GET THE FULL PICTURE

Advocating for **Data Disaggregation** by Race and Ethnicity

Robert Wood Johnson
Foundation

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Introduction

All of us want to be *visible*. There is something fundamental about being and feeling "seen"—fully acknowledged as our whole selves, as members of a community, group, tribe, or nation.

Sometimes, being seen becomes a matter of life and death. It can determine whether we are able to live a life of well-being and enjoy access to health, educational, and economic opportunities.

Being visible is especially important in decisions that guide federal, state, and local policies, funding, and institutional practices and programs. Fully understanding challenges and clearly defining opportunities requires access to information that reflects everyone.

As our nation becomes increasingly diverse in terms of race and ethnicity, advancing health equity requires an understanding of how health and health disparities are experienced across distinct racial and ethnic populations and indigenous peoples. But

when we look to existing data for answers, we rarely find this information. It is either not collected at all, or the existing information on race and ethnicity is lumped into broad categories that do not allow distinct groups to be seen.

These flaws in data collection and reporting render populations invisible, mask unique needs, and hide strengths and assets. It means that **decisions are being made that impact people's lives and well-being without complete information**.

It's time to get the full picture.

Creating that visibility is the power of disaggregated data when it is meant to advance health equity. It is the basis for systemic change and the empowerment of groups that have often not been heard.

—Angela Glover Blackwell
Founder in Residence, PolicyLink

About This Guide

This guide is written for community leaders and advocates who want to advance health equity by calling for changes in the way data are collected, analyzed, and reported. It supports efforts to make the unique health needs and disparities faced by racial and ethnic populations visible.

The story can only be told when a full picture is provided through disaggregated data. This means breaking down large racial and ethnic categories into more detailed, specific groups.

The COVID-19 pandemic has cast a glaring spotlight on the urgency to have more specific racial and ethnic data to better understand each population's access to testing, health care, and insurance, as well as infection, hospitalization, and death rates. For example, in New Mexico, American Indian and Alaska Natives have accounted for nearly 40 percent of COVID-19 cases,[1] even though Native peoples make up only 9 percent of the population.[2] But because detailed, tribal-level data are not available, there is no way of knowing which tribes are most impacted within the 40 percent infection rates across tribal nations. This prevents advocates and state decision-makers from determining where and how best to intervene.

The ability to see these differences is critical to direct resources, funding, testing, and other actions where they are most needed. As we move toward administering a vaccine, it will become increasingly important to have disaggregated data to learn about the knowledge, attitudes, and behaviors around vaccination, which are unique in different communities and cultures.

Only with accurate data can we ensure that resources and interventions are laser-focused to help address widening health, economic, and social disparities.

In the pages that follow, we provide information and messages to support advocacy for policies that ensure disaggregated data on race and ethnicity are collected, analyzed, and reported.

The vision for health equity can only be fulfilled when decision-makers see the full picture through disaggregated data by race and ethnicity.

The story can only be told when a full picture is provided through disaggregated data. This means breaking down large racial and ethnic categories into more detailed, specific groups.

A Vision for Health Equity

Ultimately, the goal of disaggregating data by race and ethnicity is to achieve *health equity for all*.

This means that everyone has a fair and just opportunity to be as healthy as possible. It requires removing obstacles to positive health outcomes, such as poverty, discrimination, structural racism, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.[3] **To achieve health equity, we must address health disparities.**

Health disparities are particular types of health differences that are directly related to the historical and current unequal distribution of social, political, economic,

and environmental resources.[4] For example, obesity, heart disease, cancer, and stroke rates are substantially higher in communities that have lower economic resources.[5] These disparities stem from systems and structures that make it a lot harder for people with lower incomes to live healthy lives.

To address health disparities, we must be able to see beyond broad categories of people, and with far greater depth and detail. This requires disaggregated data.

Health equity and health disparities are intertwined. Health equity means social justice in health (i.e., no one is denied the possibility to be healthy for belonging to a group that has historically been economically/socially disadvantaged). Health disparities are the metric we use to measure progress toward achieving health equity.[9]

—Dr. Paula Braveman
Director
**Center on Social Disparities in Health
University of California, San Francisco**

The Importance of Data Disaggregation by Race and Ethnicity

Data on the race and ethnicity of populations gathered by state and federal public agencies and other stakeholders help to direct billions of dollars in funding every year to local communities.

These data are also used to determine what types of services, resources, and supports are needed in places like schools and health clinics, and are used to pinpoint where and for whom these are most needed.

Data in broad categories

When information is collected about race and ethnicity, it is often done using federal categories guided by the Office of Management and Budget's (OMB) minimal standards.[6] The categories are very broad, as illustrated in Table 1.

It is easy to see from the table that many distinct populations—with unique cultures, lived experiences, strengths, and challenges—are bundled together. And, certain populations are left out altogether. **This makes it impossible to understand the needs, disparities, and opportunities of specific groups.**

Table 1

| OMB Category	OMB Description	
American Indian or Alaska Native	A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment.	In some classifications, American Indians and Alaska Natives are lumped under "Other" despite the fact that there are 574 federally recognized indigenous nations in the United States (2020).[10]
Asian American	A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.	"Asian American" brings together many populations with different cultures, languages and immigration histories. Wide variations exist in the health, education, and poverty levels of these populations, which are hidden without disaggregated data.
Black or African American	A person having origins in any of the Black racial groups of Africa.	"Black or African American" includes Afro-Caribbean and all of the African diaspora.
Hispanic or Latino	A person of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture or origin, regardless of race.	"Hispanic or Latino" includes individuals from a wide range of backgrounds such as Mexican, Guatemalan, Colombian, Ecuadorian, Uruguayan, Puerto Rican, and Cuban.
Native Hawaiian or Other Pacific Islander	A person having origins in any of the original peoples of Hawaii, Guam, Samoa, Tonga, or other Pacific Islands.	In some cases, Native Hawaiian and other Pacific Islanders are lumped together with Asian Americans or "Other," rendering them invisible in datasets.
White	A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.	"Middle Eastern and North African" (MENA) populations should be a separate category from "White" because of the range of diversity of people of MENA origin and their unique needs.
Other		Many racial and ethnic groups do not identify with the categories they are placed in and therefore self-identify as "Other."

Disaggregated data

In contrast, Table 2 illustrates the power of disaggregated data by breaking down a broader category—in this case, the Asian American population—into information about specific groups with regard to health insurance. This means the needs of each population can be better understood. Decisions about resources, services, and supports can also then be made in ways that make a difference to those populations.

Data on health care coverage rates give us an example of the importance of not bundling populations together into one category. Following the passage of the Affordable Care Act (ACA) in 2010, the rate of Asian Americans without health insurance dropped to 9 percent, which was very close to that of people who are white at 8.5 percent.[7] However, these non-disaggregated data masked major differences in coverage.

In reality, most recent available data show that 12.9 percent of Korean and 10.6 percent of Vietnamese people are uninsured. Clearly, these are higher uninsurance rates compared to white peers and could not be seen using the broad federal data collection category of "Asian Americans."[8] This information is critical for identifying drivers of being uninsured and for developing targeted outreach and assistance to get people insured.

Table 2

People Without Health Insurance Following Passage of the Affordable Care Act

8.5%
White

9%
Asian Americans

12.9%
Korean

10.6%
Vietnamese
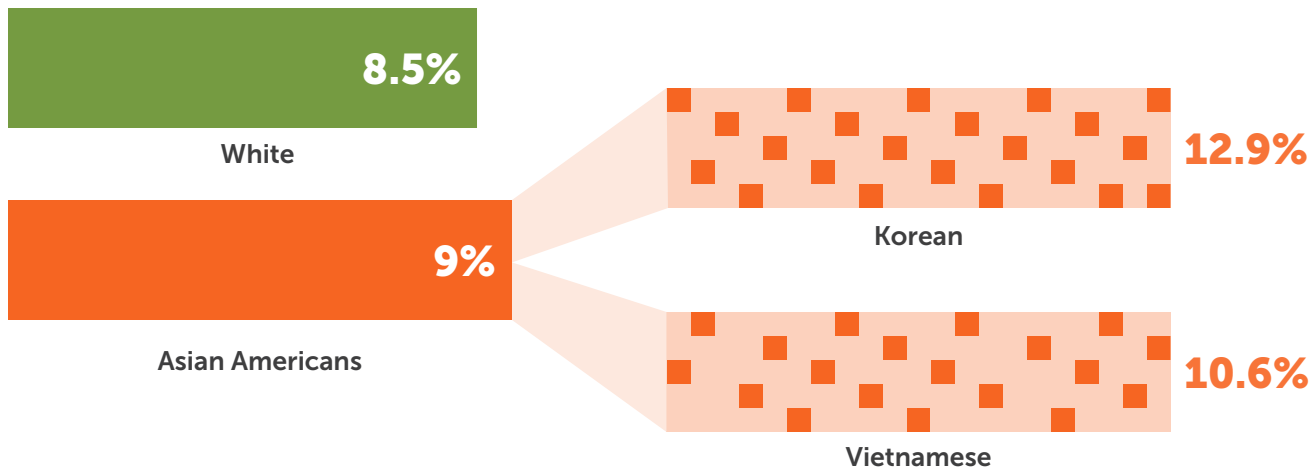
Ultimately, disaggregated data allow us to see—and solve for—the unequal distribution of social, political, economic, and environmental resources that contribute to health disparities.

Advocating for Data Disaggregation by Race and Ethnicity in Your State

In an ideal world, all states would consistently collect, analyze, and report data disaggregated by specific race and ethnicity.

Unfortunately, many state health surveys, programs, tools, and data collection instruments do not consistently capture even the most basic level of Office of Management and Budget (OMB) categories (refer to page 5 for a listing).

As you prepare to have conversations about the need to disaggregate data by race and ethnicity in your state, it is important to understand what discussions and efforts have already taken place.

Across the country, states are at very different places in terms of their progress in passing policies that support collecting, analyzing, and reporting disaggregated data.

Some states have introduced legislation or have had active policy debates on data disaggregation, so you may be weighing in on priority data to collect. Others are in the early stages of recognizing the important role

data disaggregation plays in policymaking, putting you in a position to educate and shape changes in practice. Other states are already collecting data in specific sectors, but may not be reporting it.

It is impossible to provide an up-to-the-minute guide on what is happening in every state with regard to data disaggregation policy. Instead, Table 3 illustrates four categories that will help you identify where your state might be and choose the appropriate call to action.

As you review this chart, consider: What category might your state fit in? What policy or practice changes are needed? Who else would find this issue important and can join you in these advocacy efforts?

Considerations for Data Collection and Reporting Standards

When considering policy change to support data disaggregation, at a minimum, states would start by reporting on data using the OMB categories.

Beyond the OMB categories, it is recommended that each state look at its demographics to determine which populations would benefit from further disaggregated data, and add these categories as detailed check boxes in data collection tools. Include a write-in option for people to further describe one's ethnicity or national origin.

No one should be forced to choose a category so broad that they cannot be seen.

Table 3

State Readiness Characteristics

	Early Adopter States	Experimenting States	Active Policy Debate States	Opportunity for Change States
Examples of Experiences with Data Disaggregation	Passed legislation requiring specific institutions to collect and report race and ethnicity disaggregated data beyond the federal OMB standards.	Passed laws recognizing the importance of collecting disaggregated data for specific purposes. Have not yet committed resources nor set clear guidelines for collecting and reporting data.	Legislature has introduced but not passed bills. State commission has been appointed to study the issue. Certain cities or counties have passed disaggregated data laws or have implemented policies, but no statewide action has been taken.	Lack organized public debate about data disaggregation. Have had early/limited local debates. Have introduced legislation to ban institutions from collecting disaggregated data.
Characteristics	• Large, diverse populations require data to inform policy. • Ethnic/racial communities are politically organized and active. • A network of advocacy organizations promotes data disaggregation. • Governor/state legislator(s) are allies for data disaggregation.	• Large ethnic/racial populations are politically active and calling for data disaggregation. • Experienced network of advocacy organizations promote data disaggregation. • Received federal grants to pilot data disaggregation collection (e.g., Hawaii, Washington). • Governors sign bills and state legislatures vote in favor of policies that support data disaggregation within certain institutions (e.g., health care).	• Sizeable and politically active ethnic and racial populations put data disaggregation on local or state policy agenda. • State commissions are appointed to examine the issue. • Network of advocacy organizations promote data disaggregation. • Strong grassroots and state-level political opposition has defeated proposed data disaggregation legislation.	• Smaller or less politically engaged ethnic and racial communities. • Smaller network of advocacy organizations not yet organized for policy change around disaggregated data. • Strong political opposition to data disaggregation.
Sample Call to Action	We have a law to collect and report on disaggregated data. Please demand it and don't set policy without it. Adopt consistent collection and reporting practices across state agencies and healthy systems.	Use detailed race and ethnicity categories as a minimum standard for data collection, analysis, and reporting by all state health agencies. Allocate resources to collect, report, and use these data in decision-making.	Sponsor/support a bill to implement data disaggregation in our state.	Start following the minimum OMB data collection standards.

Messages for Policymakers, Decision-Makers, and Community Leaders

The messages that follow were developed and tested in collaboration with advocates. They are an effective way into the conversation about disaggregated data on race and ethnicity for policy and practice change.

You can customize these messages with examples, stories, and other information relevant to your state or local community. These messages can also be applied to requests for data disaggregation for any population, depending on the populations in your state and your organization's stakeholders.

As with any advocacy effort, it will be important to bring along as many people as possible to support your ask. Consider reaching out to community leaders working with other populations to join the call for data disaggregated by race and ethnicity, and consult with technical experts and advisors to ensure your calls to action are feasible.

Before starting a conversation, it is important to fine-tune your messages so they are effective with the policymaker or decision-maker you are talking to. These questions may require a little research ahead of time, but will help you prepare for success.

Questions to Prepare for Success

- Where is your state in the process of considering, collecting, and/or using disaggregated data? (See Table 3.)

- What disaggregated data is your state currently collecting, monitoring, and reporting? By whom? At what level? Within which systems (e.g., health)?

- Based on the racial and ethnic populations in your state, what additional data should be disaggregated?

- Which policymakers or decision-makers can best lead this charge? What issues do they care about? Who are the priority populations they serve? How can you connect data disaggregation to their priorities?

- How much does the policymaker understand about the diverse populations in the district? *(If you do not advocate for all of these populations, make sure you bring in other organizations that work with those communities to join your efforts.)*

- Has the policymaker ever talked about the importance of using accurate data to make decisions?

- What stories and examples will help them understand the need for disaggregated data, perhaps by showing what happens when groups go unseen?

- What information might they need from you to convince other policymakers and decision-makers about the need for disaggregated data?

Message 1: **The vision**

We want health policies to effectively use resources and have the intended impact.

To make informed decisions, policymakers must have data that give them a full picture of the health needs of all constituents.

Tip:
When possible, be specific and make your messages relevant to your state or local community.

Message 2: **The problem**

The way most public agencies collect, analyze, and report data about race and ethnicity does not accurately represent many distinct populations and misses some altogether.

This makes it difficult for policies to address health disparities and improve the health and well-being of all people. And it makes it impossible to track progress and understand ongoing gaps.

- Sometimes information about race and ethnicity is collected using federal categories. The categories are broad. This makes some groups of people invisible by lumping distinct populations together. It also prevents policymakers from fully understanding their constituents' different needs and opportunities. For example, Asian Americans are lumped together in one category that does not adequately show the diversity among the many smaller subgroups that fall under this category.

- In addition, race and ethnicity information for smaller-size populations, such as American Indian, Alaska Natives, Native Hawaiian and Pacific Islanders, is often not collected, analyzed, or reported. Some populations, such as Middle Eastern and North African peoples, are lumped together in a general white category that masks important distinctions.

Tip:
Anticipate that the policy or decision-maker you're speaking with may ask for an example of disparities faced by the populations you're advocating for. Be prepared to share local examples such as uninsured rates or rates of chronic diseases.

Message 3: **The solution**

We need the full picture. More information must be collected, analyzed, and reported about distinct ethnic and racial populations.

COVID-19 has shone a light on disparities that are deepening and the need for data that go beyond OMB categories to show the disproportionate impact of the pandemic on *specific* populations. Without this information, policymakers cannot create tailored responses to keep people from dying.

Message 4: **Example calls to action**

- We have a law to collect and report on disaggregated data. Please make sure the law is carried out and implemented. Adopt consistent collection and reporting practices across state agencies and healthy systems.

- Create detailed race and ethnicity categories to be used as a minimum standard for data collection by all state health agencies. Allocate funding to ensure agencies can collect, report, and use these data in decision-making.

- Sponsor/support a bill to implement data disaggregation in our state.

- Start following the minimum OMB data collection standards.

Tip:
Refer back to the state readiness information on page 8 to inform your potential call to action.

Message 1: **The vision**

For us to promote health equity and ensure people's well-being, we need information about the health, social, and economic needs of our communities.

This information is important for us and for community organizations, policymakers, providers, and others to create tailored programs and policies that benefit our communities.

Message 2: **The problem**

The way public agencies collect, analyze, and report information about race and ethnicity does not give a full picture of distinct communities, and makes some invisible altogether. If we aren't visible, policymakers and others cannot address the disparities we experience and create custom solutions.

- Sometimes information about race and ethnicity is collected using federal categories. But these are broad and erase distinct groups of people by lumping many populations together. For example, "Hispanic" or "Latino" does not show differences between Mexican, Puerto Rican, Cuban, and many other groups of people. "Asian American" does not show differences between Chinese, Vietnamese, Nepalese, Indians, and many other groups.

- In addition, race and ethnicity information for smaller-size populations (such as American Indian, Alaska Natives, Native Hawaiian and Pacific Island populations) is often not collected, analyzed, and reported.

- Other populations, such as Middle Eastern and North African peoples, are added together in a general white category that hides important distinctions.

- When community members do not have a box or write-in option that reflects their own identity, they might choose not to participate in the data collection and are not counted. If we are not seen, our needs are not recognized as a priority.

Message 3: **The solution**

We need the full picture. More information must be collected, analyzed, and reported about distinct ethnic and racial populations.

- For our *[insert population]* communities, it is also about visibility and strength. If we want policymakers and institutions to pay attention and hear our voices, then they need to know the numbers.

- COVID-19 has shone a light on disparities that are deepening and the need for data that goes beyond OMB categories to show the disproportionate impact of the pandemic on specific populations. Without this information, policymakers cannot create tailored responses to keep people from dying.

Message 4: **Example calls to action**

- Help us communicate the importance of collecting, analyzing, and reporting information specific to distinct groups of people so that our communities are better seen and served.

- Use these messages and this guide to talk with policymakers and decision-makers about disaggregated data on race and ethnicity, and advocate for policy and practice change in your state.

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