Health Equity: Everyone Counts

The Need for Disaggregated Data on Marginalized or Excluded Racial/Ethnic Groups

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An Executive Summary of this report is available at here.

Note

The National Commission to Transform Public Health Data Systems was established in 2021 by the Robert Wood Johnson Foundation to reimagine how data are collected, shared, and used, and identify the investments needed to improve health equity. A recent paper by Alonzo Plough and Gail Christopher, Equity-Centered Public Health Data Demands New Voices at the Table, briefly summarizes the full report, Charting a Course for an Equity-Centered Data System.

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This is the seventh report in a Robert Wood Johnson Foundation (RWJF) series examining the links between health equity and a range of issues critical to achieving equity. The first report, [What Is Health Equity? And What Difference Does a Definition Make?](#), defines health equity and takes a deeper look at what it means and implications for action. The other reports are: [Early Childhood Is Critical for Health Equity](#), [Wealth Matters for Health Equity](#), [Mass Incarceration Threatens Health Equity in America](#), [What Can the Health Care Sector Do to Advance Health Equity?](#), and [Systemic Racism Is a Health Equity Issue](#). The series aims to assist those working in public health, healthcare, and other fields that powerfully shape health—such as education, child care, employment, housing, and community development—to build a world in which everyone has the opportunity to be as healthy as possible.

Contents

Introduction

The problem.

When data are unavailable on a marginalized racial/ethnic group, its needs are not counted; the group literally does not count. Lack of data renders them invisible when policies are made, resources are allocated, and programs are designed and implemented.

Regardless of intentions, the ways in which data are collected, analyzed, and reported may have inequitable consequences. The effects of policies that make data unavailable on excluded or marginalized groups can put those populations at further disadvantage, which may reflect systemic racism. In order to adequately identify and reduce health disparities affecting disadvantaged groups, racial/ethnic data need to be collected, analyzed, and reported in a way that is appropriately disaggregated—broken down into meaningful subgroups.

Data are often unavailable, for example, on the health and well-being of American Indians and Alaska Natives.[1] At times, they are grouped into an amorphous, exceedingly diverse "Other" category that cannot be very informative about anyone included in it. North American Indigenous peoples have, over hundreds of years, experienced enslavement, genocide, expropriation of ancestral lands, forced removal to reservations, and systematic coercion to compel their young to assimilate. Reflecting this long history of experiencing inequity, when data are available on American Indian/Alaska Native people, their social conditions and health indicators consistently paint a picture of severe disadvantage with respect to both health and its key determinants, in comparison with other racial/ethnic groups. Furthermore, aggregate data on American Indians/Alaska Natives as a whole can obscure marked differences within the group overall. For example, the 2005-2007 age-adjusted death rate per 100,000 due to diabetes—the fourth leading cause of death among all American Indians/Alaska Natives—was 16.3 among American Indians/Alaska Natives in the Alaska region, compared to 129.7 in the Aberdeen (now called Great Plains) region, and 23.3 among all racial/ethnic groups.[2]

Another example illustrating the need for disaggregated data is that, in the past, Asian Americans and Pacific Islanders were routinely grouped together, including people with a wide range of histories, cultures, languages, and socioeconomic resources. Some were immigrants, with very different dates and reasons for emigrating; some came as refugees fleeing war; and others as elective emigrees seeking greater educational or employment opportunities. Others (e.g., Native Hawaiians and many other Pacific Islanders) were native peoples. Average levels of social and health indicators among "Asian Americans/Pacific Islanders" in the aggregate generally appear favorable; however, when the data are disaggregated to look separately at Native Hawaiians and Other Pacific Islanders, a different impression emerges, with Native Hawaiians and Other Pacific Islanders often appearing disadvantaged on a number of important socioeconomic and health indicators. For example, the 2018 infant mortality rate for Native Hawaiians/Pacific Islanders was the second highest among all racial/ethnic groups and 2.5 times the rate among Asians.[3] Similarly, the 2019 college degree attainment rate for Asians was three times the rate among Native Hawaiians/Pacific Islanders.[4]

Concerted efforts by advocates resulted in the official separation of "Native Hawaiians and Other Pacific Islanders" from the larger "Asian American" group in the 1997 data guidelines issued by the Office of Management and Budget (OMB)—the federal authority that determines the minimum standard guidelines for how racial/ethnic data are collected, maintained, and presented and in what categories.[5] Even with this improvement, there still is great ethnic and socioeconomic diversity hidden within the broad "Asian American" category, ranging from Hmong tribespeople to socioeconomically diverse Vietnamese refugees and highly educated immigrants from South Asia and Taiwan, as well as diversity among Native Hawaiians and Other Pacific Islanders.[6]

Insufficiently disaggregated data can impact our understanding of health disparities for all racial/ethnic groups. For example, a growing share of the Black population in the United States is foreign-born; Black immigrants generally have both higher levels of education and better health outcomes than Black people born in the United States.[7, 8] Similarly, while people of Latino/Hispanic origin comprise one of the largest and most diverse racial/ethnic groups, disaggregated data on their subgroups are rarely available. When available, starkly different rates of chronic conditions are revealed, with Puerto Ricans often showing significantly worse health outcomes than their Latino/Hispanic peers.[9] Disparities also exist within the population categorized as White. For example, people originating from the Middle East or North Africa (MENA) are routinely categorized as White, despite unique characteristics, including widespread experiences of discrimination following 9/11.[10] The third section of this report provides many additional examples demonstrating the need for data disaggregation.

Even when data are collected on smaller groups such as American Indians/Alaska Natives and/or Native Hawaiians/Other Pacific Islanders, the data often cannot be reported because the samples were not designed to include sufficient numbers of people in these groups to make reliable estimates. Furthermore, racial/ethnic data alone, even when finely disaggregated, cannot capture important differences, unless combined with data on other key social characteristics—such as language, education, income, religion, urban/rural residence, and country or region of birth—that intersect with race in ways likely to affect health.

This report aims to raise awareness among wide audiences of the ways in which racial/ethnic data are collected, analyzed, presented, and used that can advance—or impede—health equity (defined below). More specifically, this report aims to:

- Define data disaggregation for non-technical readers and explain its importance in advancing equity, especially health equity.

- Describe ways that racial/ethnic data are collected, sometimes obscuring important information about disadvantaged subgroups, and why methods, measures, analyses, and reporting need to address this problem to advance health equity.

- Identify ways to increase the collection of appropriately and equitably disaggregated racial/ethnic data and ways to use it in policy and practice in support of greater equity.

This report should be relevant to those planning, conducting, or funding ethnic/racial data collection, analysis, and/or reporting. While non-federally funded sources are not required to follow the guidelines issued by the Office of Management and Budget (OMB), many are influenced by them, including large population-based sources with funding from states and/ or from private sources. The same principles apply to research conducted by public and private universities, think tanks, and other nongovernmental, non-routine data sources that often play a crucial role in informing policy.

Definitions and OMB Standards or Guidelines

Health equity

Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, powerlessness, and their consequences, including lack of access to good jobs with fair pay, safe environments, and quality education, housing, and healthcare. For the purposes of measurement, health equity means reducing and ultimately eliminating disparities in health and its determinants that adversely affect excluded or marginalized groups.(See *What is Health Equity*?)

According to this definition, health inequities are produced by inequities in the resources and opportunities available to different groups of people based on their racial/ethnic group; socioeconomic, disability, or LGBTQ status; gender; and other characteristics closely tied to marginalization or exclusion. Health equity is about justice—social justice. It is about valuing everyone equally,[11] and prioritizing addressing the needs of those who have—and historically have had—the least power, resources, and opportunities and whose health has suffered. Health equity also means that everyone counts and everyone must be represented.

*Persistent and pervasive lack of data on marginalized or excluded groups generally reflects failure to commit the resources to adequately address the needs of those groups; it may be a manifestation of systemic racism, regardless of intention.(See **Systemic Racism Is a Health Equity Issue**)*

Race, ethnicity, and race/ethnicity

Race or racial group is a term that some have proposed should not be used because it carries with it a false connotation of biological difference that has contributed to racism.[12] It is used here to refer to a group of people who share a common ancestral origin from a particular continent or other large region of the globe, without any implication of associated

biological difference. This is in keeping with the Office of Management and Budget (OMB) definitions of race as denoting ancestry "from any of the original peoples" of the different continents/regions of the globe.[5] While geographic origin may be associated with superficial secondary physical characteristics such as skin color and hair texture, these do not reflect underlying biological differences.[13-16] A common geographic origin often correlates with important elements of shared history and associated beliefs and practices. For U.S.-born African Americans, for example, the group's shared history includes the legacy of having been enslaved, suffering severe oppression and disenfranchisement for nearly a century under Jim Crow laws, and ongoing violations of rights. For North American Indigenous people, there is a shared history of experiencing genocide, expropriation from ancestral lands, and forced relocation. Scientific experts agree that, given the extent of intermixing of racial groups that has occurred over millennia, and despite differences in superficial secondary characteristics, race is fundamentally a social rather than a biological construct.[17, 18] Despite the science, however, widespread notions of race as biological persist.

"Ethnicity" has been defined in various ways; the common thread is that it is consistently viewed as a social rather than biological construct, generally denoting commonality in history, culture, traditions, beliefs, customs, or sometimes national origin.[19-22] OMB Guidelines treat Latino/Hispanic as an ethnic rather than racial group; see below.[5] This distinction has been criticized by some as implicitly contributing to a false notion of race as biological.[12] The term "**race/ethnicity**" is used widely in science and public health, reflecting a widely held perception of a lack of valid distinction between "**race**" and **ethnic group or ethnicity**. Both terms refer to groups of people who share a common geographic origin that correlates with common history and often beliefs and practices.

Race and ethnicity are complex and controversial concepts; a full discussion is beyond the scope of this report. One aspect of the complexity is the difference between self-identified and socially perceived racial/ethnic group. The racial/ethnic group(s) with which an individual identifies may not be the same as what others generally perceive them to be; both self-identified and self-perceived race/ethnic group may be important for health.[23]

Data Disaggregation

Data disaggregation

refers to breaking down data on a group of people so that it is informative not only about that group as a whole (i.e., in the aggregate), but also about subgroups (smaller groups within the whole). From an equity perspective, data disaggregation refers specifically to breaking down aggregate data so that it reflects subgroups that have been excluded or marginalized, often referred to in this report as "disadvantaged".

Information on race/ethnicity as defined above is important to guide policies and programs because it reflects important social characteristics of people, including their experiences (e.g., direct and indirect experiences of discrimination), practices, beliefs, and, often, their resources. It may reflect diet, language, and/or religion. Race/ethnicity also reflects how people are perceived by others and hence the obstacles, notably, discrimination they are likely to have faced or advantages they have experienced throughout their lives. It also may reflect the social networks and other resources and opportunities to which they have access.

OMB Standards and Guidelines

The federal *Office of Management and Budget (OMB)* has the authority to determine the minimum standard guidelines for how racial/ethnic data are collected and in what categories for all federal statistics, program administrative reporting, and civil rights compliance reporting. All federal agencies (and federally funded data sources) are required to follow the OMB's guidance, including the Census and surveys conducted by the U.S. Department of Health and Human Services (HHS). The standards were developed "to provide consistent data on race and ethnicity throughout the Federal Government."[5] They are used not only in the Census and household surveys but also in school registration, administrative forms, mortgage lending applications, and in medical and other research.[5] They apply to applications for NIH-funded research grants, contracts, and cooperative agreements.[24] OMB standards also apply to work conducted by non-federal agencies, e.g., states or academic institutions, with support from federal funds.

Since 1997, the OMB standards or guidelines have specified that federal government data collection should include a minimum of five "racial" groups, each defined by the respondent (versus an observer): Black/African American, American Indian/Alaska Native, Asian, Native Hawaiian/Other Pacific Islander, and White (origins "in any of the original peoples of Europe, the Middle East, or North Africa").[5] The OMB guidelines also specify that Latino/Hispanic be treated not as a racial group but as an ethnic group, which is recorded in a separate field ("ethnicity") from the "race" field. The 1980 Census was the first to collect data on Hispanics/Latinos in a separate field. Although all surveys conducted or funded by the federal government are directed, at a minimum, to include these six categories, in practice, insufficient numbers of American Indians/Alaska Natives or Native Hawaiians/Other Pacific Islanders may be included in samples to report meaningful results on one or both of those groups on many topics. Federal agencies may collect data that can be disaggregated on more than these six racial/ethnic categories, as long as the resultant data can be "rolled up" into the six minimum groups.

Equity concerns have been at the heart of the OMB guidelines

Data on marginalized or excluded racial/ethnic groups are vital for monitoring and enforcing civil rights. The OMB Directive of 1997 stated:

"Development of the [OMB] data standards [regarding collection of racial/ethnic data] stemmed in large measure from new responsibilities to enforce civil rights laws. Data were needed to monitor equal access in housing, education, employment, and other areas, for populations that historically had experienced discrimination and differential treatment because of their race or ethnicity."[5]

Levels of Disaggregation of Racial/Ethnic Data

The OMB distinguishes different levels of disaggregation of racial/ethnic data.[5]

- The first ("minimum" or "basic") level of disaggregation (or "minimum standard") applies to the five broad "racial" categories and the ethnicity field mandated by OMB as the minimum categories for racial/ethnic reporting:

"Race"

- Black/African American
- American Indian/Alaska Native
- Asian
- White and
- Native Hawaiian/other Pacific Islander

"Ethnicity"

- Hispanic or Latino
- Not Hispanic or Latino

In this report, we refer to the five "racial" categories plus Hispanic/Latino ethnicity as the **six minimum OMB racial/ethnic categories the OMB requires of federally funded data collection**.

- The second level of disaggregation is within each of those six groups. Federally funded surveys (and other federal data collection) may further disaggregate within any of the six required categories as long as the additional data collected can be rolled up into the six basic racial/ethnic categories.

- For example, although Middle Eastern/North African (MENA) is not one of the six minimum categories, a survey may include questions to identify people from the Middle East or North Africa, and can report results on that group separately, as long as the additional data can be merged into the White group. And the American Community Survey (ACS), used in many health and other studies, not only disaggregates data into separate categories for Asians and Native Hawaiian/Other Pacific Islanders; within the Native Hawaiian/Other Pacific Islander group, it also distinguishes Native Hawaiians from Guamanians or Chamorro and from Samoans and other Pacific Islanders. Within the global "Asian" group, the ACS also asks about origin in several specific Asian countries (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian—with a line to fill in the specific country if Other Asian is selected).

- Appendix B includes additional examples of racial/ethnic data disaggregation in major population-based data sources that are often used in health research.

Averages for Big Groups Can Hide Big Differences Within Them

America's Rich Racial/Ethnic Diversity

The United States is a heterogeneous nation of over 328 million people,[25] increasing in ethnic diversity every day. The rich diversity comes from this nation's Indigenous peoples; from African Americans, whose ancestors were brought against their will in the 17th, 18th, and 19th centuries; and from elective immigrants and refugees and their descendants from an array of racial/ethnic groups. Furthermore, there is great diversity within each of these groups, with respect to history, tradition, national origin, language, religion, socioeconomic status, and health.

Routine approaches to federal and non-federal data collection do not adequately capture the racial/ethnic diversity of the U.S. population.

American Indians and Alaska Natives

The limited data available consistently document severe disadvantage among American Indians/Alaska Natives as a whole, and among them, across different tribal affiliations and urban versus rural residence, substantial heterogeneity in health and socioeconomic indicators. As of 2019, over 5.6 million individuals in the United States identified themselves as American Indian or Alaska Native either alone (without specifying another racial/ethnic group) or in combination with another racial group; 2.8 million identified themselves as American Indian/Alaska Native alone.[26] Despite OMB guidelines, asterisks signifying lack of available data in place of numbers for Indigenous people are often seen in federal reports,[1] generally because insufficient numbers of them were included in the design of a study to produce meaningful estimates. The data that are available, however, consistently reveal some of the most adverse health and socioeconomic indicators among all U.S. racial/ethnic groups: Indigenous people have the second shortest life expectancy[27] and third highest infant mortality rates of all U.S. racial/ethnic groups.[3] The age-adjusted diabetes death rate for this population overall was 77.7 per 100,000 population, three times the rate among the U.S. population as a whole.[2] Indigenous people have the highest poverty rates[28] and lowest levels of educational attainment;[4] they have some of the lowest school enrollment[29] and highest dropout[30] rates of any U.S. racial or ethnic group.

These findings speak clearly to the need, at a minimum, to have data specifically on American Indians/Alaska Natives as a group (i.e., the first level of disaggregation). Aggregate statistics for the Indigenous population as a whole, however, obscure large differences among different tribal nations and regions. Indigenous peoples in the United States span 574
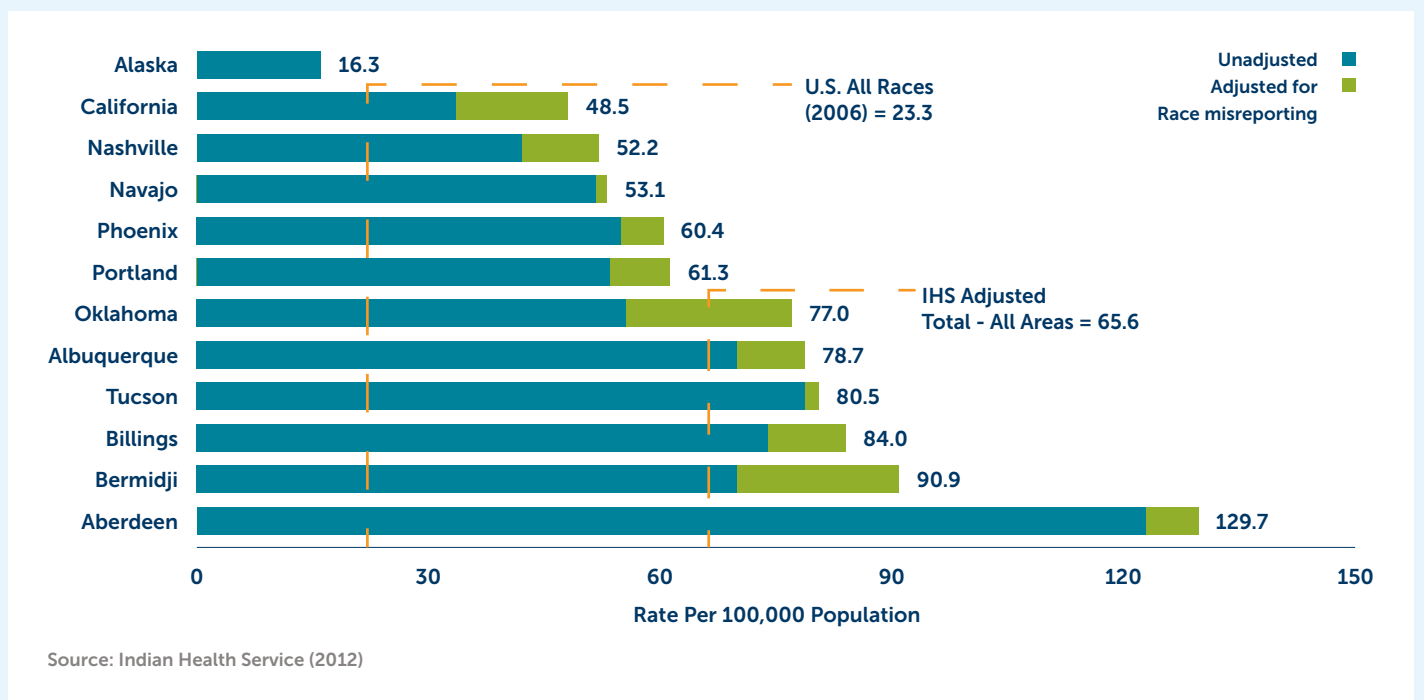
federally recognized tribes[31] speaking 150 different languages,[32] each tribe uniquely grappling with the physical and cultural genocide experienced by their ancestors, and with persistent marginalization today. While routinely disaggregated data by tribal nation/region are limited, some research has documented substantial heterogeneity in health and socioeconomic indicators across different tribal affiliations[33-35] and regions.[2] Figure 1 shows, for example, that the age-adjusted diabetes death rate in the Aberdeen (Great Plains) Indian Health Service (IHS) region is roughly eight times that in the Alaska IHS region.[2] Similarly, 2019 Census data showed that only 16.1 percent of Indigenous people overall have a bachelor's degree or higher, however, there is considerable variation across tribal affiliations. U.S. Census data from 2014 collected on 26 unique tribal groupings revealed bachelor's degree or higher educational attainment rates ranging from 10 percent to 27.7 percent[33] and rates of individuals with less than a high school education ranging from 8.2 percent to 46.3 percent across the different tribal nations.[33] Differences in health by region and tribal affiliation have also been identified across urbanization levels.[36]

FIGURE 1

Age-Adjusted Diabetes Mellitus Death Rates Among Indigenous People in Several Indian Health Service Regions (2005-2007)

Legend: Unadjusted · Adjusted for Race misreporting

U.S. All Races (2006) = 23.3

IHS Adjusted Total - All Areas = 65.6

Region	Rate
Alaska	16.3
California	48.5
Nashville	52.2
Navajo	53.1
Phoenix	60.4
Portland	61.3
Oklahoma	77.0
Albuquerque	78.7
Tucson	80.5
Billings	84.0
Bermidji	90.9
Aberdeen	129.7

Rate Per 100,000 Population

Source: Indian Health Service (2012)

Asian Americans

Asian American economic and health outcomes appear favorable in the aggregate, hiding large disparities within a highly diverse group.
A 2013 Pew Research Center report highlighted Asian Americans as the highest-earning racial group in the United States. However, a 2018 report showed that the highest income *inequality* within any U.S. racial/ethnic group was among Asian Americans,[38, 39] challenging the widespread notion of Asians in general being a "model minority" group. Asian Americans in the aggregate earned over $15,000 more annually than the average U.S. individual.[38] Asians in the top 10 percent (of Asians), however, were out-earning Asians in the bottom 10 percent by 10.7 times, a higher ratio than for any other racial/ethnic group.[39] In other words, the socioeconomic profile for Asian Americans as a whole obscures considerable diversity and socioeconomic hardship among subgroups. More recent analysis of 2017-19 American Community Survey data by the Pew Research Center underscores the continued prevalence of socioeconomic disparities within this group. Figure 2 illustrates the marked differences both in income and in poverty rates across Asian American subgroups. In addition to the marked socioeconomic diversity among Asian Americans, there is tremendous sociocultural diversity, for example, between those who have come electively as immigrants and those who came out of desperation as refugees; and considerable sociocultural and linguistic diversity among those who have come from South, East, or Southeast Asia.

Since 1980, 55 percent of refugees to the United States have originated from Asian countries.[40] In 2018, the second and fourth largest numbers of refugees of any country who resettled in the United States originated from Burma (Myanmar) and Bhutan, respectively.[41] Fleeing persecution and intolerable conditions in their home countries, and undergoing severe hardships in refugee camps, these populations have shown drastically higher rates of malnutrition and mental health concerns than the general population.[42-44] For example, in Burmese refugee camps in southeast Asia, "an average of 40.8% (range 24.8%-49.7% in nine camps) of children surveyed were found with chronic malnutrition (stunting)."[42] According

"Health inequities in Asian American communities are often invisible in the public health landscape, and addressing them has been challenging given the pervasiveness of the "model minority myth."[37]

to the CDC, chronic malnutrition (stunting) was also observed in 26.9 percent of Bhutanese refugee children in camps in Nepal and "similar rates … were detected in Bhutanese refugee children resettling in Texas from 2008-2011."[43] High rates of mental illness have been found among Nepali-speaking refugees in the United States, including a "rate of suicide nearly two times that of the general U.S. population."[44]

The extent of socioeconomic diversity and unmet needs beneath the surface of the overall Asian population are also seen in the range of rates of health insurance coverage.[45] Referencing data from the U.S. Department of Health and Human Services and the Kaiser Family Foundation, Huang (2012) states the following in regard to subgroups of Asian Americans:
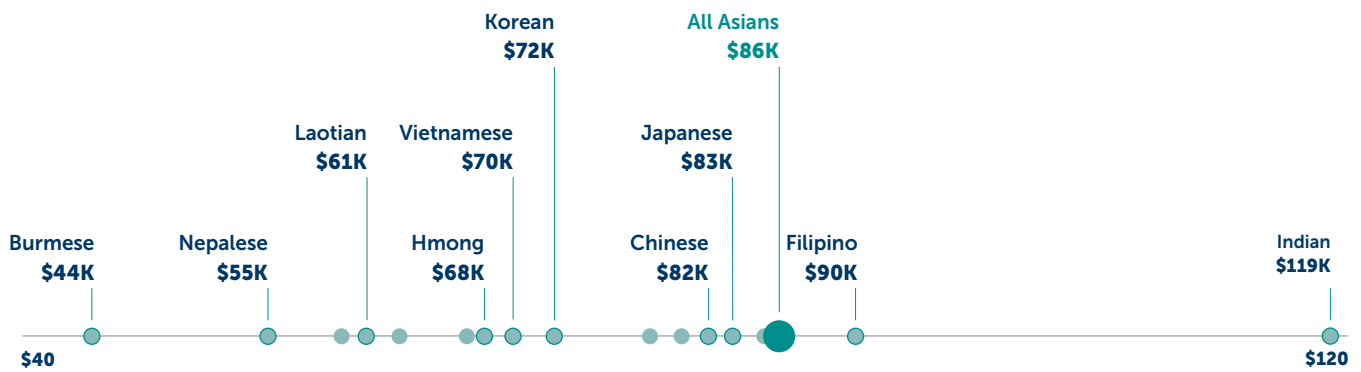
> *"Rates of the uninsured for the six largest subgroups begin, at the low end, at 6.7 percent for Japanese Americans, 11.3 percent for Filipino Americans, 11.8 percent for Indian Americans, and 13.9 percent for Chinese Americans. While rates of the uninsured for these Asian American ethnic groups are lower than the national average of 15.7 percent, Vietnamese and Korean Americans suffer from some of the highest uninsured rates in the country, with almost one in five, or 20 percent, of Vietnamese Americans and more than one in four, or 25.5 percent, of Korean Americans not covered by any health insurance plan. Furthermore, these statistics compiled by the U.S. Department of Health and Human Services do not include many minority South Asian and Southeast Asian groups, for whom rates of the uninsured have been reported to range from 17 to 20 percent (Kaiser Family Foundation 2008)."[45]*

FIGURE 2

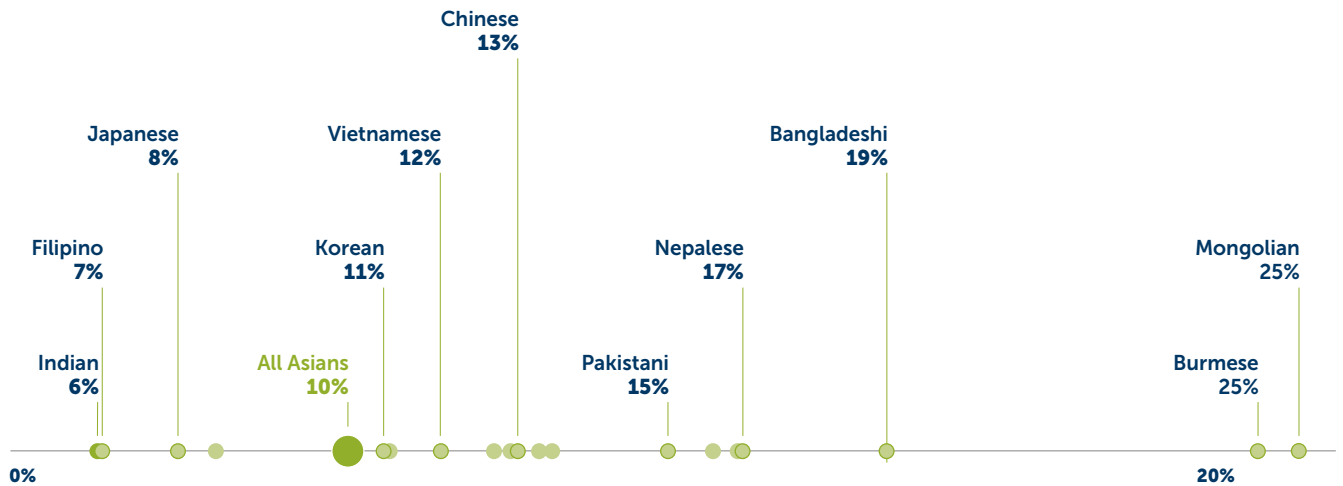# Median household income and poverty levels vary widely among Asian American subgroups.

Median household income varies widely among Asian origin groups in the U.S
Median Annual Household income, 2019, by origin group.

Korean
$72K

All Asians
$86K

Laotian
$61K

Vietnamese
$70K

Japanese
$83K

Burmese
$44K

Nepalese
$55K

Hmong
$68K

Chinese
$82K

Filipino
$90K

Indian
$119K

$40

$120

As Does the Share who Live in Poverty
% among Asain Americans who live in poverty, 2019, by origin group

Chinese
13%

Japanese
8%

Vietnamese
12%

Bangladeshi
19%

Filipino
7%

Korean
11%

Nepalese
17%

Mongolian
25%

Indian
6%

All Asians
10%

Pakistani
15%

Burmese
25%

0%

20%

Source: Pew Research Center (2021)

Black/African Americans

The experience of being "Black" in America is diverse; nativity is an important dimension of that diversity. Black people in the United States come from many different countries on the large African continent. Most African Americans (i.e., U.S.-born Black people) trace their ancestry to a large area of West Africa, where the trans-Atlantic slave trade was most active. Because slavery brutally separated families, and because of the centuries that have passed, many African Americans may not know their specific country of ancestry. Hamilton and Hummer (2011) found modest differences in health among U.S. Black adults according to country of origin (ancestry);[46] Jiagge et al. (2016) found differences in triple-negative breast cancer prevalence among patients with ancestry from West versus East Africa.[47] Differences in health have been observed between Black immigrants from Africa and those from other regions, with Africans generally having better health.[48]

Reflecting long-standing and profound social inequities they have experienced, Black/African Americans frequently have among the worst health and socioeconomic indicators in the United States. As a whole group, they have the shortest life expectancy,[49] highest infant mortality rate,[3] and lowest median household income.[50] Health data consistently show better outcomes for foreign-born versus U.S.-born Black people, however. From 2000 to 2013, the Black immigrant population in the United States grew by 137 percent.[35] The socioeconomic and health outcomes for the foreign-born Black/African American population are different in many ways from U.S.-born Black/African Americans; for example, they have higher levels of educational attainment and more favorable birth outcomes.[51]

Relatively few studies, however, have differentiated the health of subgroups of Black Americans. The studies that have examined this issue, however, have consistently observed worse health outcomes for U.S.-born Blacks than their foreign-born counterparts.[8, 51, 52] Figure 3 shows that Black immigrants have had more favorable birth outcomes (lower rates of preterm birth and low birthweight) than U.S.-born Black women;[53] Collins et al. (2002) observed similar findings.[51] In addition, a pattern has been observed of declining health for Black immigrants the longer they have been in the United States.[54] This pattern—sometimes referred to as the immigrant health paradox—has also been observed among Latino/Hispanic immigrants[55] and other racial/ethnic groups.[56] Some

have attributed it to adverse effects of acculturation to the United States (e.g., with respect to diet, substance use, and family ties).[55, 56] Others have hypothesized that better health among Black immigrants to the United States and the worsening of their health over time also may reflect racial discrimination experienced in the U.S. The thinking is that the Black adult immigrants, in contrast to the U.S.-born, experienced little or no race-based discrimination while growing up in their African or Caribbean source countries; childhood and young adulthood are particularly sensitive periods in terms of the later health impact of stressful exposures.[57] Longer time living in the United States, furthermore, may reflect longer and greater exposure to racial discrimination and its adverse health consequences.[58] For Black Americans, this accelerated decline in health outcomes over the life course has been noted across generations.[51]

Data on Black/African Americans should, at a minimum, therefore, be disaggregated according to nativity (birth in the United States versus elsewhere). As with all other groups, having socioeconomic information is also essential.

Black women born outside the United States experience lower rates of adverse birth outcomes than U.S.-born Black women. (2000-2003)

Source: Green (2012)
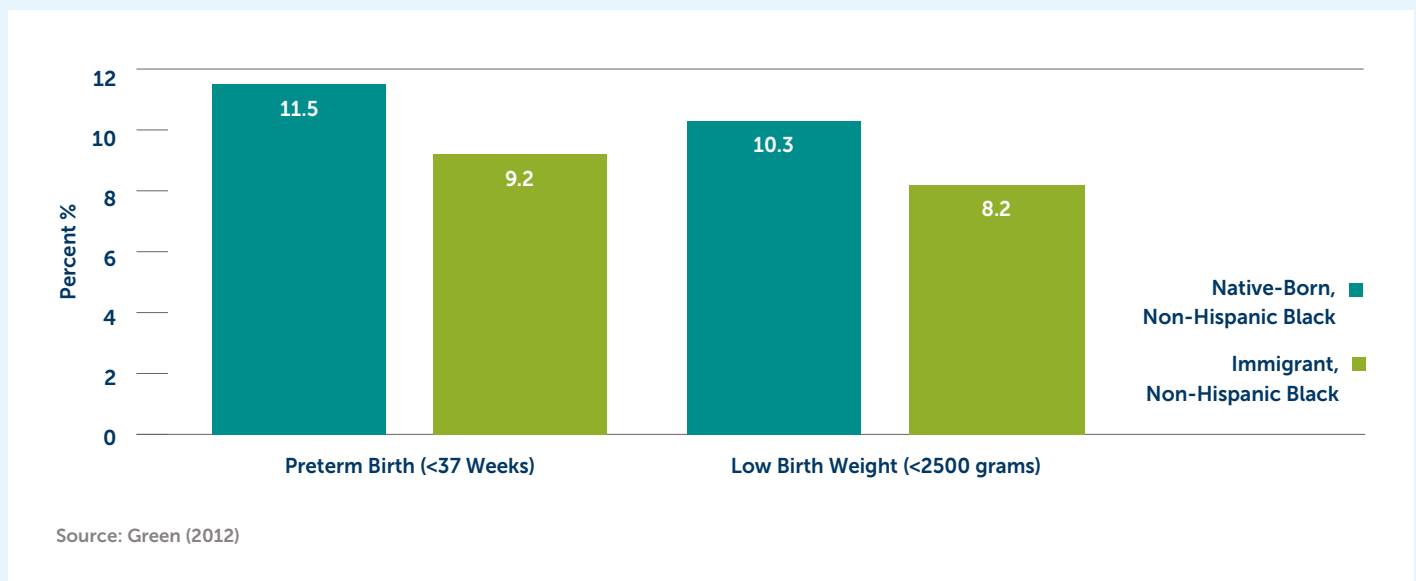
Latino/Hispanic Americans

In 2019, 18.5 percent of U.S. individuals identified as Hispanic or Latino,[25] which is defined by the Office of Management and Budget as people of "Cuban, Mexican, Puerto Rican, South, or Central American, or other Spanish culture or origin, regardless of race."[5] The earliest attempt to record the Latino population was a one-time inclusion of "Mexican" as a racial category on the 1930 census, with more comprehensive attempts to estimate the entire Latino/Hispanic population in the 1970 census and thereafter.[59]

Although 64 percent of all Latinos report Mexican heritage,[64] Latinos/Hispanics in the United States can trace their origins to over 25 countries[65]; and, because vast regions of the United States were colonized by Spain, many indigenous people also identify as Latino/Hispanic. These populations have diverse health outcomes as well as diverse levels of socioeconomic resources and educational attainment, both strong determinants of health. Studies analyzing data from the National Health Interview Survey have noted marked differences across Latino/Hispanic subgroups defined by national/geographic origin in rates of diabetes.[66] A systematic review examining Latino/a health, however, found that only 30.5 percent of studies disaggregated data further within the broad Latino/a category.[67] When

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BOX 2

As noted, official statistics since 1980 categorize Latino/Hispanic people as an ethnic group, not a race

People who classify themselves as Latino/Hispanic are asked to fill out a separate "race" field, including African American/Black, American Indian, Asian, Native Hawaiian/Pacific Islander, or White, in addition to the field for "ethnicity."[60] In some reports and many scientific papers, however there is a combined racial/ethnic field, not two separate fields; data on Latinos/Hispanics thus are inconsistently analyzed and reported.[61] The appropriateness of the separate "race" and "ethnicity" fields has been questioned, with some authors contending that the separation is unfounded and tends to reinforce erroneous assumptions about biological differences among "races."[12] Furthermore, research conducted by the U.S. Census Bureau has twice shown that a combined race/ethnicity question format produces higher-quality data, resulting in lower rates of non-response or "some other race" responses, while maintaining or increasing the level of detail.[62, 63]
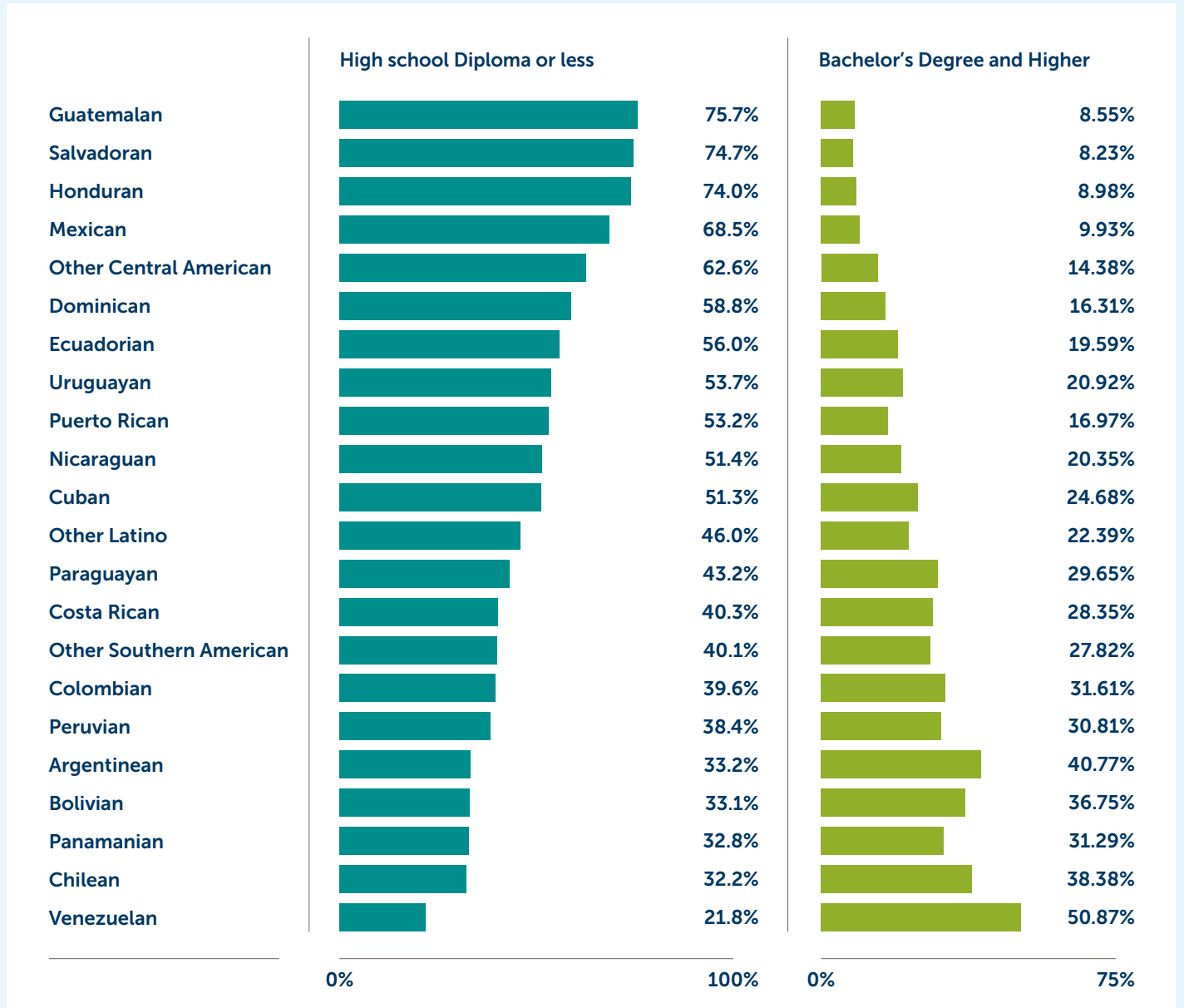
available, health data by Latino/Hispanic subgroup disaggregated according to national origin frequently show worse health outcomes for Puerto Ricans on multiple health indicators when compared to their Latino/Hispanic peers.[9, 68, 69] People of Mexican origin often have lower levels of healthcare access when compared to their non-Mexican Latino/Hispanic peers.[64, 70] Additional evidence of racial/ethnic diversity (and classification challenges) within the Latino/Hispanic group is that many people in the United States who identify as Latinos have considerable indigenous ancestry.

Latino/Hispanic Americans also represent significant socioeconomic diversity, which strongly influences health. 2019 American Community Survey data on educational attainment of Latinos/Hispanics in the aggregate, for example, show that 70.5 percent of Hispanic or Latino individuals overall have high school degrees or more schooling, and 17.6 percent have a bachelor's degree or higher.[4] Figure 4, however, shows marked differences in educational attainment by country of origin. Central Americans and Mexicans have the lowest levels of educational attainment, and South Americans generally have higher levels of schooling.[35] Educational attainment is widely regarded as one of the strongest determinants of health.[71-78]

The phenomenon of better health among immigrants than among the U.S.-born, with increasingly worse health outcomes among subsequent generations living in the United States, has been noted for Black people. However, the phenomenon was actually first observed among Latinos/Hispanics and has widely been referred to as the "Latino/Hispanic" paradox.[55] Subsequently, with the realization that it applies to a number of groups,[56] it has been referred to more broadly as "the immigrant paradox." The immigrant paradox highlights the need for information on nativity (U.S. versus non-U.S. birthplace) as well as race/ethnicity.

FIGURE 4

Educational attainment, a strong predictor of health, varies markedly among Latino/Hispanic Americans according to country of origin.

	High school Diploma or less	Bachelor's Degree and Higher
Guatemalan	75.7%	8.55%
Salvadoran	74.7%	8.23%
Honduran	74.0%	8.98%
Mexican	68.5%	9.93%
Other Central American	62.6%	14.38%
Dominican	58.8%	16.31%
Ecuadorian	56.0%	19.59%
Uruguayan	53.7%	20.92%
Puerto Rican	53.2%	16.97%
Nicaraguan	51.4%	20.35%
Cuban	51.3%	24.68%
Other Latino	46.0%	22.39%
Paraguayan	43.2%	29.65%
Costa Rican	40.3%	28.35%
Other Southern American	40.1%	27.82%
Colombian	39.6%	31.61%
Peruvian	38.4%	30.81%
Argentinean	33.2%	40.77%
Bolivian	33.1%	36.75%
Panamanian	32.8%	31.29%
Chilean	32.2%	38.38%
Venezuelan	21.8%	50.87%

High school Diploma or less: 0% – 100%
Bachelor's Degree and Higher: 0% – 75%

Source: Nguyen, Alcantar, Curammeng, Hernandez, Kim, Paredes, Freeman, Nguyen and Teranishi (2017) using 2011-2013 ACS data

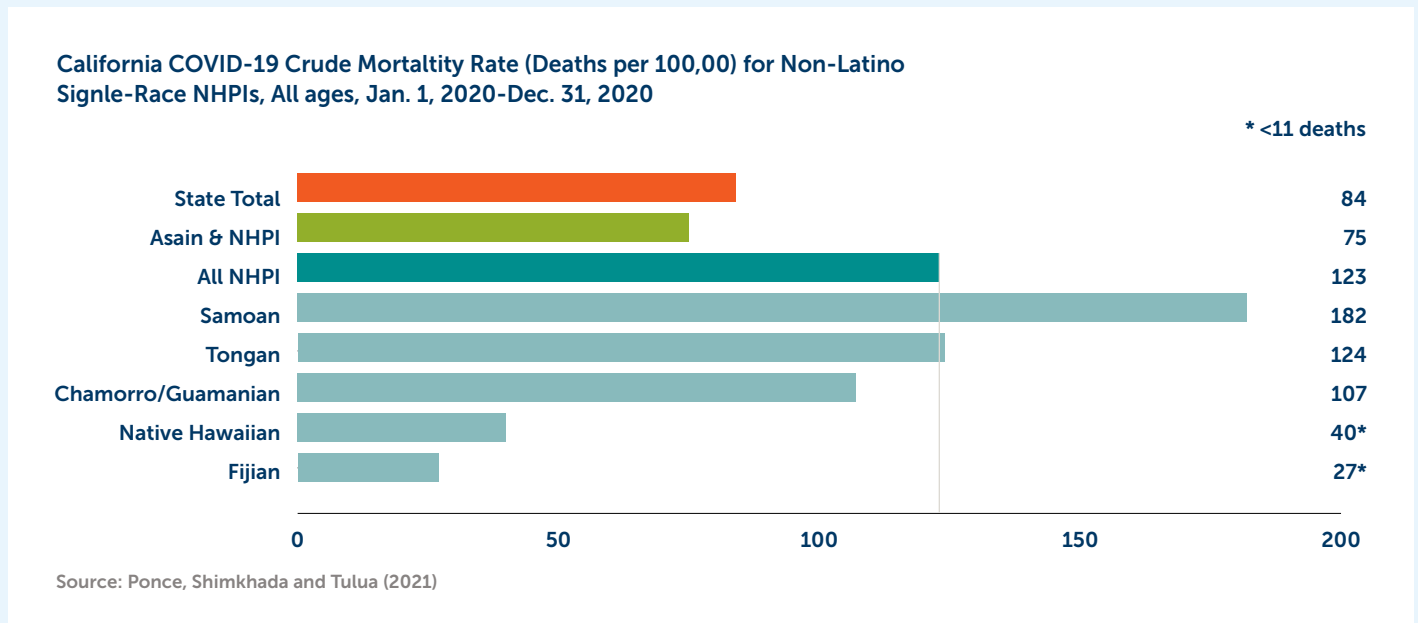## Native Hawaiians and Other Pacific Islanders (NHOPI)

Although OMB guidelines separated Native Hawaiians and Other Pacific Islanders from the broader "Asian American" category in 1997, data on NHOPI are often still lacking. **When data are available on NHOPI, they often reveal considerable social and health disadvantage**. Given the relatively small size of the Native Hawaiian/Other Pacific Islander population—0.2 percent of the U.S. population[25]—and widespread lack of adherence to the OMB rule, they are often lumped together with the broad "Asian" category or with an "Other" category. For example, although early in the COVID-19 pandemic officials and researchers signaled early the need to focus on the potential disparate impact on certain racial/ethnic groups and other marginalized communities,[79] as of August 2020, 30 states and the District of Columbia were failing to report COVID data on Native Hawaiian/Pacific Islander populations.[80] A 2021 UCLA Center for Health Policy Research report observed a COVID mortality rate 1.5 times higher among California's Native Hawaiian and Pacific Islander population than that of the state total, with Samoans at even higher risk.[81] (See Figure 5) Analysis of available state-level data has shown similar trends in states like Utah and Oregon.[82] However, little can be known at the national level without comprehensive and consistent reporting.

The diversity within the NHOPI group is rarely recognized. The NHOPI group includes "over twenty communities, each with their own distinct traditions, languages, and relationships with the United States."[83]

FIGURE 5

The COVID-19 Death Rate for Native Hawaiians/Pacific Islanders in California was significantly higher than the state average, with further disaggregated data showing even higher risk for Samoans than for the NHPI group as a whole.

California COVID-19 Crude Mortaltity Rate (Deaths per 100,00) for Non-Latino Signle-Race NHPIs, All ages, Jan. 1, 2020-Dec. 31, 2020

* <11 deaths

Group	Deaths per 100,000
State Total	84
Asain & NHPI	75
All NHPI	123
Samoan	182
Tongan	124
Chamorro/Guamanian	107
Native Hawaiian	40*
Fijian	27*

Source: Ponce, Shimkhada and Tulua (2021)

The Non-Hispanic White ("White" or European American) Population and People from the Middle East or North Africa (MENA)

There also is ethnic heterogeneity within the "White" population of the United States. Read et al (2021) recently disaggregated data on the group categorized as "White" according to ancestry and found that health frequently varied more by ancestry within the White group than between Whites and some other racial/ethnic groups.[84] There may be significant social differences between people of Western versus Eastern European origin, reflecting differences in history, and differences by national origin. The "White" group is often assumed to be comprised entirely of people

of European origin, but OMB official classifications also include individuals with origins in the Middle East and North Africa, including Arab Americans (Arabic-speaking people) in the "White" category.[5, 85] (The literature cited here uses the designation "Arab" or "Arab American." However the Bureau of the Census, at least since 2015, refers to "people with origins from the Middle East and North Africa [MENA]."[86] This is more consistent with the other racial/ethnic categories, which are based on geographic origin/ancestry.)

While official racial classifications categorize people with ancestry from the Middle East or North Africa as "White," it has been observed that this group does not necessarily benefit from "Whiteness".[10] A large literature has linked discrimination with ill health,[87] and significant discrimination against Arab Americans has been documented post-9/11. A study of 102 Arab-American residents of New York (recruited via mosques) found that 97 percent reported experiencing moderate to extreme forms of discrimination, and 70.6 percent reported experiencing one or more forms of hate crimes.[88] Studies have concluded that post-9/11 discrimination against Arab Americans has contributed to impaired mental health[89-91] and adverse birth outcomes.[92] Reviews of the literature reveal lack of consensus on rates of chronic disease among Arab Americans, with ranges of 4.8 percent to 33 percent for diabetes prevalence,[93, 94] and little to no consensus on rates of cardiovascular disease[93, 94] and cancer.[94, 95]

Existing data also have shown higher poverty and lower homeownership rates among Arab Americans than other non-Hispanic, non-Arab Whites. Aggregate data on Arab Americans overall, furthermore, hide considerable heterogeneity within that group as a whole. People with Lebanese origin, for example, comprise roughly one third of the Arab American group and have relatively positive socioeconomic indicators. Many of their Arab American peers, however, fare significantly worse on important indicators like median household income (Figure 6 below) and home ownership (Figure 7).[96] Figure 6 shows, for example, that in 2006-2010, the latest time period for which data are available, the median income of Yemeni and Iraqi Americans was roughly half that of Lebanese Americans.[96]

Between 1990 and 2010, the number of Arab Americans in the United States increased from 850,000 to over 1.5 million.[96] Some but not all of the people from MENA countries are Arabic-speaking; some are Christian, others Jews, and others Muslims. Data are limited on Arab Americans and may be inconsistent, with studies often reliant on identification of names that appear Arabic, while others have used self-report.[93]
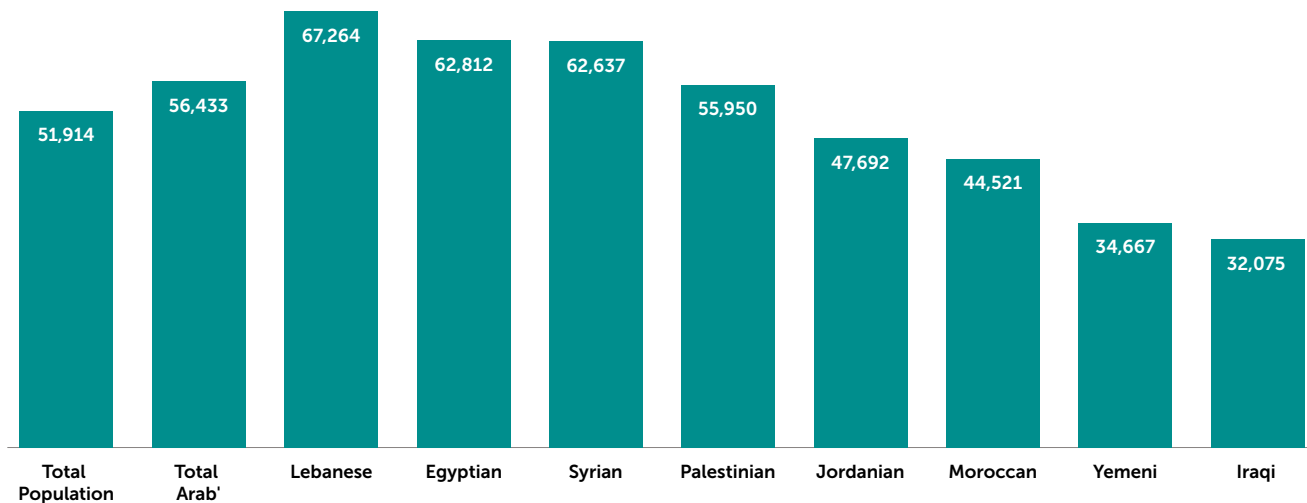
Prior to the 2020 census, the OMB explored adding a first-level (i.e., minimum) category for people from MENA countries as a separate sixth racial category—removing them from the White group.[97] They ultimately decided against it, remaining consistent with the wording that had been tested in 2018.

FIGURE 6

The median household income of Arab Americans varies considerably by national origin, with people from Yemen and Iraq having the lowest incomes.

Median Household Income by selected Arab Ancestry Group: 2006–2010
(data based on sample. for information on confidentiality protection, sampling error, nonsampling error and definitions, see www.census.gov/acs/www/)

51,914	56,433	67,264	62,812	62,637	55,950	47,692	44,521	34,667	32,075
Total Population	Total Arab'	Lebanese	Egyptian	Syrian	Palestinian	Jordanian	Moroccan	Yemeni	Iraqi

¹ The total Arab estimate includes selected ancestry groups (lebanese, egyptian, syrian, palestinian, moroccan, iraqi, jordanian and Yemeni) as well as general "Arab/Arabic" responses and other Arab groups not shown.
Note: Data on median househhold income are based on 2010 inflation-adjusted dollars.

Source: Asi and Beaulieu (2013); U.S. Census Bureau, American Community Survey Selected Population Tables, 2006-2010.

FIGURE 7

Percent household ownership by Arab ancestry group, 2006–2010.

Ancestry Group	Percent Owner-Occupied Housing Unit (%)	Margin of Error[1]
Total Population	66.6	0.2
Total Arab[2]	59.6	0.5
Lebanese	71.6	0.8
Egyptian	56.5	1.3
Syrian	69.2	1.3
Palestinian	59.6	2.5
Moroccan	36.9	2.2
Iraqi	45.3	2.4
Jordanian	50.5	3.2
Yemeni	36.7	4.3

[1] Data are based on a sample and are subject to sampling variability. A margin of error is a measure of an estimate's variability. The larger the margin of error in relation to the size of the estimate, the less reliable the estimate. When added to and subtracted from the estimate, the margin of error forms the 90 percent confidence interval.

[2] The total Arab estimate includes selected ancestry groups (Lebanese, Egyptian Syrian,

Palestinian, Moroccan, Iraqi, Jordanian, and Yemeni), as well as general "Arab/Arabic" responses and other Arab groups not shown.

SOURCE: ASI AND BEAULIEU (2013); U.S. CENSUS BUREAU, AMERICAN COMMUNITY SURVEY SELECTED POPULATION TABLES 2006-2010

Multiracial Individuals

Information about the health and social well-being of multiracial individuals is very limited, however, between 2010 and 2020, the number of people identifying as multiracial in the United States increased by 276 percent from 9 million to 33.8 million.[98] In the lives of Americans of color in general, perception plays a major role, both in how persons of color perceive themselves and how they are perceived by others. C.P. Jones et al. (2008), for example, found that self-identified persons of color who were perceived by others as White had better health than those perceived by others as persons of color.[23] The effects of perception are likely to be strong for multiracial people as well,[99] as suggested by the findings below. A 2015 Pew Research Report, *Multiracial in America*, for example, showed that different proportions of Latinos/Hispanics and non-Latinos/Hispanics (53 percent versus 36 percent respectively) reporting multiple-race "backgrounds" consider themselves multiracial. That report also showed, not surprisingly,

that rates of discrimination experienced by multiracial individuals vary considerably based on how they are perceived by the public; those perceived as Whites by other people reported less discrimination. The same report also noted that 20 percent of multiracial individuals felt pressured to identify as one race; this was highest (30 percent) among Black-White individuals.[100] 21 percent reported having attempted to change their appearance or behavior to alter how others perceive them; this was highest (42 percent) among individuals self-identifying as both Black and American Indian;[100] and 20 percent of biracial Black-White individuals reported having been treated poorly by a relative for being multiracial.[101]

Although information about the health and social well-being of multiracial people is limited, studies have observed that self-reported health varies widely across different multiracial groups.[102, 103] Sanchez (2010) has hypothesized that increased depressive symptoms may be due to the experiences of "identity denial"[104] and lack of "racial autonomy"—defined as inability to publicly self-identify one's race (as identified by oneself) and thus being forced into a socially assigned category.[105, 106] The limited information available suggests that unique experiences of multiracial people with different racial/ethnic mixture backgrounds that could have health implications; the great variability within the multiracial population presents particular challenges for data collection and analysis.

Current OMB guidelines do not mandate a separate "multiracial" category in addition to the six minimum racial/ethnic categories. They do, however, require that respondents should be able to mark more than one race.[85]

All Racial/Ethnic Groups Include Immigrants, Adding Another Dimension to Diversity

As of 2018, the U.S. population of immigrants reached 44.8 million, making the United States the country with the highest percentage globally of foreign-born residents. Immigrants and their descendants in the United States have an array of histories (including length of time in the United States), languages, traditions, beliefs, and customs. The immigrant population originated from nearly every country in the world.[107, 108] (See Figure 8.) By 2015, the U.S. Census Bureau had identified 350 different spoken languages, with nearly 200 in the New York City metropolitan area alone.[32] As of 2019, 10.4 percent of African Americans, 65.7 percent of Asian Americans, 32.8 percent of Latinos/Hispanics, and 4 percent of non-Hispanic Whites were immigrants.[109]

FIGURE 8

Immigrants in the United States represent origins from nearly every country in the world.

Migrants in
country (immigrants)

Source: Migration Policy Institute tabulation of data from the United Nations, Department of Economic and Social Affairs (2019), Trends in International Migrant Stock: Migrants by Destination and Origin (United Nations database, POP/DB/MIG/Stock/Rev.2019). Available here: www.un.org/en/development/desa/population/migration/data/estimates2/estimates19.asp.

Immigrants from the same country who arrived at different times or under different conditions may have had very different experiences; for example, those who immigrated to the United States as refugees from war, violence, famine, or extreme poverty have experienced trauma that was not part of the history of those for whom immigration was voluntary. Socioeconomic status both in the country of origin and in the United States are likely to be very important, Experiences are very different, furthermore, for immigrants who bring with them starkly different levels of economic resources and marketable skills. Similarly, immigrants with the same first language may have different levels of English proficiency, posing distinct challenges in the transition to life in a predominantly English-speaking country. The "immigrant paradox"—of often better health among immigrants and worsening health of a group with longer time living in the United States—has been noted for Black people and Latinos/Hispanics, although it applies more broadly.[55] The immigrant paradox underscores the importance of having information not only about racial/ethnic group but also about nativity.

Challenges in Collecting, Analyzing, and Reporting Disaggregated Data

Data are needed to identify needs of populations, to help make the case for addressing those needs, and—importantly—to track advances and declines in progress toward greater equity over time. However, there are significant challenges to confront:

- **Cost/resources**. Perhaps the biggest challenge is the cost of collecting population-level disaggregated data. Considerable expense may be involved in obtaining racial/ethnic data that are sufficiently disaggregated to be informative about all population groups of concern.[110] Furthermore, when groups are small and/or geographically dispersed, an oversample— sampling the groups of interest at a higher rate than their proportion in the population—will generally be needed to ensure adequate numbers for analysis, to produce reliable data. Oversamples can be costly.

- **Lack of standardized racial/ethnic categorization and data collection methods**. Although the OMB sets standards for the collection of minimum racial/ethnic data, there are not similar standards for the next level of disaggregation (i.e., disaggregation *within* the minimum categories). Different sources may ask questions in different ways, and include different levels of disaggregation (e.g., selecting only one or two smaller groups and aggregating others). Different categorizations, degrees of disaggregation and different frequencies of collection (e.g., annual, biennial, or decennial) can make it difficult to align findings across data sources. For example, Indigenous Tribal members have unique data needs stemming from their status as "sovereign governmental and political entities," and from the fact that members of tribes have dual citizenship (in their Tribal Nation and in the United States).[111, 112]

- **Widespread use of observer identification rather than self-report**, despite OMB guidance calling for self-report and ample studies demonstrating its importance. This lack of standardization of data collection methods is one of the most significant barriers to useful racial/ethnic information.

- **Logistical barriers** include a lack of interoperability across data systems (e.g., electronic health records) that limit the capability to input data on more specific racial/ethnic characteristics and data on key additional characteristics, such as socioeconomic status.[113]

- **Limited accountability to adhere to existing standards**. For example, while the OMB identified the need to separate NHOPI from the broader Asian American category in its 1997 revised standards, many states continually fail to do so.[110] In addition, there are few, if any, standards for entities beyond the reach of OMB.

- **Lack of local resources (inadequate staffing and/or lack of personnel with appropriate skills and expertise) also are frequently encountered barriers.**

- **Growing multiethnic/"multiracial" population with little consistency in reporting methods**. To account for a growing multiethnic/"multiracial" population, some data sources may allow individuals to check all racial/ethnic groups that apply, while others limit individuals to identifying one racial/ethnic group or offer a separate "multiracial" category. To avoid double-counting individuals reporting multiple races, some data sources have established "prioritization schemes" that automatically reassign multiracial respondents into one particular (primary) group.[114] However, the assigned group may not reflect what the respondent would have chosen or the reality of the respondent's experiences based on how others perceive them and how they identify themselves. Uniform standards are needed, with respondents asked to identify the group with which they identify most, if multiple groups are chosen, rather than blanket assignment rules.

- **Privacy and confidentiality concerns**. Particularly when subgroups are small (e.g., one American Indian Tribal Nation), concerns mount about being able to distinguish identities of individuals included in data collection. Whenever relatively small groups are identified in data, privacy and confidentiality issues arise. The smaller a group, the easier it is to identify an individual, even without having names and addresses. This can be done using other data elements (e.g., racial/ethnic group and: a census tract, a date of birth or hospitalization, the name of a hospital and date of hospitalization).[115] However, privacy concerns are not the only concerns; they must be balanced against the need for relatively small excluded groups to be represented in data. Consulting with group leaders may be important.

- **Ensuring that crucial information is included to permit meaningful use of disaggregated data**. Meaningful use requires information on other key characteristics often associated (and intersecting) with racial/ethnic identity or group, such as: socioeconomic measures (income, education, wealth); markers of health; measures of acculturation; and highly sensitive issues such as immigration status and, for immigrants, length of time in the U.S. For example, birth in the United States versus elsewhere is a key piece of information to interpret data on Black Americans. Socioeconomic characteristics such as educational and income level are key for examining the health of everyone, and data on a given racial/ethnic group generally should be disaggregated by education and income.

Addressing the Challenges: Recommendations and Guiding Principles

Multiple strategies are needed to address the multifaceted challenges to producing and using needed disaggregated data, including the following:

- **Allocate the resources** necessary to accomplish the strategies noted below. For example, resources are needed to overcome logistical barriers such as lack of interoperability of data systems and to ensure accountability. Resources are needed for questionnaire development and testing, as well as for staff training. Resources are needed to oversample small groups.

- **Update the OMB standards for racial/ethnic designations**. The OMB last updated the *Race and Ethnic Standards for Federal Statistics and Administrative Reporting* in 1997. These standards need to be updated, with public input, to address the issues noted in this report and to reflect the shifts in the U.S. population that have occurred during the intervening 24 years. While no change is simple, these changes do not require legislation and they would reflect the current widespread support in our nation for equity and social justice.

- **Promote changes at the national level that support disaggregation**. National policies are crucial to produce the requisite consistency to make cross-state comparisons. Data consistency is needed for information both on health and on social determinants of health; the latter may not be collected by public health entities, but it powerfully influences health and well-being.

- **Further standardize methods of collection of racial/ethnic information**.[116] Standardization is essential to be able to share and compare across studies. Commitments from institutions to collect more finely disaggregated data will be essential but not sufficient without clear agreements on how the questions about racial/ethnic identity will be asked. Input from representatives of the affected groups will be essential on this and other issues, as noted below. Both the content of the questions and the detailed methods used to ask them must be uniform across institutions involved in data collection. Standardization will require collaboration across governmental and other funders and researchers. (The public-private National Collaborative on Childhood Obesity Research (NCCOR) provides a model for standardizing research measures and methods, including training resources and a registry of measures).

- **Develop and implement accountability mechanisms**. Current health and socioeconomic data routinely fail to meet the OMB standards. Revisions will be largely ineffective without attention to accountability mechanisms.

- **Support the need for disaggregated data on excluded or marginalized groups as a health equity issue**. In the face of evidence that the needs of excluded or marginalized subgroups are hidden within aggregate data, continuing to support the way that data have been collected—that is, collecting data in a way that inherently and systematically obscures differences, masking the needs of those who are worse off—may reflect a type of systemic racism. This rationale should be articulated when advocating for data to be disaggregated in ways that provide information about excluded or marginalized groups. (Arguments for disaggregation of data that are not about socially disadvantaged groups should not be confused with equity concerns.)

- **Commit to using disaggregated data to inform policies, practices, and programs**. There must be serious commitment to collecting, analyzing, and using disaggregated data on disadvantaged groups to inform policies, practices, and programs. This needs to come from governmental (mainly) and nongovernmental (in some instances) agencies involved in funding data collection, analysis, and reporting of population-based data on health and its determinants. Data collection and reporting are insufficient; the use of disaggregated data is critical to advancing health equity.

- **Involve—and listen to—the racial/ethnic group(s) of concern.** These individuals/communities are the experts on their own experiences and needs, and know how to approach their own people. They can provide crucial guidance on how to ask questions about racial/ethnic origins; how to ensure adequate participation in surveys/studies; and how to adequately characterize the needs of their people. There may be important issues to consider, such as how group members define themselves, verbal and nonverbal communication preferences, and whether there is a need to build trust prior to data collection (e.g., with the help of trusted community and/or religious organizations). Input is also crucial in analyzing and reporting disaggregated data to ensure that: meaningful questions are examined; the findings are interpreted in light of the historical and contemporary context for the groups/subgroups of concern; reports using the data are respectful of the populations they describe,[103] including privacy/confidentiality concerns. Input of the group(s) of interest should carry considerable weight when designing methods for collecting data that pertains to them. As advocates, they also can be instrumental in achieving the political will needed to produce adequate racial/ethnic data disaggregation and ensuring that findings are used to improve health and well-being.

- **Work with advocates, community leaders, and leaders of the institutions responsible for implementation.** There is a large body of literature on how to collect data on excluded/marginalized groups of people; a review by Shaghaghi, Bhopal and Sheikh (2011) is a helpful starting point.[117] Alliances are needed to strengthen efforts to overcome institutional and other resistance, and secure the resources needed for data collection and its use to inform decision-making—on policies, programs, and resource allocations. Creating and sustaining this commitment will require action among:

  - Advocates, who must make the case for why data disaggregation is important and help disseminate the findings from analyses

  - Leaders and other decision-makers, who must commit to equity goals, support the funding and use of data that identifies the needs of disadvantaged groups, and tracks progress toward equity

- **Use an equity lens to determine which groups should be represented by disaggregated data.** This should not be determined only by the groups with the loudest voices or the most political clout. Consider which groups have been disadvantaged—excluded or marginalized—and how disaggregated information about them can guide action to address disparities.

The extent of social and health disadvantage should be the key criterion: the extent to which the groups under consideration have experienced marginalization, exclusion, exploitation, discrimination, or disenfranchisement. This is primarily an issue of social justice. Social disadvantage is among the strongest determinants of health. Evidence of social disadvantage includes but is not limited to higher rates of poverty/low income; lower levels of educational attainment; lower levels of home ownership or other measures of wealth; or evidence of being the victim of hate crimes or other manifestations of discrimination or social exclusion/marginalization. Historic as well as contemporary trauma is relevant. Evidence of health disadvantage would mean poorer health on a consistent basis across multiple important health indicators, not just one isolated indicator.

From an equity perspective, it is important to consider all marginalized or disadvantaged groups, regardless of size. As a practical matter, however, it would probably not be reasonable in most cases to collect detailed data on a group of only 50 persons. It does not seem possible, however, to specify any absolute cutoff, any size below which a group would be considered too small for reporting of information on that group separately. Group size will always, however, be a practical consideration, which should be weighed against the severity of a subgroup's social and health disadvantage and how different it is from the larger group, based on available information. When privacy concerns jeopardize the ability to represent a small group in data, leaders of the affected groups should be consulted. For smaller groups, consideration should also be given to alternative methods of collecting pertinent information.

- **Ensure adequate sample sizes of small, disadvantaged groups to permit meaningful analysis, even if it means more financial resources are needed.** A commitment to achieving equity must include a commitment to paying for the collection and thoughtful analysis of appropriately disaggregated data that can be meaningfully used to guide decision-making. This means not only including questions to identify marginalized/excluded groups, but also ensuring an adequate sample size of people in the group and ensuring that information vital to interpreting the data is included. Sample size calculations should be done in advance to guide recruitment.

- **Always consider privacy/confidentiality and community input on issues in design, analysis, and reporting, but also always consider the need for a group to be represented in data.** Information regarding immigration status—or that could be used to infer immigration status—is especially sensitive. A 2021 report from the Asian and Pacific Islander American Health Forum recommends implementing "methods such as pooling of data over time and analysis for larger areas and regions to protect privacy and allow the release of data for small sample sizes in a protected manner…" The same source recommended consulting "with tribal nations on the best ways to collect and report state-level tribal data for American Indians and Alaska Natives; some tribal nations may not want tribal level data reported publicly but will want it used in local policy decisions. Data-sharing agreements are needed to govern the ownership, use, and protection of tribal data."[118] Measures may be taken to reassure respondents about the confidentiality of their data, such as carefully crafted preambles or accompanying videos. The California Health Interview Survey, a large statewide population- based survey in California, has an NIH Certificate of Confidentiality, prohibiting the sharing of data with government officials if it might endanger a respondent in any way.[119]

APPENDIX A: RESOURCES

- Robert Wood Johnson Foundation, National Commission to Transform Public Health Data Systems: Charting a Course for an Equity-Centered Data System

- PolicyLink: Counting a Diverse Nation

- Population Research and Policy Review, Special Issue: Disaggregating Health Data within U.S. Racial and Ethnic Populations

- Asian and Pacific Islander American Health Forum (APIAHF): Policy Recommendations: Health Equity Cannot Be Achieved Without Complete and Transparent Data Collection and the Disaggregation of Data

- Center for Medicare & Medicaid Services (CMS): Inventory of Resources for Standardized Demographic and Language Data Collection

- Institute of Medicine: Future Directions for the National Healthcare Quality and Disparities Reports

- Institute of Medicine: Race, Ethnicity, and Language Data: Standardization for Healthcare Quality Improvement

- Office of Management and Budget (OMB), 2016: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity

- Oregon Health Authority: Race, Ethnicity, Language, and Disability Implementation

- U.S. Department of Health and Human Services, 1999: Improving the Collection and Use of Racial and Ethnic Data in HHS

- U.S. Department of Health and Human Services, 2011: Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language and Disability Status

APPENDIX B: LIST OF SEVERAL MAJOR POPULATION-BASED SECONDARY DATA SOURCES ON HEALTH OR ON THE DETERMINANTS OF HEALTH IN THE U.S, SHOWING THE LEVEL OF DISAGGREGATION OF RACIAL/ETHNIC DATA

Selected National Surveys with Level of Disaggregation by Race/Ethnicity/Origin

American Community Survey
Data collected monthly, surveys 3.5 million households annually

5. Is person 1 of Hispanic, Latino, or Spanish origin? (see Ethnicity question)

- No, not of Hispanic, Latino, or Spanish origin
- Yes, Mexican, Mexican Am., Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin
  - Print origin, for example, Argentinian, Colombian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on

6. What is person 1's race? Mark one or more boxes (See ACS Race question)

- White
- Black or African American
- American Indian or Alaska Native
- Print name of enrolled or principal tribe
- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian
  - Print race, for example, Hmong, Laotian, Thai, Pakistani, Cambodian, and so on
- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander
  - Print race, for example, Fijian, Tongan, and so on

13. What is this person's ancestry or ethnic origin? (For example: Italian, Jamaican, African Am., Cambodian, Cape Verdean, Norwegian, Dominican, French Canadian, Haitian, Korean, Lebanese, Polish, Nigerian, Mexican, Taiwanese, Ukrainian, and so on.) (See Ancestry or ethnic origin question)

How this data is reported: ACS Demographic and Housing Estimates

Note: Health and socioeconomic data is not broken down into this much detail by race/ethnicity
(e.g. ACS Health Insurance Coverage, race/ethnic data is less disaggregated)

Decennial Census
About: Survey of entire population that occurs every ten years
(See Race/ethnicity questions on slide 11)

8. Is Person 1 of Hispanic, Latino, or Spanish origin?

- No, not of Hispanic, Latino, or Spanish origin
- Yes, Mexican, Mexican Am., Chicano
- Yes, Puerto Rican
- Yes, Cuban

- Yes, another Hispanic, Latino, or Spanish origin
  ○ Print origin, for example, Salvadorian, Dominican, Colombian, Guatemalan, Spaniard, Ecuadorian, etc.

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9. What is Person 1's race? Mark one or more boxes AND print origins.

- White
  ○ Print, for example, German, Irish, English, Italian, Lebanese, Egyptian, etc.

- Black or African Am.
  ○ Print, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc.

- American Indian or Alaska Native
  ○ Print name of enrolled or principal tribe(s), for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, etc.

- Asian Indian
- Chinese
- Filipino
- Japanese

- Korean
- Vietnamese
- Other Asian
  ○ Pakistani, Cambodian, Hmong

- Native Hawaiian
- Samoan
- Chamorro
- Other Pacific Islander
  ○ Print, for example, Tonga, Fijian, Marshallese, etc.

- Some other race
  ○ Print race or origin

See 2010 Decennial Census data (2020 not yet released)

Current Population Survey

About: Monthly survey of about 60,000 households
(See full CPS Questionnaire, race/ethnicity questions on p. 12-14)

(Are / Is) (name/you) of Hispanic, Latino, or Spanish origin?

- Yes
- No

(Are / Is) (name/you) Mexican, Mexican American, or Chicano, Puerto Rican, Cuban, Cuban American, or another Hispanic, Latino, or Spanish origin; for example, Argentinean, Columbian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on?

If multiple answer, Probe: Which group (do/does) (you/he/she) most closely identify with?

- Mexican
- Mexican American
- Chicano
- Puerto Rican
- Cuban
- Cuban-American
- Other Spanish, Hispanic, or Latino group

I am going to read you a list of five race categories. You may choose one or more races. For this survey, Hispanic origin is not a race. (Are/Is) (NAME/you)

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander

Which of the following Asian groups (are/is) (you/he/she)?

- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian group

Which of the following Native Hawaiian or Other Pacific Islander groups (are/is) (you/he/she)?

- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander group?

Health and socioeconomic data reported by race/ethnicity is not disaggregated to this level, for example, see 2017 Health Insurance Coverage data

National Health Interview Survey (NHIS)

About: Face to face interviews, sample size varies based on budget
(See full 2020 Questionnaire, race/ethnicity questions below and on p.34)

What race or races do you consider yourself to be? (Select one or more)

- White
- Black/African American
- American Indian
- Alaska Native

- Native Hawaiian
- Other Pacific Islander
- Asian
- Some other race

- Refused
- Don't know

NHIS data available here: https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm

National Health and Nutrition Examination Survey (NHANES)

About: Annual survey of 5,000 people from 15 counties across the country
(See 2017 Interview Procedures Manual, Race/ethnicity/origin questions below)

Do you consider "x" to be Hispanic, Latino, or of Spanish origin? Read if necessary: Where do their ancestors come from?

- Puerto Rican
- Dominican (Republic)
- Central/South American

- Cuban/Cuban American
- Mexican/Mexican American
- Other Latin American

- Other Hispanic or Latino

What race do you consider "x" to be? Select all that apply.

- American Indian or Alaska Native
- Asian

- Black or African American
- Native Hawaiian or other Pacific Islander

- White
- Other

If Asian is selected: Please give me the group that represents (your/SP's) Asian origin or ancestry. Please select one or more of these categories. (Probe: Where do your ancestors come from?)

- Asian Indian
- Bangladeshi
- Bengalese
- Bharat
- Bhutanese
- Burmese
- Cambodian
- Cantonese
- Chinese
- Dravidian
- East Indian
- Filipino
- Goanese
- Hmong
- Indochinese
- Indonesian
- Iwo Jiman
- Japanese
- Korean
- Laohmong
- Laotian
- Madagascar/Malagasy
- Malaysian
- Maldivian
- Mong
- Nepalese
- Nipponese
- Okinawan
- Pakistani
- Siamese
- Singaporean
- Sri Lankan
- Taiwanese
- Thai
- Vietnamese
- Refused
- Don't Know

If Native Hawaiian or Other Pacific Islander is selected: Please give me the group that represents (your/SP's) Native Hawaiian or Pacific Islander origin or ancestry. Please select one or more of these categories. (Probe: Where do your ancestors come from?)

- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander
- Refused
- Don't Know

NHANES data available here: https://wwwn.cdc.gov/nchs/nhanes/

Behavioral Risk Factor Surveillance System (BRFSS)

About: Telephone surveys of roughly 400,000 adults annually
(See full 2019 Questionnaire, race/ethnicity questions below and on p.31-32)

C08.02 Are you Hispanic, Latino/a, or Spanish Origin? If "yes", are you... (one or more categories may be selected)

- Mexican, Mexican American, Chicano/a
- Puerto Rican

- Cuban
- Another Hispanic, Latino/a, or Spanish origin

C08.03 Which one or more of the following would you say is your race? (If Asian or Pacific Islander is selected read and code subcategories underneath major heading. One or more categories may be selected.)

- White
- Black or African American
- American Indian or Alaska Native
- Asian
    - Asian Indian
    - Chinese
    - Filipino
    - Japanese
    - Korean
    - Vietnamese
    - Other Asian

- Pacific Islander
    - Native Hawaiian
    - Guamanian or Chamorro
    - Samoan
    - Other Pacific Islander

If multiple options are selected for C08.03, question C08.04 asks participants to select which "best represents" their race (same options as C08.03).

BRFSS data available here: https://www.cdc.gov/brfss/annual_data/annual_data.htm

APPENDIX C: References

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