

# The Challenges of Collecting Data on Race and Ethnicity in a Diverse, Multiethnic State

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## Abstract

*Race and ethnicity are commonly used predictor variables in medical and public health research. Including these variables has helped researchers to describe the etiology of certain disease states. Including race and ethnicity in research has been hypothesis generating in terms of the relationship between genetic and environmental factors in the development of disease. Eliminating health disparities among different racial and ethnic groups has become a national priority. However, incorporating race and ethnicity into health research is complex because these variables are difficult to define and individuals often identify with more than one race or ethnicity. As a "minority-majority", multiethnic, multiracial state, Hawai'i faces unique challenges in incorporating race and ethnicity into research. As the demographics of the United States continue to evolve, many of the challenges faced in Hawai'i will apply to the United States as a whole.*

## Introduction

Health outcomes are the result of a complex interplay among genetically determined factors and socially mediated exposures. Because race and ethnicity are integral to both of these, they are almost always measured as potential predictor variables in medical and public health research. In some studies, race and ethnicity are the most important predictor variable for a particular outcome. From differences in the prevalence of diseases like Thalassemia, to differences in the prognosis of diseases like ovarian cancer, to the unequal utilization of health care resources, disparities among different racial and ethnic groups exist throughout the medical literature.<sup>1-3</sup> For example, the incidence of cystic fibrosis is reported to be one in 2000 for Caucasians but is only one in 15,300 for African Americans.<sup>4</sup> Black women have higher rates of unintended pregnancy (16.3%) than Hispanic (9.0%), non-Hispanic white (9.4%), and Asian (8.5%) women.<sup>5</sup> Native Hawaiian and Filipino women with breast cancer tend to be diagnosed at later stages of disease and have lower survival rates than other ethnic groups even after controlling for stage of disease.<sup>6</sup>

Hawai'i is considered to be unique because of its ethnic and racial diversity. It is one of a handful of "minority majority" states in which non-Hispanic whites do not form a majority of the population. Census data from 2010 indicates that 24.7% of individuals living in Hawai'i identified themselves as being white-alone, 38.6% identified themselves as Asian-alone and 10.0% identified themselves as Native Hawaiian- or Pacific Islander-alone.<sup>7</sup> It is also common for individuals in Hawai'i to identify with multiple races and ethnicities. Nearly one-quarter of respondents in the 2010 Census reported that they identified with more than one race.<sup>7</sup> In 2000, more than 60% of all babies born in Hawai'i were identified as being of mixed race or ethnicity.<sup>8</sup> In comparison, California, a state known for its racial diversity, reported that only 1.7% of mothers indicated more than one race on their child's birth certificate.<sup>9</sup> It is in this milieu that medical and public health research in Hawai'i is conducted. In this commentary, we will discuss the challenges we face in Hawai'i in incorporating race and ethnicity into medical and public health

research. We suggest that these will be important concepts to incorporate into all areas of research given the increasing heterogeneity of the United States.

## Why We Care

Incorporating race and ethnicity into research has been fruitful for medical and public health researchers. It has been hypothesis generating in terms of the etiology of disease and the interaction between genetic and environmental factors. For example, the incidence of breast cancer for women born in Japan is significantly lower than that of their counterparts, born in Hawai'i, California, and Washington state.<sup>10</sup> This has led to hypotheses about how lifestyle, particularly dietary factors, influences breast cancer risk.

The Healthy People 2010 initiative called for the reduction of racial and ethnic health disparities as a national health priority.<sup>11</sup> This highlights one of the most important reasons why race and ethnicity are studied in medical research. Disparities exist in health care outcomes among racial and ethnic groups in almost all fields of medicine. Sometimes these disparities are marked. However, even when they are subtle, they demonstrate which groups should be targeted for allocation of health care resources. Since different interventions can work in certain groups and not in others, identifying disparities helps in designing culturally appropriate interventions to improve health outcomes.

## Current Categorization

Race and ethnicity do not have standard scientific definitions making these variables difficult to measure. Without a standard scientific definition, many question whether meaningful comparative research can be done when there is so much opportunity for misclassification.<sup>2,12-14</sup> Indeed, many highly-respected health researchers have advocated for the abandonment of race and ethnicity as legitimate scientific variables.<sup>15,16</sup> With this in mind, race is generally considered to be a biological construct based on observable physical characteristics including skin color or body habitus. Ethnicity has come to represent a social construct that could be defined as an individual's sense of culture.<sup>17</sup> Individuals in the same ethnic group often share linguistic, dietary, and religious traits and potentially share similar outlooks on health and health care.<sup>18</sup>

To categorize race and ethnicity, the US Office of Management and Budget uses a two-question format in which information on race is obtained using 5 categories (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or other Pacific Islander, White) and information on ethnicity is collected using 2 categories (Hispanic or Latino versus Not Hispanic or Latino).<sup>19</sup> This classification system has been used in both the US Census as well as all medical research that is funded by the National Institutes of Health.<sup>20</sup>

## Multiracial and Multiethnic

In 1970, estimates from the United States Census indicated that there were only 500,000 multiracial individuals living in the United

States. By 1990, this number had increased to nearly 2 million.<sup>21</sup> In the 2000 census, 2.4% of the population, roughly equivalent to 6.8 million people, were identified as multiracial.<sup>22</sup> Multiracial individuals will continue to factor more prominently into the demographics of the United States as a whole.<sup>8</sup> Based on current estimates, by the year 2050, 21% of the United States population will identify with multiple races.<sup>23</sup>

Although groupings of DNA sequences called Single Nucleotide Polymorphisms (SNPs) hold some eventual promise of objectively quantifying race,<sup>24-26</sup> data on both race and ethnicity are most accurately obtained using self-identification. In addition, it is important for categories to be meaningful to the outcome in question and to the respondents in the sample.<sup>27</sup> In Hawai'i, it is practical to differentiate Native Hawaiians from other Pacific Islanders because of factors that have historically affected this indigenous group. Other groups such as Micronesians are small in number in terms of overall population. While they could be easily incorporated in the Pacific Islander category, in some instances it is important to consider this group separately as they are uniquely affected by recent emigration status, infectious disease burden, and exposure to ionizing radiation from US nuclear weapons testing.<sup>28</sup>

The categories of race and ethnicity defined by the US Office of Management and Budget usually do not adequately reflect the multiethnic and multiracial population in Hawai'i. Thus, medical and public health researchers have utilized different methodologies in an attempt to more accurately delineate race and ethnicity in this group. One technique involves providing individuals with a comprehensive list of race and ethnicity choices as well as a "refused" and "don't know" category. In one question, individuals are allowed to select all of the races and ethnicities that apply to them. Individuals with multiple races and ethnicities can thereby select more than one race or ethnicity. In a second question, individuals are asked to select the race or ethnicity that they most identify with. Depending on the medical or public health question being studied, different analysis can draw on what is most meaningful to the particular outcome.

US Census data shows that allowing multiracial individuals to select more than one race can result in marked differences in the resulting statistics. In the 1990 census, when individuals were allowed to select only a single race, census data showed there were nearly 2 million American Indians living in the United States. In 2000, when respondents were allowed to select more than one race, 4.2 million individuals reported they were either American Indian alone or in combination with another race. This corresponded to an increase of 110 percent.<sup>29</sup> A similar increase was seen for Native Hawaiians. In 1990, approximately 139,000 individuals living in Hawai'i were Native Hawaiian. In 2000, there were 282,000 people reporting that they were Native Hawaiian alone or in combination with another race.<sup>30,31</sup>

The Hawai'i Health Survey, a continuous statewide household survey conducted by the Department of Health, uses a similar though slightly different approach to race and ethnicity.<sup>32,33</sup> Respondents are given a list of races and ethnicities and can select four categories from a list of 20 (including refused, "I don't know," and other) for their mother and their father. This results in up to eight indicators of ethnicity for the respondent. Multiethnic, multiracial respondents are then assigned to a single ethnic category by means of an algorithm determined by the Office of Health Status Monitoring. Specifically,

if Native Hawaiian is listed as an ethnicity for either the mother or father, the individual is categorized as Native Hawaiian. Otherwise, the person is considered to be the first non-Caucasian ethnicity listed for the father. If the first listed ethnicity for the father is Caucasian or unknown then the individual is considered to be the first non-Caucasian ethnicity listed for the mother. Use of this algorithm increased reporting in the Native Hawaiian group. Statistics derived from this technique are considered more accurate measures of the overall number of Native Hawaiians living in Hawai'i. For example, a larger number of Native Hawaiians were reported in the Hawai'i Health Survey than in the 1990 census. However, one can see the shortcomings of using an algorithm rather than self-identification as it assumes the importance of ethnicity for multiethnic and multiracial individuals.

In the "blend methodology", which has also been used in Hawai'i, the ethnicity of the individual is determined by ascertaining the ethnicity of the individual's parents and grandparents and deriving a percentage.<sup>34</sup> For individuals with many different races or ethnicities, asking about a specific person in their family, may initiate more detailed thinking about race and ethnicity. In the blend methodology, ethnicity can be used as a categorical or as a continuous variable in which the proportion of a given ethnicity is incorporated into the analysis. Using a similar methodology, our group ascertained that of nearly 6,000 babies born at a medical center in Hawai'i between 2007 and 2010, 11.6% had 5 or more racial or ethnic groups.<sup>35</sup>

In terms of the multiracial, multiethnic group, there are many unanswered questions. Are there common or shared experiences for multiracial or multiethnic individuals beyond living in a relatively mono-racial society? While the psychiatric literature historically described a kind of "double rejection" among multiracial individuals which included disapproval from both communities,<sup>36,37</sup> it is unclear whether these experiences still apply or whether this will change as the United States becomes more diverse. In recent studies, the multiethnic, multiracial group was identified as having different prevalence of various health outcomes that range from diabetes to low birth weight.<sup>38, 39</sup> A study from 1996 showed that individuals who were full Native Hawaiian had more than double the age-standardized mortality as part Native Hawaiians.<sup>40</sup>

Many social and societal factors can influence how multiethnic, multiracial individuals identify their own race and ethnicity. Studies have demonstrated that multiracial and multiethnic individuals tend to report fewer races and ethnicities as they get older.<sup>41</sup> The boundaries of race and ethnicity can also depend on how questions are asked, the context in which they are being asked, and how the answer will be used. Situational ethnicity refers to identifying with a particular ethnicity within specific contexts.<sup>42</sup> Factors that can influence what an individual identifies with include where one lives and the perceived loss or benefit that could result from one's answer. The acceptance or denial of a certain culture, belief system, religion, or even a particular family member as well as phenotypic appearance can also play a role in self-identification.

Additionally, individuals may not know their racial or ethnic background. Individuals may be multiracial but may not report it because they do not know about a detailed family history from generations past. This is especially true in places like the United States which has a history of institutionalized racism. Literature from the 1930s includes descriptions of Native Hawaiians as "indolent," "in

need of constant supervision,” and “deceptive”.<sup>43</sup> This is believed to have prompted many individuals to report they were a different race rather than suffer discrimination.

In Hawai‘i, certain groups, particularly those that are smaller in overall number such as the Native Hawaiian group, are commonly multiracial and multiethnic. A study done by the Office of Hawaiian Affairs estimated in 1984 that of the 200,000 Native Hawaiians living in Hawai‘i, 8,000 had a “100% Hawaiian blood quantum.”<sup>44</sup> As the indigenous race, however, there is substantial cultural awareness and many Native Hawaiians may primarily identify with this ethnicity when asked. Thus, in the 2000 Census, more than 80,000 individuals reported themselves as only Native Hawaiian.<sup>30</sup> With this type of cultural identification, that could play a role in lifestyle and health care outcomes, it is typically more useful to group multiracial individuals who are part Native Hawaiian in the Native Hawaiian category than in an overarching multiracial category.

### Immigration and Assimilation

The relationship between ethnicity and health outcomes is influenced by acculturation and assimilation, which may manifest as changes in language, food preferences, social activities, and religious identification. In some cases, a higher degree of acculturation is accompanied by poorer health outcomes, including obesity and obesity related illness.<sup>45-47</sup> For many ethnic groups, differences in health care beliefs and practices have been anecdotally noted among different generations. For example, first generation Chinese Americans have been described as incorporating a family centered decision making process into health care while later generations may take a more individualistic approach.<sup>48</sup>

The phenomena of immigration and assimilation can make studying race and ethnicity difficult. In 1998, 10% of the population in the United States, the equivalent of 26.3 million people, were born in another country.<sup>23</sup> Access to health care and health care outcomes for these individuals can be different than that of individuals whose families have been residing in the United States for generations. For example, recent immigrants from China may have divergent health care needs than Chinese Americans whose families may have been residing in Hawai‘i since the 1800s. Yet, they would all fall under the same ethnic category. This can hide important disparities that affect one group and not the other.

### Other Challenges

Ethnic minorities are often small in number making it challenging to find representative samples and adequate sample sizes. To overcome this, researchers frequently aggregate different racial and ethnic groups together. The Asian group encompasses a large number of races and ethnicities including Chinese, Filipino, Laotian, Hmong, Korean, Japanese, and Vietnamese among others. Considering these genetically and culturally different groups together can introduce substantial error and bias into study design. In real terms, it is unclear whether the Asian racial/ethnic group exists as a self-identity or as an identity for the US public as a whole.<sup>34</sup> Further complicating the issue is the Native Hawaiian and Pacific Islander category that often gets lumped together with Asians into an Asian/Pacific Islander/Native Hawaiian group. In data analysis, the Native Hawaiian and the Pacific Islander group typically gets numerically overwhelmed when it is combined with the Asian group. Although aggregation

can increase sample size, if the groupings are not meaningful, it detracts from the analysis and its applicability.

While there are genetic diseases that predominate in certain racial groups, in most instances, race should be used as the primary determinant variable with caution. More often, race is a proxy for the socioeconomic and demographic variables that are associated with disease but race itself is not usually the cause of the disease. For example, an increased risk of substance abuse and sexually transmitted infections has been associated with race in several studies.<sup>49,50</sup> However, when socioeconomic and environmental information are incorporated into the analysis, race is no longer a significant variable.<sup>51</sup> In analyses where race is serving as a proxy for socioeconomic or demographic factors, particularly for outcomes that involve health behaviors, it is more accurate to report that factor as the primary determinant of health rather than the corresponding race or ethnicity. Care must be taken to collect comprehensive cultural and economic information on study participants to allow for detailed analysis of potential confounding variables. While disparities on race and ethnicity should be reported, if the hypothesized relationship between race or ethnicity and the health outcome exists because of confounding factors such as socioeconomic status, this should be apparent.

### Conclusion

Race has been a defining issue in the social and political history of the United States. Research that has incorporated race and ethnicity has led to a significant increase in our understanding of the factors that affect disease and health. The demographics of the United States continue to change. Four states, Hawai‘i, California, Texas and New Mexico have been “majority-minority” states since 2005.<sup>52</sup> Based on current estimates, by the year 2050, the United States as a whole will have a “majority-minority.”<sup>53</sup>

Just as the demographics of this country continues to change, the way in which we collect information on race and ethnicity represents a continual metamorphosis and it is likely that the classification systems we use will become more complex as the world becomes more integrated. We should continue to explore how to capture the concepts of race and ethnicity, drawing in the important biologic, cultural and social factors that need to be examined and utilizing other explanatory variables when they more precisely play a role in etiology.

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The authors do not have any relevant financial relationships to disclose.

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**Ka manu kahea i ka wa'a e holo (1478). "The bird that calls the canoe to sail." Said of the kioea (bristle-thighed curlew), whose early morning call was often a signal to canoes to go fishing or traveling.**

**Mary Kawena Pukui's 'Olelo No'eau: Hawaiian Proverbs & Poetical Sayings (Bishop Museum Press 1983)**