

Breakout Session Topic: Advancing AANHPI Data Equity and Disaggregation (AAPILC)

Session Description: Asian American and Native Hawaiian and Pacific Islander organizations, researchers, and policy advocates have consistently emphasized the need for timely, detailed, and accurate data that can inform better decision making, policy development, and policy implementation. Addressing the health, economic, political, and social inequities of AA and NHPIs rests on the capability to accurately collect and report disaggregated data. While legislation has been passed in California to break down racial and ethnic data beyond the broad categories (e.g., AB 1088 and AB 1726), many agencies have yet to operationalize the collection of these data on AAs and NHPIs. The collection of data has been a challenge for many government agencies, researchers, and other public institutions interested in better understanding the state of AA and NHPI communities, but new methodology and data collection approaches are addressing these gaps, such as the California Health Interview Survey NHPI data policy lab dashboard and the AAPI Data Survey and Initiatives. This session explores how we can advance more equitable data collection to ensure more comprehensive demographic data for AA and NHPI communities, in particular smaller populations.

Moderator + Researcher: Ninez Ponce, M.P.P, Ph.D.

Professor and Endowed Chair at the UCLA Fielding School of Public Health, Director of the UCLA Center for Health Policy Research, Principal Investigator for the California Health Interview Survey

Researcher: Karthick Ramakrishnan, Ph.D.

Professor of Public Policy at UCR, Executive Director at California 100

Researcher: Calvin Chan, M.S., J.D.

Data Analytics Director of the NHPI Data Policy Lab at UCLA's Center for Health Policy Research

Community Reactors: Doreena Wong, J.D.

Policy Director at Asian American Resources, Inc (ARI)

Please visit <https://www.aasc.ucla.edu/aapipolicy/default.aspx> to view the researchers' policy briefs.

Session Overview

Session researchers, Dr. Ninez Ponce, Dr. Karthick Ramakrishnan and Calvin Chan, each provided brief presentations discussing their respective foci within the topic of AANHPI Data Equity and Disaggregation. Community Reactor, Doreena Wong, addressed various aspects of the presentations and provided a community/practice-based reaction to the content presented; there was an audience Q/A at the end.

The Fundamentals of Data Access and Inclusivity

The UCLA Center for Health Policy Research (UCLA CHPR), directed by Dr. Ninez Ponce, is also home to the California Health Interview Survey (CHIS), the largest state-level health survey in the nation. Dr. Ponce discussed the ways in which surveys and data access is a crucial aspect to increasing the breadth of knowledge on health-related issues, and how non-sensitive data is accessible for free by the public. Students can access sensitive data (i.e. SOGI and race) in the restricted data file for a fee, but can get a full scholarship to access it.

"We democratize the data. You can't just collect data... it has to be released, and freed, and it can't be expensive. You want to make it free."

Dr. Ponce also discussed the need for inclusivity in language access and translation services as part of the survey process itself, and that sometimes, even if the translation services aren't utilized, should be included as a method of trust-building; Dr. Ponce gives the example of including Tagalog in CHIS

"We also conduct the survey in not just to English and Spanish but in Cantonese, Mandarin, Korean, Tagalog, [and] Vietnamese missing something. Cantonese, Mandarin. Korean, Vietnamese, Tagalog... We don't do Japanese [but] we did the first year... We're very evidence criteria based. And so because resources are scarce... we can't do all 100 plus languages, right? In a survey. So we put criteria of linguistic isolation and the probability of encountering and getting that person in a population based survey with a sample [and] set a target sample 20,000. So based on those two, that we chose those languages, Asian

languages, and really Tagalog not make the cut the first time and I got a lot of flack in the Filipino community... It was based on 1990 census, because the 2000 census ... hadn't been out yet. So sort of part of it was, ... data is always too late, you know, so, and that's one of the criticisms of data. And that time there were the cohort of Filipinos were not linguistically isolated. So different cohorts, different waves occurred, and so by the time the next test occurred, we saw high linguistic isolation because of family reunification laws... I do get asked like, will you continue Tagalog because my team says, Ninez, there's only like, five Tagalog interviews this year, of 20,000; don't you think we should stop it? And I and I said no, no, like any public policy once you give you no entitlement, you can't take away. So I said no, we just have to go to we did it. It's like to see like a lot of things are legacy. Let's make this legacy. Let's continue the patch. Let's expand."

Data Discrepancies, Policy and Data Equity as a Civil Rights Issue

Calvin Chan discussed the discrepancies in data sets related to COVID-19 disparities and health, as well as the issues emerging as a result of multiracial AANHPI folks, specifically Native Hawaiians and Pacific Islanders (NHPI) who were also Latinx, being categorized solely under the "Hispanic/Latino" category as opposed to multiracial and/or also under NHPI. He also notes that there's a need for multiracial self-identification, given that they are one of the fastest growing people in the country and NHPI have the highest rate of multiracial folks in their communities than any other major racial or ethnic group.

"Now at the Federal level, Latino is considered an ethnicity and it's possible to have both an ethnic category and racial category to define who you are. Now, the California dashboard, and this table, treats Latino as it goes, another racial or ethnic group, [or] another racial identity. And what that means is that all the other racial categories are treated as non-Hispanic. So NHPI here refers to an API, non-Hispanic."

Calvin also notes that the NHPI Data Policy Lab at UCLA CHPR, which he directs as the Data Analytics Director, works on increasing data access and improving data categorization and collection processes

Dorina commented on the presentation, stating that:

"If we're not seen and we don't have the data, then we won't be able to affect policies, funding, institutional change, so ... data is just foundational to that... Especially in the health field, in order to address health disparities and ensure health equity... we can't do that without really data to kind of identify health disparities. And so we need ... community level data and disaggregated data in order to kind of understand the root causes of disparate health outcomes."

Dorina also expanded upon the Office of Management and Budget (OMB) Standards for classifying race and ethnicity on the federal level, as the current requirements and standard is just five (5) minimum categories. Currently, there's decision making surrounding the expansion of these categories into broader or disaggregated/specific ethnic identities being included in the categorization.

"There's an opportunity here to try to respond to the public comment period. They have given us 60 days until April 12. So some of us are going to be trying to organize some comments; we might try to draft like a template letter that to give to other CEOs, researchers, interested stakeholders"

Calvin notes in the Q/A section of the session that:

"The reality is that the modern use of race and ethnicity to help address disparities, going back to the civil rights movement, [is] something that federal agencies are required to collect data in order to ensure that they're in compliance with civil rights laws. So when we present this to policymakers, we don't present this just as something that will get you extra dollars into the district, but as a fundamental civil rights issue that prevents discrimination from occurring and that I think, needs to be part of the messaging."

Collectively, during the Q/A, all session members mentioned the need for the Department of Finance, in particular, to disaggregate data, as well as the need to use and refer to different data sources to put together the pieces of data (i.e. administrative data, private data, etc.).

Dr. Ponce also notes that there are systematic errors in data collection, and how there are frequent errors that have been found in institutional classifications of NHPI. Dr. Ponce also mentioned that changes need to come from the Department of Finance in terms of data equity and disaggregated data access, stating that

"I absolutely agree that it has to start with Department of Finance because we use the Department of Finance as our denominators for everything; cases, for deaths. We use it as what we call control totals to do our weights for population."

Calvin also touches on the impacts of colonization, racial record keeping and exclusion of data as a result.

"A staffer from the Office of Inspector General talked about Medicare imputes race data, using their records from Social Security Administration... but those records come from a time when the only racial categories are like white, black and white, which leaves out communities that have been forced to essentially change their names in order to integrate with the United States in order to afford themselves and their children economic opportunities... So unfortunately, one of the impacts of colonization has been poor race data... So I think what Karthick said in terms of looking for private sources of data and other administrative records, is something that might need to be done"

The Politics of Data Disaggregation

Dr. Ramakrishnan starts by discussing racialization and how race in itself goes beyond just categorization, but social/cultural perception.

Dr. Ramakrishnan also noted that legacy data systems play a large role in data access for racial/ethnic data, stating that:

"Sadly, California is a state of innovation, and yet we can't even get our data systems upgraded enough to do that should be a priority."

Dr. Ramakrishnan also discusses how AAPI Data takes a deeper look into political opinions of AANHPI community members and the value of opinion or self-reported perception data is crucial in assessing policy issues, drawing from a recent study on gun violence and opinions surrounding them. Dr. Ramakrishnan discussed that with regard to gun violence,

"Native Hawaiians, Pacific Islanders and Asians are top of the list in terms of being ... very worried or somewhat worried about [it]," yet experience some of the lowest rates of death from guns. In an interview with KNF, the reporter asked, "How do you explain the difference between the actual risk of being killed and the anxiety?"

Dr. Ramakrishnan also touched on hate crime rates and the ways in which racial justice and flexibility in the intent of legislation is needed when addressing hate directed toward AANHPI community members.

"What it [the data] shows is that yes, Asian Americans have been experiencing hate incidents. And yes, Pacific Islanders have also been experiencing hate incidents, and Black people are experiencing some hate crimes more than Asians... It's just important for us to recognize that. And that's important too, because when the state passes policies combating hate, we are not the only ones. Right? And it's just really important to have those difficult conversations and like, why is it money going into a non-Asian group? It's because they are experiencing it. That's what the legislation is for."

Dr. Ramakrishnan also discussed that in terms of self-reported hate crimes and incidents, it was higher among Asian men; however, the data is limited and the issue of hate incidents have been primarily framed as a larger issue among Asian women. Building on this idea, he emphasizes the need for policy and activism centered around data and facts.

"DNA: Data, Narrative and Action. we cannot continue spinning narratives that are consistently going against data ... at some point, we need to start updating it and just face the truth, and then think about the kinds of interventions that are needed."

Dr. Ramakrishnan also discusses how the advocacy for data disaggregation, though a seemingly non-partisan issue, is actually highly politicized and was highly opposed on the state and federal level as far as policy change goes.

"When it came to a lot of opposition, certain Chinese immigrant [and] Chinese American communities started calling it segregation... So misinformation is quite strong." He also emphasized the need to use more accessible language, expressing that "I really also like that the frame is moving to data equity now. I actually think we need to retire data disaggregation; it is not something that really works well in a large audience. People have no idea what it is. People know what equity is. And then you can talk about detail race details, ethnicity collection. You don't want someone to like basically become a social scientist while you're talking."

Dr. Ramakrishnan also presented on how there is a need from the state to increase access to information as a way to support civic engagement and knowledge surrounding policies

"Think of AB 60 as an example that should have benefited everyone. But is the state doing enough in terms of outreach to make people aware of what they're entitled to? And does it have the kind of language access and other type of active community outreach to give them the chances? The answer's no."

Dr. Ramakrishnan also emphasized that there's a "disaggregation plus agenda," which transcends the conversation of only data disaggregation and seeks to improve data capacity, community data accessibility, etc.

"Of course, detailed collection is important, but you got to expand it to not only the collection, but the timeliness, the accessibility, human centered design, community inclusion, and federal agencies recognition of subject matter expertise and population expertise. So just like the Census Bureau has a scientific advisory committee and the National Advisory Committee needs to have that for every single statistical agency in the federal government, including Health and Human Services. Right. So we have several recommendations that flow out of them. "

Dr. Ramakrishnan concludes with the need for data and narrative as vehicles of policy change and political power, noting that

"Narrative is important, but narrative that is informed by the data is what I would say but data in and of itself is not going to save the world. People save the world, and it needs to be tied to strategic action. Community voices are important. How data is interpreted, is critically important. I mean, one of the things that's like trying to pitch a news story to a reporter just based on data. Data journalism is a thing but mostly they're like yeah, do you know me humans, that I can talk to the stories related to this. So that's, that's really vital. And then finally, after the dissemination that we face, engage with community members of research, evaluation that changes to data criteria."

Doreena notes that

"I think it's probably really, really helpful to have kind of a focus, just our communities and you know, not only their website, but on the infographics and the reports that you're able to generate and usable information because we haven't been able to have that kind of focus before. "

Doreena goes on, discussing that the need for disaggregated categories opens up challenges, such as need for more funding to do so, capacity building and updating technical systems to host such data.

"Funding is always an excuse that government agencies use; oh, I can't do it that cost too much. So we really do need permanent, dedicated funding for that. And I think we are able, you know, I think an example of that is the advocacy that went around the API budget... maybe one time I gotta make can try to get it again. But it actually even allocated like \$10 million for data inequity. So I think it can be done. But we really have to get the agencies to commit the state to commit to changing not only the IT systems, but I tell when you said this, too. We have to train the staff, so they know how they're affected."