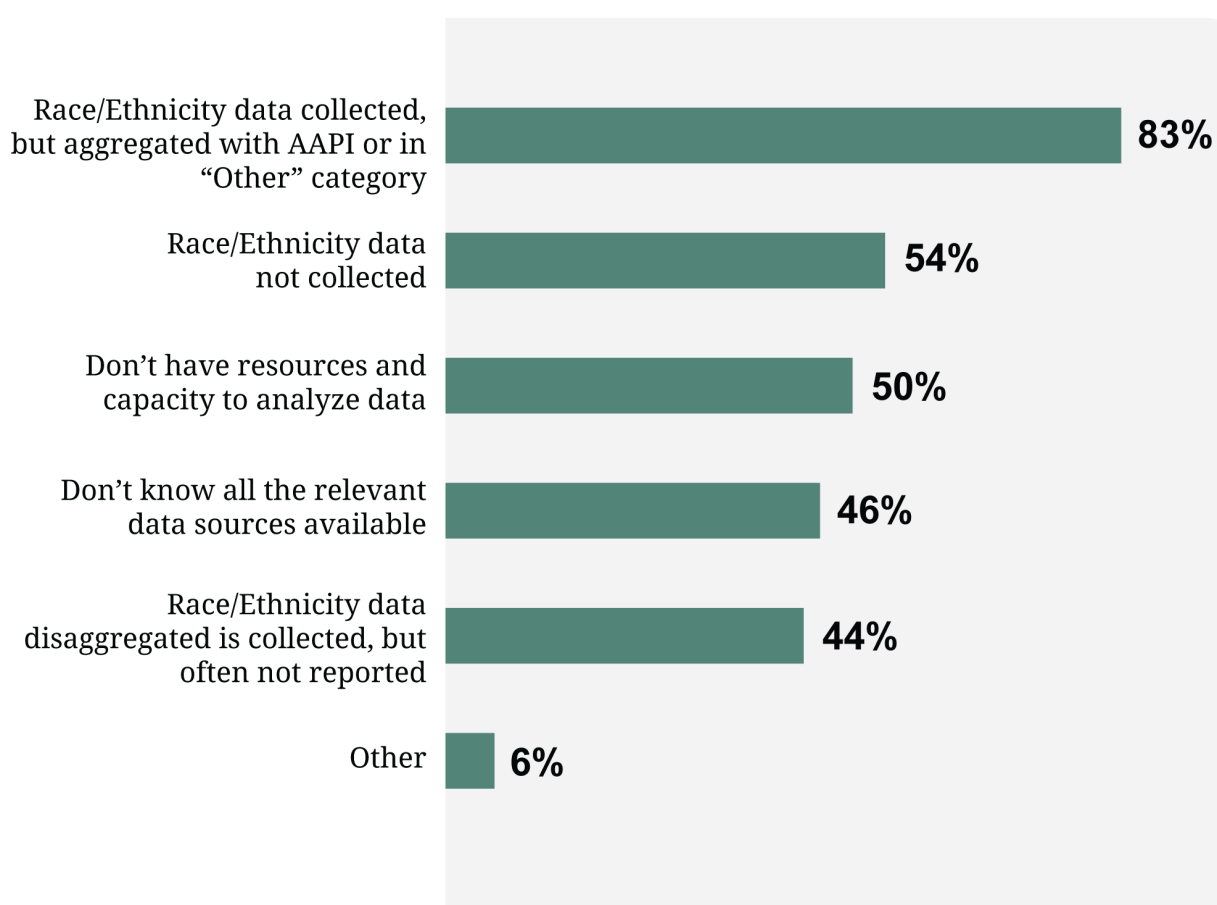
Image caption: *The Native Hawaiian Pacific Islander Community Toolkit included graphics and public service announcements. Many organizations downloaded and shared the outreach materials on social media.*

Photo courtesy: *Southern California Pacific Islander Community Response Team*

Community Usage and Need for Disaggregated Data

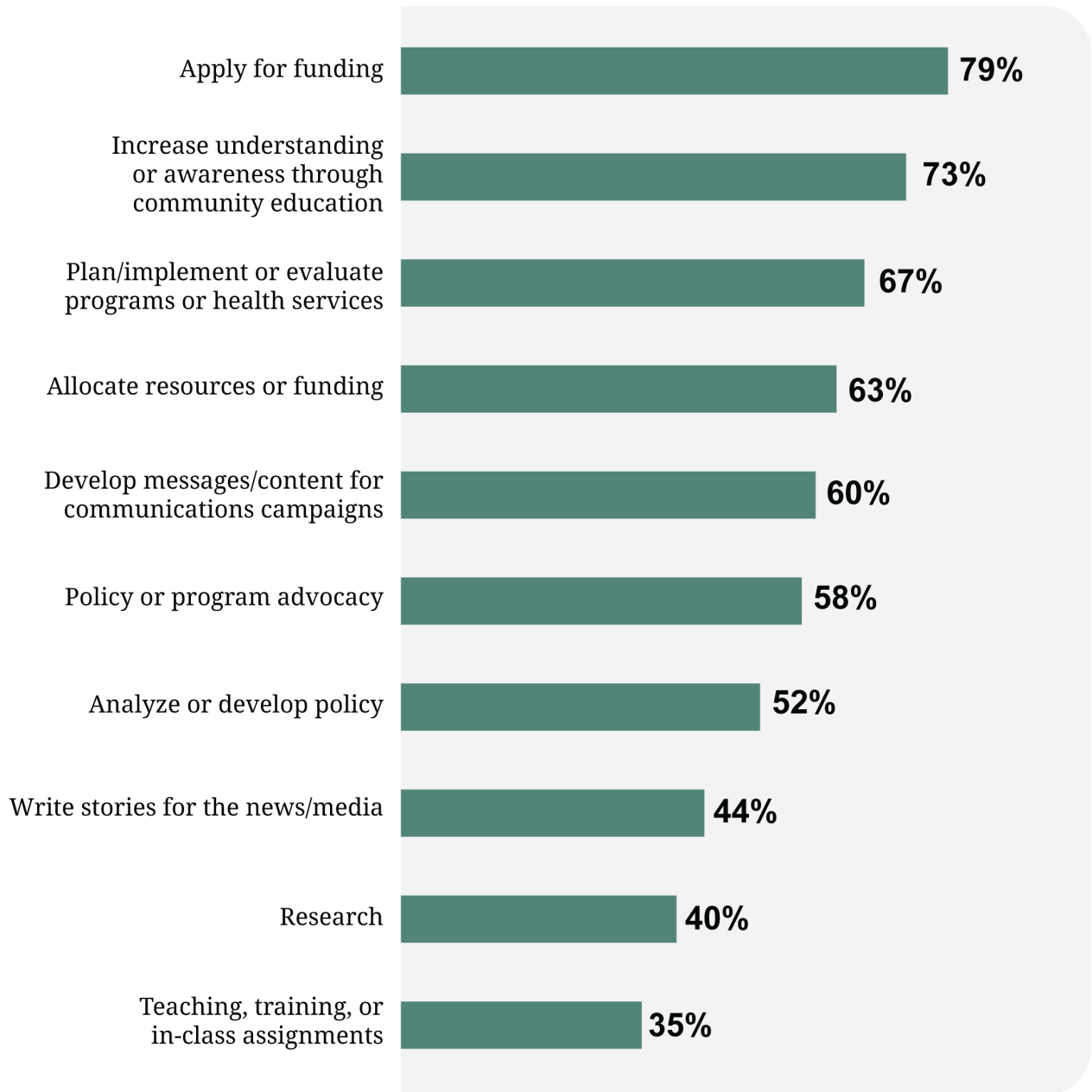
A community needs assessment was conducted in 2021 to understand community usage and need for race and ethnicity data. A community questionnaire was adapted from the Native Hawaiian and Pacific Islander (NHPI) Data Policy Lab at the UCLA Center for Health Policy Research.⁶ DEHP’s steering committee provided a list of 200+ Pacific Islander and/or Asian American-serving organizations in California including ethnic media, community-based organizations, faith-based organizations, cultural organizations (dance, museums, civic clubs), federally-qualified health centers, philanthropy, unions, and more. Forty-eight organizations responded to our survey.

Figure 1: Community barriers to using race/ethnicity data



⁶ <https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2023.307503>

Figure 2: Community uses for race/ethnicity health data



Legal Mapping of Pacific Islander and/or Asian American Data Collection Policies

We adapted the legal epidemiology framework to understand the benefits and harms of racial and ethnic data collection policies in public health. Legal epidemiology is the scientific study and deployment of law and policy as a factor in the cause, distribution, and prevention of disease and injury in a population.⁷ We focused on data disaggregation policies and reviewed how each county public health department in California was practicing the following policies:

Office of Management & Budget Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (OMB SPD 15, 1997)⁸

- **Ethnicity:**
 - ▶ Hispanic or Latino
 - ▶ Non Hispanic or Latino
- **Race:**
 - ▶ American Indian or Alaska Native
 - ▶ Asian
 - ▶ Black or African American
 - ▶ Native Hawaiian or Other Pacific Islander
 - ▶ White

⁷ https://www.cdc.gov/dhdsp/policy_resources/legal_epi.htm

⁸ The 1997 OMB SPD 15 is the federal data standards policy used during our study analysis from 2021-2023. As of writing this report, OMB SPD 15 has new revisions effective March 29, 2024. <https://www.federalregister.gov/documents/1997/10/30/97-28653/revisions-to-the-standards-for-the-classification-of-federal-data-on-race-and-ethnicity>; <https://www.federalregister.gov/documents/2024/03/29/2024-06469/revisions-to-ombs-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and>

State of California Government Code 8310.5 Amended (AB 1088, 2011) requires each state agency, commission, or board must collect demographic data⁹:

- ▶ Asian: Chinese, Japanese, Filipino, Korean, Vietnamese, Asian Indian, Laotian, Cambodian
- ▶ Pacific Islander: Hawaiian, Guamanian, Samoan

State of California Government Code. 8310.7 Amended (AB 1726, 2016) requires State Department of Industrial Relations, Civil Rights Departments, and the Department of Public Health on or after July 1, 2022 to collect demographic data¹⁰:

- ▶ Asian: Bangladeshi, Hmong, Indonesian, Malaysian, Pakistani, Sri Lankan, Taiwanese, and Thai
- ▶ Pacific Islander: Fijian, Tongan

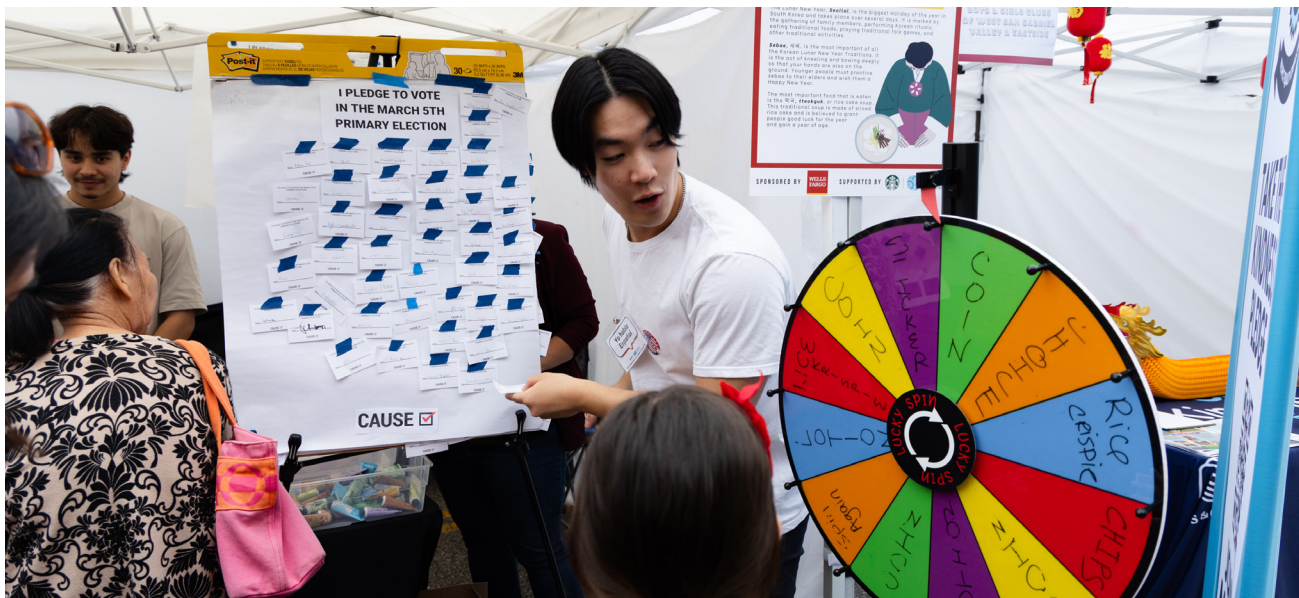


Image caption: CAUSE conducting voter education in San Gabriel Valley of Los Angeles County, the largest Asian American community in the U.S. When Asian Americans are disaggregated by voter status (being registered to vote, eligible but not registered to vote, or noncitizen), we gain new insights about the factors that predict civic engagement.

Photo courtesy: Center for Asian Americans United for Self-Empowerment.

9 https://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?lawCode=GOV§ionNum=8310.5

10 This policy was enacted in July 2022 and was not included in our project implementation but might have confounded our findings. https://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?lawCode=GOV§ionNum=8310.7.

DATA NARRATIVE: Impact of disaggregated data

By Cevadne Lee

In the 1990s, cancer advocates and cancer researchers advocated to the California Cancer Registry to disaggregate Asian ethnicity data. Disaggregated data about cancer in Asian populations became publicly accessible and detected Vietnamese Americans dying at high rates from liver cancer, a result of increased risk for contracting Hepatitis B. These findings guided cancer research, health education, and organizations tailored to the Vietnamese American community. The impact led to the founding of Vietnamese American Cancer Foundation in Little Saigon, Orange County, CA by Vietnamese American oncologists, cancer researchers, and cancer patients. In 2018, the University of California, Irvine, Chao Family Comprehensive Cancer Center created a Vietnamese Outreach Navigation Program tailored for Vietnamese American cancer patients seeking cancer care. The cumulative influence of advocacy, disaggregated data, partnerships, and community engagement led to the development of culturally appropriate cancer programs. Being visible in data helped Vietnamese Americans improve their health access. The benefits of disaggregated data can result in appropriate resources and can ultimately impact all our communities to be seen.

VIÊM GAN B

- Viêm gan B thường ảnh hưởng nhất đến những người ở Châu Á, Quần đảo Thái Bình Dương và một phần Châu Phi.
 - Nếu không được điều trị, có tới 1 trong 4 người mắc bệnh viêm gan B mãn tính sẽ phát triển các vấn đề về gan như xơ gan và ung thư gan.
 - 1 trong 12 người Mỹ gốc Á Châu và Thổ Dân Đảo Thái Bình Dương mắc bệnh viêm gan B mãn tính.
- Các khuyến cáo phòng ngừa viêm gan B theo CDC
 - Truy Tâm và Xét Nghiệm
 - Tất cả người trưởng thành 18 tuổi trở lên ít nhất một lần trong đời.
 - Người đang mang thai cho mỗi thai kỳ, bất kể tình trạng chủng ngừa.
 - Tất cả mọi người bất kể độ tuổi nếu họ có rủi ro.

Image Caption: *Disaggregated cancer data has made an impact in the ability to tailor and create cancer educational materials in Vietnamese. Created by Vital Access Care Foundation (dba Vietnamese American Cancer Foundation), this social media post describes Hepatitis B risk factors and screening recommendations.*

Photo courtesy: *Vital Access Care Foundation.*

This report weaves in our stories of resilience, perseverance, and belonging in data. The **Southern California Pacific Islander and Asian American Data Equity and Health Policy Collaborative** strives for data equity and belonging, where belonging entails our visibility and contributions in public health data.

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<https://www.uihi.org/projects/data-genocide-of-american-indians-and-alaska-natives-in-covid-19-data/>

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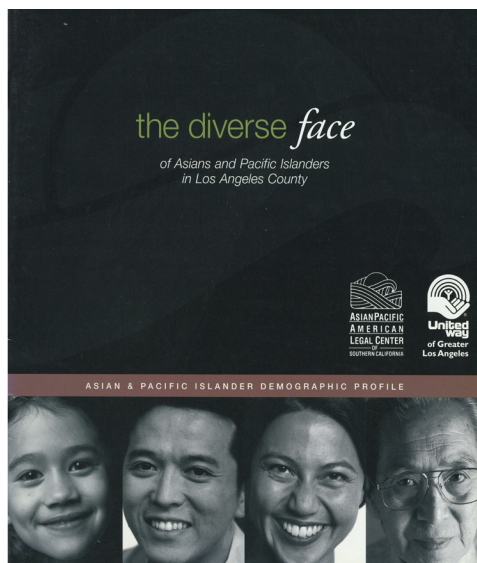


Image caption: *Diverse Faces in 2004 was one of the first demographic reports providing key characteristics of Pacific Islander and Asian American communities disaggregated by ethnic group and geography. Twenty years later, many CBOs still use these reports to inform advocacy, funding, and outreach. These series of demographic reports were produced by Asian Americans Advancing Justice SoCal (formerly known as Asian Pacific American Legal Center).*

