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The Native Hawaiian and Pacific Islander National Health Interview Survey: Data Collection in Small Populations

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On March 15, 2015, the National Center for Health Statistics at the Centers for Disease Control and Prevention released data from the Native Hawaiian and Pacific Islander (NHPI) National Health Interview Survey (NHIS).[1] This project was jointly supported by the Office of Minority Health at the US Department of Health and Human Services (HHS), and it was the first national health survey to use a sample frame consisting of NHPI households. This project was the result of years of advocacy by Asian American, Native Hawaiian, and Pacific Islander community organizations, leaders, and health researchers, combined with advancements in federal policies on data collection standards for racial/ethnic populations.

In 1985, HHS released a landmark report, the *Report of the Secretary's Task Force on Black & Minority Health*, also known as the *Heckler Report*, named after former HHS Secretary Margaret Heckler.[2] This report highlighted the health status of Asians/Pacific Islanders, black people, Hispanic people, and Native Americans, and it thrust the health disparities of racial/ethnic populations in the United States to the national stage. The report acknowledged that data for the Asian and Pacific Islander populations were limited. In addition, data were not disaggregated for these subgroups, thereby making this population appear healthier than other racial/ethnic minority groups. Data collected from Asian American, Native Hawaiian, and Pacific Islander respondents were aggregated under a single Asian and Pacific Islander racial/ethnic category, potentially masking differences in health status and behaviors.

One of the most important developments after the release of this report was the creation of HHS's Office of Minority Health in 1986. The Office of Minority Health was charged with improving the health and well-being of racial/ethnic minority populations through the development of programs and health policies with the aim of eliminating health disparities and achieving health equity in these populations. Another development was that advocates representing Asian American, Native Hawaiian, and Pacific Islander communities organized themselves in that same year to work with the federal government and advocate for policies addressing the health of Asian American, Native Hawaiian, and Pacific Islander populations.[3]

According to the 2010 US Census, approximately 1.2 million people identify as NHPI, either alone or in combination with at least 1 other race, reside in the United States, and represent about 0.4% of the total US population.[4] Based on limited available data, NHPI people have a persistent, disproportionate share of health problems, compared with other demographic groups, including high rates of chronic health conditions such as high blood pressure, diabetes, and heart disease.[5] NHPI people are nearly twice as likely as white people to be diagnosed with diabetes.[6] NHPI people are almost 4 times as likely as Asians to be obese,[3] one of the leading risk factors for many chronic conditions such as diabetes, heart disease, and several cancers.[7,8] Native Hawaiian men and women in Hawaii and California have mortality rates from heart attacks and other heart diseases that are almost twice as high as those of white people.[9] However, the paucity of health data at the national level has limited our ability to fully understand the range and depth of health issues of the NHPI population.

To understand the underlying causes and consequences of health disparities faced by the NHPI population, better data are needed. Data collection was facilitated through changes in data policies. In 1997, "Native Hawaiian or Other Pacific Islander" officially became a distinct racial group for federal purposes, when the Office of Management and Budget began requiring federal agencies to use a minimum of 5 race categories including NHPI.[10] The 2010 Affordable Care Act[11] further promoted disaggregation in data collection. Specifically, §4302 of the Act required that, to the extent practicable, sufficient data should be collected in federal public health surveys to generate statistically reliable estimates for all racial/ethnic groups. In response, HHS promulgated standards for data collection on race/ethnicity, primary language, sex, and disability status.[12] The HHS data standards distinguished Native Hawaiian from Pacific Islander and expanded

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the NHPI race category to include "Guamanian or Chamorro" and "Samoan." §4302 provided an opportunity to improve the collection and reporting of data on NHPI communities and increase the capacity to conduct more reliable statistical research for NHPI populations.

Despite policies promoting detailed data on race/ethnicity, agencies conducting federal surveys struggle to meet the demands for reliable NHPI health information. It is challenging to include NHPI people in sufficient numbers in most national surveys because of the population's small size and geographic concentration, rendering traditional oversampling strategies infeasible. For example, the annual NHIS sample comprises 35 000 to 45 000 households, but it typically includes only 100 to 150 NHPI households. As a result, only small samples of NHPIs are available even in the largest health studies.[13] This challenge is similar to that of obtaining adequate sample sizes of Asian Americans.[14] Furthermore, to protect respondent confidentiality and meet reliability standards, distinct NHPI health statistics are usually suppressed or aggregated with data on Asian Americans. Suppressing or aggregating data masks important health differences among Asian American, NHPI, and other racial/ethnic groups. The lack of adequate sample sizes leads investigators to conduct regional and state-level surveys of the NHPI population, such as the Pacific Islander American Health Study[15] and the California Health Interview Survey.[16] Such studies are instrumental in describing the health status and disparities of the NHPI population and indicate that aggregation of data from the Asian American, Native Hawaiian, and Pacific Islander populations into a single group suppresses data on health disparities. These projects, however, are limited in that they do not provide nationally representative health estimates.

To address this longstanding NHPI health information gap and the sampling challenge of a rare, geographically concentrated population, the National Center for Health Statistics and Office of Minority Health made use of a new policy on using the US Census Bureau's American Community Survey as a sampling frame for federal surveys of rare populations.[17] The American Community Survey, which replaced the US Census long form in 2006, surveys more than 3 million households annually. The National Center for Health Statistics applied for and received approval from the Interagency Council on Statistical Policy Subcommittee on the American Community Survey to conduct an in-person survey, using households identified in a single year of the American Community Survey as including at least 1 person of any age who was reported to be NHPI, alone or in combination with 1 or more other races. This novel use of the American Community Survey sampling frame made it possible to conduct a national NHPI health survey using the HHS flagship population-based survey, the NHIS. The survey was conducted in 2014 in all 50 US states and the District of Columbia. The US Census Bureau's trained interviewers collected data for the NHPI NHIS, following standard NHIS in-person survey protocols. All interviewers were trained on NHPI cultural sensitivity, awareness, and outreach. Respondent materials such as the advance notice and thank-you letters were also tailored to ensure cultural appropriateness.

One of the key barriers to participation of racial/ethnic minority groups, including NHPI people, in health research studies is the lack of culturally appropriate communication at all stages of the process.[18] In particular, negative feelings about the goals and intentions of the research may discourage NHPI participation. Conversely, clear explanations about the ways that the research could be used to benefit the community could increase likelihood of participation.[19] Taking these challenges into consideration, the National Center for Health Statistics and the Office of Minority Health developed a strategy to increase awareness of the survey and to engage NHPI leaders, stakeholders, and community members. The aims of this approach were to educate the community about the purpose and value of the survey and to encourage participation. Studies show that engaging communities in health data collection leads to shared ownership and leadership, which often result in increased participation by the community members, especially in small and hard-to-reach populations.[20,21] Otherwise, the NHPI NHIS followed the standard protocols so that the results would be comparable with those from the regular NHIS. The public-use data file can be accessed via the project website.[1]

Changes in federal data collection policies on race/ethnicity, coupled with the unprecedented and novel use of the American Community Survey as a sampling frame for rare populations, provided a unique opportunity to collect high-quality health data in the NHPI population. The NHPI NHIS provides the first nationally representative data to fill the gaps in knowledge on the health of the NHPI population and makes it possible to compare these data with national estimates for other racial/ethnic groups. The results from this project will give voice and visibility to the NHPI people and will allow researchers, policy makers, and NHPI community leaders the opportunity to better understand the burden of health disparities faced by this population and identify strategies to achieve health equity.

Authors' Note

The findings and conclusions in this article are those of the authors and not necessarily of the US Department of Health and Human Services.

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