UCLA
AAPI Nexus: Policy, Practice and Community

Title

Making the Invisible Visible: The Role of Public Health Critical Race Praxis in Data Disaggregation of Asian Americans and Pacific Islanders in the Midst of the COVID-19 Pandemic

Permalink

https://escholarship.org/uc/item/38b5h7c8

Journal

AAPI Nexus: Policy, Practice and Community, 17(1-2)

ISSN

1545-0317

Authors

Bacong, Adrian Matias
Nguyen, Alex
Hing, Anna K.

Publication Date

2020

Copyright Information

Peer reviewed

Resource Paper

Making the Invisible Visible: The Role of Public Health Critical Race Praxis in Data Disaggregation of Asian Americans and Pacific Islanders in the Midst of the COVID-19 Pandemic

Adrian Matias Bacong, Alex Nguyen, and Anna K. Hing

Abstract

The COVID-19 pandemic has revealed the challenges in gathering case and mortality data by race and ethnicity, especially for Asian Americans and Pacific Islanders (AAPIs). The typical response would be to gather and disaggregate data among AAPI people. However, to what purpose does data disaggregation serve outside of describing disparities? We argue that collection of data both during and after the COVID-19 pandemic should be framed within principles of equity and justice, ideas put forth by Public Health Critical Race Praxis (PHCRP). Applying a PHCRP framework to data collection and disaggregation allows for researchers and policy makers to approach pandemic data collection and future data collection with both equity and community partnership in mind.

Introduction

Since March 2020, the novel coronavirus 2019 (COVID-19) pandemic has profoundly altered social life in the United States. It has led to massive shutdowns in work, school, and other nonessential services in favor of "stay-at-home" orders to curb its spread. In the United States, there have been efforts to identify risk factors that are associated with contraction of the disease. Early reports noted that this disease infec-

tion and mortality "do not discriminate." However, recent data have shown that COVID-19 indeed discriminates, particularly among Black and Latinx communities (Scott, 2020; Shah, Sachdeva, and Dodiuk-Gad, 2020). Obtaining data to identify these disparities were difficult, however, as not all states were reporting COVID-19 cases and mortalities by race and ethnicity (Kaiser Family Foundation, 2020). Thus, the actual impact of COVID-19 on AAPI communities has been rendered invisible.

While COVID-19 disparities have been relatively ignored for AAPI communities, the pandemic has increased visibility for Asian Americans as a result of the virus's origins in Wuhan, China. With this visibility has come increased discrimination against Asian people altogether, not just those of Chinese origin (Gee, Ro, and Rimoin, 2020). We have also seen baseless accusations that COVID-19 was created in a Chinese laboratory, policies hindering travel to and from China, and action by the federal government to pull out of international agencies because of distrust of Chinese health officials (Gee et al., 2020).

Thus, the COVID-19 pandemic places AAPIs in a position of precarious visibility. On one end, AAPIs are seen as vectors of disease and targets of racism and xenophobia. On the other end, AAPI communities have not been included in conversations to ensure the health and well-being of all. Further, this precarious visibility coincides with the implementation of the decennial census, a nationwide activity that gathers finer statistics on the state of AAPIs. The census should provide an opportunity to highlight the needs of the growing AAPI community. Instead, initial reports show that responses to the census have been low across all race and ethnic groups (Ong, Ong, and Ong, 2020). Given this problem, the ideal response would be to gather more data on AAPI people and all undercounted groups, then disaggregate the data to allow for a more detailed look at the needs of each AAPI ethnic group. However, numerous surveys conducted since the official calls to disaggregate data by the U.S. Office of Management and Budget in 2000 have noted the lack of data on smaller AAPI groups (Adia et al., 2020; Bacong, Holub, and Porotesano, 2016; Holland and Palaniappan, 2012; Korngiebel et al., 2015; Srinivasan and Guillermo, 2000). This brings two critical questions. First, what purpose does data disaggregation serve? And second, how can data disaggregation be used for equitable policies for AAPIs?

Using the COVID-19 pandemic as a lens, we critically examine the idea of "data disaggregation" in the collection of data for AAPIs. We begin this resource paper by examining the development of data disag-

gregation practices among AAPIs. We then present PHCRP (Ford and Airhihenbuwa, 2010), a methodological framework that can enhance data disaggregation. Finally, we discuss the implications of data disaggregation for the COVID-19 pandemic. At minimum, data disaggregation has been used to identify disparities. However, we argue that data disaggregation practices can move forward by incorporating PHCRP to (1) interrogate the idea of race and ethnicity to see how AAPIs have been made visible and invisible; (2) critically examine what counts as "knowledge" in the data collection and disaggregation; (3) implement an intersectional analysis to examine the ways in which history and social structures have perpetuated the visibility of AAPI health, but invisibility of AAPI illness; and (4) build a sense of data ownership among AAPIs to make the needs of smaller communities visible. Due to data's importance both during and after the COVID-19 pandemic, researchers and policy makers should disaggregate data as a method to measure equity and work in partnership with communities to make the invisible visible.

Data Disaggregation and the Asian American and Pacific Islander Community

The conception of who is an "Asian American and Pacific Islander" has long paralleled the ways in which this community has been disaggregated in the United States. The U.S. Census did not include any AAPI groups until 1870, rendering them "invisible" for 80 years of the 230 years of the decennial count (Pew Research Center, 2020). Since 1870, inclusion in the census changed over time following the AAPI population. Initial counts of Asians in the census began with inclusion of Chinese people, until Japanese people were included in the 1900 census. In 1920, the "Asian" category expanded to include Filipinos, Koreans, and South Asians (termed "Hindi" at the time). In 1960, the first "Pacific Islander" groups were aggregated with Asians, with the inclusion of Hawaiian people. The 1980 census saw an expansion of Pacific Islander groups under the Asian race category with the inclusion of Samoan and Guamanian groups. However, it was not until the 2000 Census that we saw the formal policy to disaggregate AAPIs into separate groups.

The implementation of policy for data disaggregation was important in developments to disaggregate AAPIs in socioeconomic and health data. This push has remained strong. In 2012, President Barack Obama signed Executive Order 13515, an effort to increase participation of AAPIs in federal programs, including the census (*White House Execu-*

tive Order 13515, 2009).

For many scholars, the practice of data disaggregation sought to undo the long-standing stereotype of the Model Minority Myth—the neoliberal notion that Asian Americans achieved financial success due to their hard work and quiet demeanor. Disaggregating data counteracts the myth and other notions of a hegemonic AAPI population, showcasing the diversity underneath the umbrella term, AAPI. This practice explicitly deconstructs AAPI data, to uncover the inequitable health and economic outcomes within and between the various ethnic groups.

The practice of data disaggregation has not been without its limitations. Small sample sizes in surveys of harder to reach AAPI groups has been an issue that has complicated data disaggregation efforts. Because of continued small sample sizes, publicly available datasets continue to aggregate certain Asian American groups or simply ignore Pacific Islanders altogether. Additionally, research funding efforts to support AAPI communities have remained largely stagnant despite the increasing AAPI population (Đoàn et al., 2019).

With regard to the COVID-19 pandemic, data disaggregation has been largely delayed and unavailable. Initial reports indicated only case numbers, but less about how these case numbers are stratified (Kim and Vann, 2020). This initially led to the idea that COVID-19 did not discriminate. However, once disaggregated data were available, Black and Latinx people were disproportionately diagnosed with COVID-19 and had higher mortality than white people whereas data for AAPIs was mostly unavailable (Kaiser Family Foundation, 2020).

Moving Data Disaggregation Forward: The Role of Public Health Critical Race Praxis

The common approach to address the limits of data disaggregation would be to continue to collect data. However, it is important not to take the methods for gathering and disaggregating data for granted. How should we gather data and what should we do when we have it?

PHCRP can provide a guide for future conduct of data disaggregation for health data. Created by Ford and Airhihenbuwa (2010), PHCRP provides four focuses of consideration when conducting research: (1) contemporary patterns of racial relations; (2) knowledge production; (3) conceptualization and measurement; and (4) action.

Focus #1: Contemporary Patterns of Racial Relations

The first focus challenges researchers and practitioners to examine

how racialization and racism operate within a study. As we think about data disaggregation among AAPIs, we must consider the historical racialization of this group, from its invisible origins in early censuses, to the renewed focus on disaggregation. We must question the logic that has led to AAPI's invisibility and challenge these historical perspectives. Researchers and practitioners should consider the fluidity of this racial category rather than view it as a monolith. Moreover, as we plan for data collection and disaggregation, we must ask how different AAPI ethnic groups are racialized. In a larger racial hierarchy and racial binary, where do certain AAPI groups fit (Bonilla-Silva, 2002; Kim, 1999; Omi and Winant, 2014)? How does the presence of racialized hierarchies affect the perception of perceived healthiness among AAPI groups but also the lack of resources to address disparities?

Focus #2: Knowledge Production

The second focus asks researchers to reflect on how racialization influences the production of knowledge and how reporting of results may reinforce stereotypes based on race. This focus has two important points to consider for data disaggregation. First, does our discussion of disparities by group reinforce racialized stereotypes of groups? For example, in many health studies, AAPIs as an aggregate have better health outcomes than other race and ethnic groups. However, when disaggregated from Asian Americans, Pacific Islanders have worse health outcomes. Moreover, when each group is further disaggregated by ethnicity, we see even greater heterogeneity. Too often the narrative on AAPI health focuses on the healthiness of this combined group, extending the Model Minority Myth to health (Tendulkar et al., 2012). When data indicate disparities by ethnic group, the explanation of the heterogeneity of these results revert to claims about different cultural practices rather than the historical and structural factors (i.e., racism) that beget poorer health in certain ethnic groups. Second, how are we collecting the data on why these disparities exist? This question is especially important as researchers consider the limitations of their data. Quantitative data are limited in their ability to explain the reasons for differences between groups. However, utilizing a mixed-methods, community-informed, and community-engaged approach could allow for researchers to fill in the gaps of knowledge.

Focus #3: Conceptualization and Measurement

The third focus challenges the researchers to focus on the ways

that health research defines race and ethnicity. As we consider data disaggregation among AAPIs, researchers must remember that neither race nor ethnicity are fixed categories. Instead, they are fluid identities that change over time and are relational to groups who hold greater power. Moreover, this idea of fluidity also allows us to critique the typical, "business as usual" methods of comparing across race and ethnic groups. For example, in quantitative analyses among AAPIs, who should be used as the reference group? Do we use Chinese as the reference group because they are the largest group in the United States? What are other indicators should we consider? This approach of having a reference group in quantitative analyses centers the discussion of disparities on a single ethnic group, when instead all ethnic groups should have a chance to have their data story told. Instead of relying on comparisons to a single group in data disaggregation, a PHCRP-inspired approach should seek to obtain the marginal values and allow for comparisons to all groups. Another issue to consider is the aggregation of groups into an "Other" category, despite some groups being disaggregated. The "business as usual" strategy is to maintain the "Other" category in fears of unstable estimates. Though this is a valid reason from a statistical standpoint, this practice does not make these invisible communities visible. Instead, researchers should report for smaller ethnic groups and be honest about their limitations. It is more equitable to know something about these smaller groups than nothing at all. These methods of best practice also extend to qualitative analyses. For example, when comparisons between groups should center on the group of interest first, rather than discussing one group in comparison to the other. Moreover, it is important to take an intersectional approach to measurement, such that studies measure how structures (represented by identities) work to either alleviate or exacerbate the burden of disease.

Focus #4: Action

The final focus challenges researchers to engage with the moral implications of data collection. Are we collecting and disaggregating data for only knowledge production? Or are we collecting data for the advancement of equity? Who "owns" the data and how will the data be used? A rebuttal to these questions might include concerns about maintaining privacy and confidentiality of participants, especially people from smaller AAPI populations. Though concerns of privacy and confidentiality are important, this should not deter researchers from being more actively engaged with these smaller communities to document the com-

plete story. The lack of data on smaller communities cannot be blamed on the lack of participation by these individuals. Instead, it indicates the larger structural and institutional barriers that prevent the voices of these groups from being heard. The publication of public data serves as another institutional barrier in which people from smaller groups cannot know about the state of their community or let their voices be heard.

Implications of Data Disaggregation in the Time of COVID-19

Applying a PHCRP lens on data disaggregation provides a framework for purposeful data collection with a lens for health and social equity. The lack of data disaggregation in the COVID-19 pandemic has sparked frustration within public health and medicine to identify the communities most in need. Moreover, the COVID-19 pandemic has come at a time that data disaggregation is of the utmost importance, the 2020 U.S. Census.

The 2020 Census has direct consequences for political power and voice—it determines how seats are allocated for the House of Representatives, how district lines are drawn, and how federal assistance for housing, schools, health care, transportation, and business investment is distributed (Leadership Conference on Civil and Human Rights, 2020). AAPIs are at particular risk of being excluded from this power because they tend to live in hard-to-count census tracts and may be more difficult to reach because of structural barriers, including higher rates of poverty, unemployment, language barriers, and limited Internet access (Leadership Conference on Civil and Human Rights, 2020). Specific policies impacted include Title 1 Funding, Head Start programs, Supplemental Nutrition Assistance Program, and Medicaid access (Leadership Conference on Civil and Human Rights, 2020). By disaggregating data, bringing attention to AAPI communities, and recognizing these barriers for particular groups, we can make sure that resources are directed to the most marginalized to make sure their voices are counted and heard. Knowing which groups live in which neighborhoods can have as simple a consequence as providing ballots in the appropriate languages so that everyone is able to vote.

The threat of the virus spreading as hundreds of citizens gather in a polling place has prompted consideration of alternative solutions for the November 2020 presidential election. Most commonly, vote-by-mail (VBM) ballots are suggested. However, this process could disproportionately harm AAPI voters. AAPI VBM ballots are more likely to be rejected by election officials compared to the average, and this risk in-

creases for foreign-born voters (Asian Americans Advancing Justice—California, 2017). Further, use of VBM ballots varies with ethnicity, with 72 percent of Vietnamese voters in California using VBM compared to 59 percent of Filipino voters, as do rejection rates (Asian Americans Advancing Justice—California, 2017). These data suggest that to increase political power, we should examine the different experiences of AAPI voters to identify whose voices go unheard.

Beyond the census, data disaggregation has direct consequences for power redistribution. Data provides knowledge, and this knowledge can empower. With knowledge about the distribution of risks and resources for AAPI subgroups, we can argue against false narratives of oppression. We can continue to disprove the Model Minority Myth; we can demand resources for the most vulnerable and make sure they are not overlooked. We need to confirm that Pacific Islanders are at the front lines of COVID care, risking their lives for others, and getting sick as a result. We need this information to trace patterns of exposure, to know where to provide interventions, and to recognize the contributions of these humans that we tend to make invisible.

The lack of health data and explicit reports of COVID-19's burden on AAPI communities is especially concerning. While institutions like the Kaiser Family Foundation provide disaggregated race data on COVID-19, the data for AAPIs are scarce, especially for Pacific Islander populations (Kaiser Family Foundation, 2020). Therefore, greater efforts are needed to ensure that the burden of disease in this community is not invisible and untreated.

Conclusion and Recommendations

The lack of data on AAPIs amid the COVID-19 pandemic is reflective of a history of invisibility for this group. There are more focused efforts at obtaining data on cases, mortality, and the effects of the pandemic by race and ethnicity. However, we ask that data collection become more purposeful, rather than collecting data for data's sake. As a potential solution, we apply PHCRP to data collection and disaggregation, so that data collected both during and after the COVID-19 pandemic reflect a commitment toward achieving equity.

In the following text we provide four policy and practice recommendations related to data collection of COVID-19 for the remainder of the pandemic and after:

1) Contemporary Patterns of Racial Relations: Federal, state, and local governments, and academic institutions

should fund the study of factors related to the burden of COVID-19 and effects of the pandemic among AAPIs. This work should focus on the role that racialization and racism have played in advantaging/disadvantaging this community relative to other race and ethnic groups.

2) Knowledge Production: Reporting of COVID-19 data among AAPIs should be disaggregated by both race and ethnicity and be made readily available to the public with care for possible identification by governments and other data-collection institutions. Investigation of social and economic effects of the pandemic on the AAPI community should also focus on disaggregation.

3) Conceptualization and Measurement: Reporting COVID-19 disparities among AAPIs should be clear on which group is used as the reference group. Care should be taken with the reporting of smaller ethnic groups.

4) Action: COVID-19 data should be made readily available and easy to navigate to concerned communities and stakeholders. Investments should be made to explain how data were gathered and analyzed and input should be garnered in the interpretation of data, especially in affected communities.

Employing these four recommendations, grounded in PHCRP, can provide a framework for more equitable research and policy making in the midst of the COVID-19 pandemic and moving forward postpandemic.

References

Adia, Alexander C., Jennifer Nazareno, Don Operario, and Ninez A. Ponce. 2020. "Health Conditions, Outcomes, and Service Access among Filipino, Vietnamese, Chinese, Japanese, and Korean Adults in California, 2011–2017." *American Journal of Public Health* 110 (4): 520–6.

Asian Americans Advancing Justice—California. 2017. Asian Americans Face Higher Than Average Vote-by-Mail Ballot Rejection Rates in California. Asian Americans Advancing Justice.

Bacong, Adrian Matias, Christina Holub, and Liki Porotesano. 2016. "Comparing Obesity-Related Health Disparities among Native Hawaiians/Pacific Islanders, Asians, and Whites in California: Reinforcing the Need for Data Disaggregation and Operationalization." *Hawai'i Journal of Medicine and Public Health* 75 (11): 337.

Bonilla-Silva, Eduardo. 2002. "We Are All Americans! The Latin Americanization of Racial Stratification in the USA." *Race and Society* 5 (1): 3–16.

Doàn, Lan N., Yumie Takata, Kari-Lyn K. Sakuma, and Veronica L. Irvin. 2019. "Trends in Clinical Research Including Asian American, Native Hawaiian, and Pacific Islander Participants Funded by the US National Institutes of Health, 1992 to 2018." *JAMA Network Open* 2 (7): 1-16.

Ford, Chandra L, and Collins O. Airhihenbuwa. 2010. "The Public Health Critical Race Methodology: Praxis for Antiracism Research." *Social Science and Medicine* 71 (8): 1390–8.

Gee, Gilbert C., Marguerite J. Ro, and Anne W. Rimoin. 2020. "Seven Reasons to Care about Racism and COVID-19 and Seven Things to Do to Stop It." *American Journal of Public Health* 110 (7): 954–5.

Holland, A. T., and L. P. Palaniappan. 2012. "Problems with the Collection and Interpretation of Asian-American Health Data: Omission, Aggregation, and Extrapolation." *Annals of Epidemiology* 22 (6): 397–405.

Kaiser Family Foundation. 2020. "COVID-19 Cases by Race/Ethnicity" [June 15]. https://www.kff.org/other/state-indicator/covid-19-cases-by-race-ethnicity/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D (accessed June 15, 2020).

Kim, Claire Jean. 1999. "The Racial Triangulation of Asian Americans." *Politics and Society* 27 (1): 105–38.

Kim, Soo Rin, and Matthew Vann. 2020. Many States Are Reporting Race Data for Only Some COVID-19 Cases and Deaths. In *FiveThirtyEight*: ABC News.

Korngiebel, Diane M., Maile Taualii, Ralph Forquera, Raymond Harris, and Dedra Buchwald. 2015. "Addressing the Challenges of Research with Small Populations." *American Journal of Public Health* 105 (9): 1744–7.

Leadership Conference on Civil and Human Rights. 2020. *Asian Americans and Native Hawaiians and Pacific Islanders in the 2020 Census*. The Leadership Conference Education Fund 2020. http://civilrightsdocs.info/pdf/census/2020/Fact-Sheet-AA-NHPI-HTC.pdf (accessed June 16, 2020).

Omi, Michael, and Howard Winant. 2014. *Racial Formation in the United States*: Rout-

ledge.

Ong, Paul, Jonathan Ong, and Elena Ong. 2020. 2020 Census Response Rate Falling Behind: Over 11 Percentage Points Lower Than 2010. UCLA Luskin School of Public Affairs.

Pew Research Center. 2020. *What Census Calls Us*. Pew Research Center, February 6, . https://www.pewresearch.org/interactives/what-census-calls-us/ (accessed August 6, 2020).

Scott, Dylan. 2020. Covid-19's Devastating Toll on Black and Latino Americans, in One Chart. Vox Media LLC.

Shah, Monica, Muskaan Sachdeva, and Roni P. Dodiuk-Gad. 2020. "COVID-19 and Racial Disparities." *Journal of the American Academy of Dermatology*: S0190-9622(20)30659-9.

Srinivasan, Shobha, and Tessie Guillermo. 2000. "Toward Improved Health: Disaggregating Asian American and Native Hawaiian/Pacific Islander Data." *American Journal of Public Health* 90 (11): 1731.

Tendulkar, S. A., R. C. Hamilton, C. Chu, L. Arsenault, K. Duffy, V. Huynh, M. Hung, E. Lee, S. Jane, and E. Friedman. 2012. "Investigating the Myth of the 'Model Minority': A Participatory Community Health Assessment of Chinese and Vietnamese Adults." *Journal of Immigrant and Minority Health* 14 (5): 850–7.

White House Executive Order 13515: Increasing Participation of Asian Americans and Pacific Islanders in Federal Programs. 2009. https://www.hsdl.org/?abstract&did=799535 (accessed June 15, 2020).

Adrian Matias Bacong, MPH is a current doctoral student in the Department of Community Health Sciences at the UCLA Fielding School of Public Health.

Alex Nguyen is a graduate of UCLA who received his Master of Public Health and Master of Arts in Asian American Studies.

Anna K. Hing is a current doctoral candidate in the Department of Community Health Sciences at the UCLA Fielding School of Public Health.