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Resource Paper

Counting Race and Ethnicity for Small Populations during the COVID-19 Pandemic

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Abstract

We discuss the importance of data disaggregation in the time of the COVID-19 pandemic for small race and ethnic groups. In normal times, the lack of data for the Native Hawaiian and Pacific Islander (NHPI) populations is a problem of representation. During a pandemic, it means that resources and messages will not be targeted to these communities. As we adapt to the new reality, we argue that there is an important need for consistent and timely data disaggregated by race and ethnic groups in anticipation of future infectious disease epidemics.

Introduction

“After seeing these numbers ... I couldn’t sleep last night,” said Natalie Ah Soon, public health professional and co-chair of the Regional Pacific Islander Taskforce in Northern California, on a recent online meeting. “We are obligated to act on this information.” She was reporting on the recently released statistics showing that by April 15 four Native Hawaiians and Pacific Islanders (NHPIs) in California had died from COVID-19 and, less than two weeks later, on April 24, thirteen more people had died. Despite the fact that the overall numbers were seemingly low, at that time, these deaths represented a *fourfold* difference between the proportion of COVID-19 deaths and the NHPI population representation in California.

This disproportionately severe impact on vulnerable populations

strikes fear in the psyches of public health advocates like Ah Soon. She knows that it requires seeing disparities in numbers to move people to action to address the need.

The lack of data that disaggregates small populations, like NHPIs and others, from broader catchall racial/ethnic categories is a major threat to public health response to COVID-19 in highly vulnerable populations. California data suggest a disproportionate burden of cases and deaths for the NHPI population. But the data are reported only for single race non-Hispanic NHPI, despite the fact that more than 50 percent of the NHPI population are *multiracial* (Empowering Pacific Island Communities and Advancing Asian American Justice, 2014). Therefore, the number of COVID-19 cases and deaths for NHPI communities may be significantly different than what is currently being reported. We could have an incomplete picture of what is happening in the NHPI community with COVID-19 cases and death rates.

The NHPI population has pushed for data disaggregation for decades. In 1997, the Office of Management and Budget (OMB) approved the creation of NHPI categories separate from Asians. In subsequent years, however, further disaggregation into NHPI subgroups has failed to be completely adopted by many federal agencies (Panapasa, Crabbe, and Kaholokula, 2011). There has been coordinated calls to address the vital need for disaggregated racial and ethnic data for health disparities research (Empowering Pacific Island Communities, 2014; Rubin et al., 2018). More recently, data disaggregation during the COVID-19 pandemic by nonfederal public health agencies at the county and state levels have been limited, often due to confidentiality concerns.

These concerns arise from the possibility that, given the small numbers of NHPI in certain geographic areas, an individual can be identified through the release of public data; thus, data is presented in a more aggregated form or into larger race categories such as “Other.” While identification of individuals is a valid concern, there are methods for releasing disaggregated data that make it difficult or impossible to identify individual NHPI. We discuss a few of these in the concluding remarks.

The lack of data makes it difficult to identify populations with high infection rates and to target interventions. This isn’t an issue isolated to just NHPIs; it affects other groups that comprise a small percentage of the total population such as Asian American subgroups, American Indians, and Alaska Natives. In California, more than 60 percent of American Indian/Alaska Natives (AIAN) are also either multiracial or Hispanic/Latinx. The risks to this community are hidden if AIAN cases

are reported under the catchall “multiracial” or “Hispanic” categories. This is also medically unscientific and obfuscating. Another example is the concern in the Filipino community about risks to Filipino healthcare workers. Notably, in California, one in five nurses are Filipino. Yet the COVID-19 risks are often hidden for this group because in racial statistics Filipinos are aggregated within the Asian American category.

As we have seen in many communities of color such as African Americans, the pandemic highlights the existing economic inequalities among racial minorities in the United States. Income and wealth inequality have a profound negative impact on the access to healthcare and prevention. Recent analyses have shown that preexisting health conditions exacerbate the incidence and impact of COVID-19. These preexisting health conditions in communities of color are the direct result of decades of systemic racism that manifests in economic inequality and health disparities.

Having a valid understanding on who is being affected by COVID-19 is vital to develop effective messages and interventions in response to the pandemic. However, our ability to assess the magnitude and impact of the problem is based on having accurate and timely data disaggregated by race and ethnic group. As of June 2020, only forty-eight U.S. states were reporting COVID-19 cases by race and ethnicity and only forty-two states were reporting the race and ethnicity of COVID-19 deaths (COVID Tracking Project, 2020). Even with this, there are inconsistencies with how counties report race and ethnicity data to the states, and how the states report or reaggregate categories of Asian Americans and Pacific Islanders as APIs, or reaggregate categories of Asian Americans, Native Hawaiians and Pacific Islanders, and American Indians / Alaskan Natives as Other.

A lack of disaggregated reporting is compounded by miscategorization of race or ethnicity. Too often, race and ethnicity data are erroneously collected with error due to misalignment of categories over time and groups—and without asking the participant or family. Individuals may decide to self-identify as a single race or ethnic category in a particular situation and multirace in others. Alternatively, a coroner or medical official may mistakenly assign a person an incorrect race or ethnic group based on appearances or assumptions. Finally, not all race or ethnic groups may be separately identified in federal, state, or local data-collection efforts; for instance, the Centers for Disease Control and Prevention (CDC) has continued to include NHPI COVID-19-related deaths under the category of “Other” (Centers for Disease Control,

2020).

This is a particularly troublesome issue for small populations, such as American Indians, Alaska Natives, Native Hawaiians, and Pacific Islanders. A few misclassifications when calculating the numerator or denominator can result in overestimating or underestimating death and/or incidence rates. Discrepancies in classification may be negligible for some of the larger race and ethnic groups, but they may drive the services and results for these smaller groups.

Of particular concern is the fact that the COVID-19 pandemic is occurring while the U.S. Census Bureau is conducting the 2020 Census. There is concern that the current COVID-19 pandemic, associated job losses, and national protests in response to the George Floyd killing by police in Minneapolis will further diminish response rates for the current census enumeration efforts. Unfortunately, the most acutely affected communities due to COVID-19, job loss, and those protesting police violence against African Americans may be the very ones that have the lowest census response rates. Recent analysis has shown that those parts of Los Angeles County with the highest proportion African American or Hispanic households have the largest gaps in census response rates (Ong, Ong, and Ong, 2020). This would mean that our population counts that serve as the basis for countless health and vital statistics, as well as housing, education, and other funding formula, will undercount some of our most vulnerable communities for at least a decade. To the extent that the NHPI and AIAN and other smaller race and ethnic groups are similarly affected by the COVID-19 pandemic, job losses, and protests against police brutality, these communities may also be less likely to respond to current Census 2020 enumeration efforts.¹

What Should Be Done?

The CDC should require accurate data collection and transparent reporting of race and ethnicity using the data standards set in OMB 1997 and Section 4302 of the Affordable Care Act.² During a pandemic, accurate and timely data is critical in assessing the severity of the crisis and the populations at greatest risk. Public health reporting, at minimum, should report data for all five OMB race categories³; by Hispanic/Latinx ethnicity; by tribal affiliation or enrollment for AIANs; and, for Asians, data should be reported at a minimum by three of the largest racial/ethnic groups in the county or the state (and perhaps Southeast Asians as a high-risk group); and for NHPIs, data should be disaggregated from other categories and include those who identify as multiracial NHPI.

Data that are obscured by poorly articulated or recorded race and ethnic categories leaves these communities invisible and impotent/highly compromised to advocate for their needs.

Interdisciplinary research and collaboration is an essential means to incorporate information from diverse sources. During a pandemic, the integration of community voices and insight with academia's methods and tools of analysis are important to help formulate actionable messages for policy makers and to advocate for vital resources. Improving these relationships and pathways to collaboration must be strengthened to facilitate more joint work in the future.

Finally, extending and utilizing various outlets for dissemination of information and research in emergencies is crucial. Publicizing research reports through social media and on research center websites and in-language resources is increasingly an important method to inform and make available data and analysis in a timely manner. These public venues facilitate and improve the content of op-eds, legislative testimony, and interviews in the media. We must maintain high standards for the data and analysis produced alongside the absolute speed required to formulate solutions and interventions as expeditiously as possible. Being armed with accurate disaggregated data is essential and should be ubiquitous.

Notes

¹ On May 22, 2020, the U.S. Census Bureau announced that some of the field operations that had been suspended due to the COVID-19 pandemic would resume. The U.S. Census Bureau has extended the self-response deadline for the current enumeration from June 31, 2020 to October 31, 2020. In particular, the update/leave operations that target hard-to-reach households and communities have begun anew. For the update/leave operations, an invitation to participate and paper questionnaires will be left at more than five million households.

² OMB Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity, 62 Fed. Reg. 58782-58790, October 1997.

³ The five OMB race categories are White, Black, AIAN, NHPI, and Asian.

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