EXPANDING RACE AND ETHNICITY CATEGORIES ON SURVEYS: A COMMUNITY GUIDE

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INTRODUCTION

You may have seen the question, **"What is your race and ethnicity?"** included on forms and documents in places like the doctor's office or as part of a job application. These data collection forms are meant to give a "snapshot" of the population, and can help make decisions about different policies, like investments in culturally-specific health education programs.

Still, it can be hard to answer a race/ethnicity question when you feel that none of the options presented are an accurate reflection of your identity. Inaccurate and missing race/ethnicity data is a big problem in the U.S. - and can prevent solutions to inequalities. Soon, you may see changes to the typical questions about race/ethnicity on surveys (like patient intake forms and the U.S. Census) that attempt to be more useful and accurate.

Specifically, there are increasing discussions about **disaggregating**, or separating the existing race/ethnicity categories into more specific groups. This would expand the number of existing categories so people have more options of terms they can select to self-identify.

More and more states and counties are making this change to their official forms, and in 2021, New York passed a law that will soon require all state agencies› forms to provide more specific race/ethnicity options for those who are Asian American and Native Hawaiian or Pacific Islander. This means that people can distinguish themselves from the larger categories and will be able to select options such as Pakistani, Chinese, Korean, Filipino, and others.

These kinds of changes may occur across the country and affect many different racial/ethnic groups. In 2022, the U.S. Census Bureau made a major announcement that the agency will reconsider the way we ask about race and ethnicity on the U.S. Census. Likewise, **the U.S. Office of Management and Budget (OMB)**, the federal agency that determines the minimum standard race/ethnicity categories, will also hold public deliberations to get community opinions about race/ethnicity data collection.

WHY DOES DATA DISAGGREGATION MATTER?

Different places might ask you to fill out a survey or intake form that includes questions about race and ethnicity. Examples include the doctor's office, a social service organization, or your child's school. This information might seem unnecessary, but it is important for people who make decisions about program development and funding to understand the community. Demographic data, including self-reported race, ethnicity, and language, can show whether certain groups are, on the whole, **treated unequally** or ignored.

The current race and ethnicity standards, which are defined by the OMB, are limited to broad categories that don't necessarily **reflect how people see themselves**. This may partly explain why the second-largest race group reported on the 2020 Census was "Some Other Race."

Changing the current federal standards might help provide a clearer picture of the nation's **diversity**. Each group is also diverse in itself, so disaggregating the broad categories into more specific ethnic groups gives more information about racial and ethnicity diversity, and may even prevent stereotyping. For instance, the National Cancer Institute found that when you disaggregate

the Asian category in cancer registries, the data shows much higher cervical cancer rates among Vietnamese and Cambodian Americans than Chinese and Indian American women (Vo & Shing, 2022). In this example, data disaggregation shows that Asians are diverse and thus, they have diverse health needs. This can help **health systems invest** in culturally-appropriate cancer-control strategies aimed at populations with higher risks.

The advantages of **being counted** go beyond health. Race/ethnicity information that comes from the census often gets used to make decisions about where to provide additional funds and resources to certain communities. When some racial/ethnic groups are overlooked by these surveys, they can miss out on important benefits.

HOW ARE RACE AND ETHNICITY USUALLY DEFINED?

According to the Journal of the American Medical Association: "In general, **ethnicity** has historically referred to a person's cultural identity (e.g., language, customs, religion) and race to broad categories of people that are divided arbitrarily but based on ancestral origin and physical characteristics." In other words, race is mostly centered on physical appearance, while ethnic identification is more about having a shared culture.

It is important to remember words "race" and "ethnicity" **do not have a clear biological meaning**. The idea of dividing humans into "races" is socially constructed, but it's still important to document race to help measure the widespread **impacts of racism**. The OMB requires that state and federal agencies collect race/ethnicity using the following standard definitions:

OMB Race Categories

- **White** – A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.
- **Black or African American** – A person having origins in any of the Black racial groups of Africa.
- **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.
- **Asian** – 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.
- **Native Hawaiian or Other Pacific Islander** – A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

OMB Ethnicity Category

- **Hispanic or Latino** - a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.
  - Note: People who identify their origin as Hispanic, Latino, or Spanish may be of any race.

If data disaggregation practices become the norm, the response options above may look a bit different. This guide can help you understand these new options and how you can select them.

WHAT MIGHT I EXPECT ON FUTURE SURVEYS ASKING ABOUT RACE/ETHNICITY?

Disaggregation means expanding the existing OMB categories, dividing them into more specific groups. There will probably still be large "umbrella" race/ethnicity terms to keep some consistency across the data collected in different regions of the U.S. However, policymakers in specific regions may only decide to add certain categories - those that represent **the most common ethnic groups in an area**. An example can be found in the State of Hawai'i, which disaggregates the Asian category into the state's largest ethnic communities, including Filipino and Japanese Americans (among others).

If you identify with an ethnic group that doesn't have a very big community in your area, it's possible that you won't see your identity represented on all forms. This is to help make data more manageable. You may see an open-ended response option, which you can use to write in the race/ethnicity with which you most strongly identify if you don't see it listed. You may also see options such as "**Decline to specify**" or "**Another race/ethnicity not listed here.**"

DO YOU KNOW HOW COMMUNITY MEMBERS WANT TO BE ASKED ABOUT THEIR RACE AND ETHNICITY?

In 2022, researchers at the New York Academy of Medicine conducted a series of focus groups with community members who self-identified as belonging to one of thirteen racial and ethnic categories (including African American, Asian, Native Hawaiian/Pacific Islander, White, Middle Eastern/North African, Multiracial/Multiethnic, and others).

In these groups, participants were asked to discuss how they identify their race and ethnicity, and share preferences related to answering these questions on surveys and forms. Across groups, participants said they **preferred questions that offered an opportunity to provide detail about their race and ethnic identities beyond the broad categories** normally seen. Participants also generally preferred that the OMB ethnicity category "Hispanic or Latino" be combined into one question with the OMB race categories described above (e.g., Black, Asian, White, etc.).

Here is a quote from one of the many conversations we had with focus groups about the way surveys and forms ask about race/ethnicity:

> "I don't really get why that's everywhere, that, "Are you Hispanic or Latino?" How is that so different from being Black, Middle Eastern, or Asian? I've never quite understood that… And I've liked the idea that if you choose Middle Eastern or North African something else shows up so that you can further self-identify. I think it's more true to form."
> - Black-identifying focus group participant

WHAT IS "PERCEIVED RACE"?

When answering questions about race, two different things might come to mind:

1. **How you personally identify**
2. **What others tend to assume about your race/ethnicity (or what you think they assume)**

Self-identification is the most accurate way to describe one's race or ethnicity, but the second option gives a lot of important information about how **perceived or socially assigned race** impacts people over time, such as ways in which they experience discrimination regardless of how they self-identify. Some researchers call this description your "**street race**," because it is the race that strangers might think you are when they pass you on the street:

> "For example, if we ask about someone's race or ethnic origin in one question and the person says, Cuban, Puerto Rican or Mexican, and stop there, we may miss an opportunity to find out if Puerto Ricans who are light-skinned and probably not seen as Black or Brown are treated differently from those who are their siblings but may be seen as Black or Brown when walking down the street."

Again, **self-identity** is the most important and accurate response you can give, and you have the choice of also taking your perceived race into account.

CAN THIS INFORMATION BE USED AGAINST ME?

It is understandable for people to feel fearful of disclosing certain information, because the U.S. government has a long history of using data to monitor and discriminately harm people. Nowadays, there are more **privacy protection laws** to protect people from such practices, especially when it comes to information collected in health settings. First, any information about you that is documented (such as on your medical record) is required by law to be **stored in a secure way** and protected. Data disaggregation will not change this requirement. Next, when large datasets are used to calculate statistics (like COVID-19 disease rates) by race/ethnicity, this information **cannot be linked to personal identifiers** like names and phone numbers. People who work with data go through very rigorous **privacy and confidentiality training**, and data access is meant to be **limited** to only certain individuals and purposes.

Also, there are more community organizations, including cultural and faith groups, being involved in the development of data collection tools and rules, which can prevent harm and make sure that all people are counted appropriately. We recommend that anyone who asks for this information be **transparent** about how it will be used and protected. You will always have the option of refusing to answer (see below).

WHAT ARE THE CONSEQUENCES IF I DON'T PROVIDE MORE SPECIFIC RACE/ETHNICITY INFORMATION, OR IF I DON'T USE IT AT ALL?

There are no consequences. It is **not mandatory** to provide your race/ethnicity on any form or survey. All such forms should provide an option such as "Decline to specify." You should select this option rather than leaving the question blank so it is clear that you are not interested in providing this information.

SUMMARY

Soon, you may see changes to race/ethnicity questions on typical forms and surveys. While these changes might not be perfect ways to capture everyone's racial or ethnic identification, we hope they are a step forward in making data collection tools that are more inclusive and are flexible as our understanding of race and ethnicity changes over time. Disaggregated data will never be used to make assumptions about you as an individual, but take a snapshot of the population. And while race/ethnicity disclosure is never required, this information is important to give decision-makers in health, education, housing, and other sectors a more accurate reflection of the communities they serve. This will ultimately strengthen efforts in supporting diversity and inclusion, ensuring that no one is left out of important policy decisions.

RECOMMENDED READINGS

Gupta, S. **To fight discrimination, the U.S. census needs a different race question.** Science News. 2020 March 8. Available from: https://www.sciencenews.org/article/census-2020-race-ethnicity-questions

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