



# DISAGGREGATING PATIENT RACE AND ETHNICITY

A data equity guide for hospitals  
and healthcare leaders





## BACKGROUND

Health disparities on the basis of race and ethnicity are well-known. However, there are still many gaps in our collective knowledge due to the limitations of the current federal reporting standards. These standards were determined by the Office of Management and Budget (OMB) in 1997 and consist of five minimum race categories (White, Black or African American, American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander), and one ethnic group (Hispanic/Latino).

Studies find that race/ethnicity data can be more accurate and complete when patients self-report racial or ethnic identity. It is important to note that the OMB recommends expanding, or disaggregating, the minimum categories into more specific groups based on the local population, but this practice is rarely implemented. All the while, an increasing number of individuals select “Other” as their race, or decline to self-identify at all. Further, the standard categories homogenize groups that diverse and populous, often masking critical within-group health disparities (see FAQ below).

To overcome these issues, health researchers, patient advocates, and physicians have called for disaggregation practices to be implemented on a widespread scale. However, health systems are often designed using the federal data standards, making providers and healthcare leaders default to using these categories.

## USING THIS TOOLKIT

This document is part of a toolkit is aimed at medical practices seeking to implement more equitable data collection procedures for their patients. It includes answers to frequently asked questions (FAQs) and recommended tools that can help train health providers and other personnel on new procedures and explain expanded race/ethnicity options to patients. Accompanying this document is a slide deck brings a selection of these resources together in a more concise, visual format.

Local health systems encompass medical providers of all sizes and specialties. We understand that some of the recommendations are not feasible for solo providers or small practices. We encourage larger, more well-resourced institutions to initiate resource exchanges and knowledge sharing with community stakeholders, including local solo and small practices. These collaborations can maximize the outcomes of data policy changes, however incremental, by broadening data collection practices beyond the organizational level.

## WHO WE ARE

The Innovations in Data Equity for All Laboratory (IDEAL) initiative is led by the NYU Center for the Study of Asian American Health and Coalition for Asian American Children and Families with support by colleagues from the New York Academy of Medicine, NYU Langone Health, and the New York State Department of Health. Our goal is to reduce racial/ethnic health disparities using data collection and analysis methods that are inclusive, equitable, and patient-centered.

# DISAGGREGATED RACE/ETHNICITY: FAQs

## - WHY IS DISAGGREGATION IMPORTANT FOR MEDICAL PRACTICE?

There is evidence that more granular race/ethnicity categories can increase and reduce the number of “Other” or missing responses to these questions. Increasing race/ethnicity response rates is critical for addressing health disparities on a local and national level (Webber et al, 2022). Yet, the current OMB categories might not fully align with patients’ self-defined race/ethnicity. Therefore, offering expanded options that fall within the standards may provide more culturally and linguistically appropriate terms for self-identification.

Crucially, the OMB categories mask numerous within-group health disparities. For example, Torre et al. (2016) find that distinct groups that are combined in the Asian American and Native Hawaiian/Pacific Islander (AA/NHPI) categories have vastly different cancer rates. Using data from the National Cancer Institute’s SEER program, researchers found significant “variation in cancer rates in AANHPIs are related to risk factors including lifestyle factors, use of screening and preventive services, and exposure to cancer-causing infections.” Similarly, a study of disaggregated black ethnic groups found vast differences in heart disease risk between Black ethnic groups, including African immigrants, African Americans, and Afro-Caribbean individuals (Baptiste et al, 2022).

## - SHOULDN'T PROVIDERS WAIT FOR THE FEDERAL GOVERNMENT TO OFFICIALLY AMENDING THE STANDARD CATEGORIES BEFORE CHANGING PATIENT DEMOGRAPHIC QUESTIONNAIRES?

Federal changes to the race/ethnicity standard are forthcoming. In May 2022, the US Census Bureau announced that it will consider deviating from OMB standards for the Census questionnaire. The proposed changes include adding a Middle Eastern and North African race category and combining the 5 current race categories and the Hispanic/Latino ethnicity category into a single question.<sup>3</sup> One month later, the White House announced that the OMB would also examine these recommendations. A federal interagency working group has subsequently begun evaluating research and public comments to inform its recommended revisions to the federal minimum reporting requirements.

However, the lack of a formal change has not precluded state and local health departments from disaggregating data among their constituents. In fact, one of the Robert Wood Johnson Foundation’s current key initiatives is “Advancing state and local policy change to promote data disaggregation.”

To illustrate, the State of Hawaii, the County of Santa Clara, and the State of Michigan are just a few jurisdictions that have collected COVID-19-related data from disaggregated racial/ethnic groups that are particularly populous in the region. This helped the health departments address potential disparities that wouldn’t have otherwise been detected in data findings. In all cases, the disaggregated race/ethnicities could be “rolled up” into the OMB standards, allowing for data harmonization (include State Review in toolkit?).

New York State is following suit; in December 2021, the state governor signed New York State Law S.6639-A/A.6896-A. Following a two-year implementation period, the bill will require all state agencies’ race/ethnicity questionnaires to include disaggregated response options for Asian Americans (AA) and Native Hawaiian or Other Pacific Islanders (NH/PI), allowing constituents to identify with a more specific group. Thus, it is in the best interest of providers and patients alike to begin planning for a more flexible, dynamic demographic data collection scheme even in the absence of a federal mandate.



## - HOW DO WE DECIDE THE RACE/ETHNICITY CATEGORIES TO INCLUDE IN MY PATIENT FORMS?

Although space limitations should not be an excuse for excluding disaggregated categories, it might not be feasible to include all possible groups. In this case, there are ways to systematically select the limited categories to include on survey or form.

One option is to review ancestry data from the American Community Survey (ASC) in your local area. This data can be found at [data.census.gov](https://data.census.gov). The Ancestry tables show disaggregated racial/ethnic groups with which respondents identify at county and even municipal levels. This can give providers a sense of the most populous ethnic groups that may comprise the local patient population. Other existing data sources may provide similar information.

Existing survey data can be a starting point for testing disaggregated race/ethnicity questions on patient forms. However, it is important to work directly with communities and community-based organizations to determine categories and the appropriate terms to describe different ethno-cultural groups. Community ownership and participation at all stages is critical for community buy-in and advancement of “health equity goals in ways that are respectful of cultures, local contexts, and people” (PolicyLink, 2018).

It is also important to note that disaggregated surveys/forms should include a response option such as “Another group not listed here” (along with a write-in/free text option) to account for those excluded groups. Although they may not be appropriate to include in reports, patterns in the responses may give valuable information about gaps in inclusivity. Avoid using language such as “Other” for this response option.

## - WHAT IF MY ELECTRONIC MEDICAL RECORDS SERVICE DOES NOT PROVIDE EXPANDED CATEGORIES?

EMR companies may not expand categories past the minimum federal standards without a cost, leaving providers with an additional financial burden to bear. This is an important investment for the future of health equity, so it is recommended to consider increasing line items related to information technology in annual budgets for this purpose.

## - WHAT IF PATIENTS DO NOT WANT TO PROVIDE RACE/ETHNICITY INFORMATION?

There are a number of statements or questions that you may hear in response to inquiries about patient race/ethnicity. The resources below from the American Hospital Association (AHA) and the Agency for Healthcare Research and Quality (AHRQ) include scripts that can help staff respond to a variety of patient questions and concerns, such as:

- “Can’t you tell by looking at me?”
- “I’m human.”
- “It’s none of your business.”
- “I’m not sure.”

The most important takeaway is that race/ethnicity reporting is voluntary, and if a patient is not comfortable answering these questions, staff should move on right away. They may simply record “Declined” as the response (AHA).





## - CAN STAFF DOCUMENT PATIENTS' RACE/ETHNICITY BASED ON OBSERVATION INSTEAD OF ASKING DIRECTLY?

No. Patients should self-report their race/ethnicity either on a written form or verbally to the healthcare provider or staff. A third party's observation of an individual's appearance is not reliable, and can lead to misclassifications that distort health data over time.

## - HOW DO I USE THE DISAGGREGATED RACE/ETHNICITY DATA ONCE IT'S COLLECTED?

It may take some time for patients and staff to become accustomed to new race/ethnicity questionnaires. Therefore, health systems should monitor data closely and make quality improvement adjustments when there are visible patterns or frequent challenges get documented. There may not be enough disaggregated data available to draw conclusions about health disparities right away, but frequent monitoring and evaluation during the implementation period will ensure high quality and reliability of the responses received.

## - HOW OFTEN SHOULD PATIENTS BE ASKED FOR THEIR RACE/ETHNICITY INFORMATION?

AHA recommends implementing some policy or mechanism to “flag” a patient's race/ethnicity response when it has been recorded AFTER the new data collection procedures have been implemented. That way, patients do not have to repeat their answer every time except for periodic updates (for example, setting up a system that prompts new demographic responses every 2 years). If these mechanisms are not possible or too difficult to automate in your practice, AHA recommends asking patients for their race/ethnicity every time.

# RECOMMENDED TOOLS FOR HOSPITALS AND HEALTHCARE LEADERS

The organizations below have developed evidence-based guides to collecting more granular race and ethnicity in the medical setting. They offer numerous strategies that you can adapt to your own practice. The slide deck that accompanies this document includes some excerpts from these recommended resources.

For a resource list related to data analysis, please see the document and accompanying slide deck entitled, “Equity-centered data governance, analysis, and reporting of disaggregated race/ethnicity.”

### Staff training guides, including patient scripts and explainers:

- Data improvements through educating and training of hospital staff (Agency for Healthcare Research and Quality)
- Staff training: patient question and response matrix (American Hospital Association)
- Staff training: reference booklet on data collection (American Hospital Association)
- Training Frontline Data Collectors (Agency for Healthcare Research and Quality)
- Explaining race/ethnicity standards to patients (Oregon Health Authority)
- Toolkit for collecting granular race/ethnicity - includes workflow template, patient response guides, training slides and recordings (Oregon Health Authority)



**Sample questionnaires:**

- How to ask race/ethnicity questions (American Hospital Association)
- “Help us know our patients better”: sample patient form (New Mexico Dept. of Health)
- Model/Recommended Standard for Health Data Collection, Analysis, and Reporting (Asian and Pacific Islander American Health Forum)
- Multi-Lingual questionnaires for adult patients & parent/guardians of pediatric patients (Oregon Health Authority)

**Comprehensive best practice guides on communication and community collaboration**

- Patient-centered communication guide (American Medical Association)
- Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health (PolicyLink)

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