RACE/ETHNICITY DATA DISAGGREGATION:

A primer for community-based organizations (CBOs) and advocates

BACKGROUND

There are many well-known health disparities related to race and ethnicity. However, there are still gaps in our collective knowledge due to the limitations of the current federal data reporting and collection 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 people self-report racial or ethnic identity. In the 2010 census, "Some Other Race" became the third-most selected category in the US, demonstrating people's resistance to labeling themselves on official documents using OMB standard language (Jones et al, 2021).

It is important to note that the OMB recommends expanding, or disaggregating, the minimum categories into more specific groups based on the local population. In 2014, the OMB's Interagency Working Group for Research on Race and Ethnicity proposed more inclusive ethnic subcategories as a potential method of addressing nonresponse (OMB, 2016). Doing so allows patients to select a racial and ethnic identity that more closely represents how they identify themselves than the options typically presented to them. Furthermore, by collecting information about identities that are more granular than the broad, often ambiguous standard race/ethnicity categories, providers can determine within-group inequities related to health, education, and other sectors.

To overcome these issues, civil rights groups, health equity researchers, and other stakeholders have long advocated for collecting disaggregated race/ethnicity data on a widespread scale (see the resource list below). However, officials often express resistance to doing so in the absence of a federal requirement. This toolkit has been developed to explain why and how community-based organizations can advocate for data disaggregation locally, as well as existing resources that can be adapted for future advocacy and community mobilization efforts.

USING THIS TOOLKIT

This document is part of a toolkit prepared for CBOs interested in advocating for data equity among local officials. CBOs may also wish to develop community education and organizational strategies surrounding disaggregated race/ethnicity data collection. There are many existing efforts that can help guide and support these activities. The document lists recommended resources and includes answers to frequently asked questions (FAQs). Accompanying this document is a slide deck which brings a selection of these resources and recommendations together in a more concise, visual format.

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 HEALTH?

The United States is a racially and ethnically diverse nation, and the distribution of different racial/ethnic groups changes from state to state. Many states, especially those with large metropolitan areas, include large, longstanding ethnic enclaves and growing immigrant populations with a range of health issues and needs. Overreliance on OMB categories can mask disparities that require attention from local health departments. For example, studies find vast differences in heart disease rates between those who identify as African American and Black immigrants from the Caribbean and Africa. The Asian category similarly includes disparate ethnic groups, such as Indian, Korean, or Chinese Americans, and hides numerous chronic disease disparities.

Taken together, these data demonstrate that while structural racism is a chief contributor to adverse health outcomes for certain racial groups, there are other drivers of health disparity that are connected to language, culture, and other factors related to ethnic subgroup identity. Analyses of medical practice data that stratify patients by subgroup can support the allocation of resources in areas that have been previously overlooked. Such resources can include staffing of more bilingual patient navigators, more personal protective equipment for hospitals that serve zip codes with large ethnic enclaves, or funding culturally and linguistically competent public health programs. Thus, data disaggregation can aid more appropriate targeting of preventive resources and efforts, lowering healthcare costs and reducing healthcare burdens over time.

WHY SHOULD WE CARE NOW?

Federal changes to race/ethnicity standards are likely coming soon. The US Census Bureau announced in May 2022 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. 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. Therefore, it is important for institutions and localities to start planning for disaggregation practices that are inclusive, collaborative, and equity-driven.

Even without these national-level changes, communities may see changes to race/ethnicity data collection forms issued by state and local governments. New York State recently passed a community-driven data disaggregation law (NYS S6639/A6896), which requires agencies to provide disaggregated Asian and Native Hawaiian and Other Pacific Islander race options, such as Bangladeshi, Filipino, Hmong, Korean, and other traditionally homogenized identities. To learn more about models of data disaggregation in state policy, you may find a report in this toolkit that highlights other states' efforts to disaggregate race/ethnicity in different ways, providing models for implementing this practice that depend on regional factors.

HAS DISAGGREGATION BEEN SUCCESSFUL AT THE LOCAL LEVEL?

Some data disaggregation policies at the state and local level have already been enacted. The Hawaii State Department of Health is the first state to publicly present disaggregated COVID-19 case data on the state's most populous ethnic groups to highlight key within-group health disparities within Native Hawaiian/Pacific Islander and Asian American racial groups (Yan et al, 2020).

There are also hospital administrative databases that collect data on populous ethnic subgroups in particular regions. For example, a large health system in metropolitan Detroit includes an 'Arab American' response option. Analysis of patient data found that there are differences in various disease rates between Arab American and White patients. This type of information is critical for providers to inform and tailor local prevention interventions, and has supported the allotmentof resources specifically for Arab Americans in Michigan (Dallo et al, 2016).

CAN OFFICIALS USE THIS TO TARGET AND HARM SPECIFIC ETHNIC/CULTURAL GROUPS?

Before implementing data disaggregation policies, officials must establish safeguards that will clearly delineate how the data should be collected and stored along with how disaggregated data can be used. It is important for community leaders and CBOs, especially those that advocate on behalf of specific ethnic, racial, or cultural groups, to engage in discussions with agencies to make these concerns known. At all levels of data collection (institutional, local, state, and federal), these community representatives should be working with decision-makers to co-develop transparent policies and procedures (written in plain language) on data anonymization, privacy protection for respondents, information security, and guidelines for accountability on how the data should be properly accessed and used.

We understand that there are some concerns within communities over how race and ethnicity data will be used, but we expect government agencies to adhere to the same guidelines that they have used to date in managing other sensitive data that they already collect on our communities and all communities in the United States (examples include US Census data, health data, employment data). Furthermore, the data collected must be anonymizedin keeping with existing state and federal law prior to its release to the public.

On surveys/forms themselves, it is important to preface disaggregated race/ethnicity questions with a written caveat about privacy. For examples, healthcare personnel should let patients know in plain language that their demographics will be kept confidential and used only for health purposes. Developing standard scripts to help describe data purposes and the benefit of disaggregated race/ethnicity. The component of this toolkit that is aimed toward health professionals and healthcare executives includes relevant examples.

While a conversation with the patient about race/ethnicity reporting can ease any apprehensions about privacy or data misuse, there should also be standard practices to inform (both verbally and in written form) individuals that this reporting is optional. All community members should understand that they are free to refuse to respond to granular inquiries about race/ethnicity.

▪ WHAT IF DISAGGREGATED DATA RESULTS LEAD TO MORE STEREOTYPING OF CERTAIN COMMUNITIES?

We encourage that procedures developed to implement disaggregated data collection, analysis, and reporting include current recommendations for presenting data sensitively. The Race Matters Institute, for instance, recommends framing data "aspirationally" to avoid reinforcing stereotypes. For example:

"Instead of '% of families in poverty,' consider '% of families earning a family-supporting wage.' The former frame triggers racialized stereotypes around poverty, while the latter frame is more likely to open up discussion about available jobs and adequate wages." (Race Matters Institute, 2019)

Another recommendation is to provide background information and interpretive text when reporting data that shows racial/ethnic disparities. For example, offering historical or sociopolitical contexts behind the statistics can help avoid harmful mischaracterizations and stereotyping of groups that experience disparities in health, income, education, or other outcomes (UCLA, 2021). CBOs must continue to work with stakeholders and officials that publish data to ensure such practices.

▪ HOW CAN CBOS PREPARE COMMUNITIES FOR NEW RACE/ETHNICITY INQUIRIES THEY MIGHT SEE ON OFFICIAL FORMS?

Because disaggregated race/ethnicity response options will be new to most patients, it would be helpful to provide either verbal or written explanations of this more detailed inquiry. Examples that have been recommended for collecting granular race/ethnicity in various settings include:

> *"We are now collecting race, ethnicity and tribal affiliation information from all of our patients to help us know them better. We can learn more about the communities we serve if we know your race and ethnicity and tribe or pueblo. We can better meet the needs of all patients if we know more about race, ethnicity, and tribal affiliation." (New Mexico Department of Health)*
>
> *"We strive to create programs and services that represent the full diversity of the _____ community. We are asking the following question about race and ethnicity to ensure that we are meeting this goal." (Charles and Lynn Schusterman Family Philanthropies)*

The resource list below includes more recommended forms that include different formats, category options, and explainers that can be adapted for specific communities. It is important that CBOs utilize their expertise to tailoring existing materials and resources in ways that are culturally appropriate and specific for the communities in their own localities. For example, the National Center for Education Statistics recommends sending letters and holding public forums for explaining disaggregated race/ethnicity to parents who may see changes in demographic data collection in local schools. CBOs have an opportunity to be at the forefront of educational efforts, responding to concerns and collecting immediate feedback about data collection tools.

WHAT IS RECOMMENDED FOR MULTIRACIAL/MULTIETHNIC INDIVIDUALS?

Racial and ethnic identity is rarely singular. If it is not feasible to allow open-ended written responses to race/ethnicity questions on a data collection form, we recommend allowing individuals to select multiple disaggregated race/ethnicity categories. While this adds complexity to analyses, this toolkit includes a separate guide for data managers with resources on coding complex data and including multiracial identities in reports.

RECOMMENDED TOOLS FOR CBO ADVOCACY AND EDUCATION

BEST PRACTICES, DATA EQUITY, AND ADVOCACY GUIDES:

- Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health (PolicyLink, 2018)

- Advocating for Data Disaggregation by Race and Ethnicity (Robert Wood Johnson Foundation, 2021)

- Sample messaging to increase census responses (Connecticut Data Collaborative, 2020)

- The Racial Heterogeneity Project (ACT Inc., 2017)

- Race data disaggregation: what does it mean? (Minnesota Compass, 2018)

- The Essentials of Disaggregated Data for Advancing Racial Equity (Race Matters Institute, 2019)

- Webinar: Legal and Regulatory Guidance for Racial/Ethnic Data Disaggregation in Health Data Sets (UCLA, 2022)

- Webinar: Disaggregated Racial/Ethnic Data Decision-Making – Who, What, When? (UCLA, 2021)

POPULATION-SPECIFIC DATA EQUITY GUIDES AND REPORTS:

- **Asian, Pacific Islander, and Native Hawaiian Americans**

  - Data disaggregation one-pager – Invisible No More (Coalition for Asian American Children and Families)

  - President's Advisory Commission on AANHPI – Recommendations (Data Disaggregation Subcommittee)

  - Understanding the Culture of Health for Asian American, Native Hawaiian and Pacific Islanders (AANHPIs) (PolicyLink)

  - No Equity without Data Equity: Data Reporting Gaps for Native Hawaiians and Pacific Islanders as Structural Racism (Journal of Health Politics, Policy, and Law)

- **American Indian and Alaska Native Americans**

    - Data disaggregation policy recommendations (National Congress of American Indians)

    - Policy brief: indigenous data sovereignty in the United States (University of Arizona)

    - Best Practices for American Indian and Alaska Native Data Collection (Urban Indian Health Institute)

- **Black/African American**

    - Health Disparities and the Heterogeneity of Blacks/African Americans in the United States: Why Should We Care? (Health Promotion Practice)

    - Black Is Diverse: The Untapped Beauty and Benefit of Cancer Genomics and Precision Medicine (JCO Oncology Practice)

- **Hispanic/Latino(a) Americans**

    - Disaggregating Latina/o Surveillance Health Data Across the Life Course: Barriers, Facilitators, and Exemplars (Robert Wood Johnson Foundation)

    - Uncovering Unique Challenges: Variation in Unmet Mental Health Needs Among Latinx Ethnic Groups in California (UCLA Center for Policy Research, 2021)

- **Middle Eastern/North African American**

    - Educational materials for encouraging Arab Americans' census response (Yalla! Count Me In)
    - Will You Count? MENA in the 2020 Census (The Leadership Conference Education Fund)

- **Multiracial populations**

    - Half measures: California's Journey Toward Counting Multiracial People by 2022 (Multiracial Americans of Southern California)

    - Improved Race and Ethnicity Measures Reveal U.S. Population Is Much More Multiracial (U.S. Census Bureau)

SAMPLE QUESTIONNAIRES:

- "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)

- More than numbers: a guide toward DEI in data collection (Charles and Lynn Schusterman Family Philanthropies)

- Forum Guide to Collecting and Using Disaggregated Data (National Center for Education Statistics)

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