Federal Policy to Advance Racial, Ethnic, and Tribal Health Equity

Key Actions for Ensuring Collection and Reporting of Data Are Representative and Accurate

Achieving health equity—the state in which everyone has an opportunity to attain their full potential for health and well-being—requires efforts to address inequities around access to quality health care, education, employment opportunities, and more. The National Academies of Sciences, Engineering, and Medicine assembled an interdisciplinary committee of experts to analyze federal policies that contribute to such inequities, specifically for racially and ethnically minoritized populations. The resulting consensus study report, Federal Policy to Advance Racial, Ethnic, and Tribal Health Equity, provides recommendations for change.

HOW CAN IMPROVED DATA COLLECTION ADVANCE HEALTH EQUITY?

Accurate, high-quality data are the cornerstone of evidence-based policymaking. However, federal-level data collection is not currently detailed or comprehensive enough to allow for a deep understanding of the current state and future needs of minoritized racial, ethnic, and tribal groups. When population-wide data are inadequate, inequities can be hidden or ignored and progress to rectify these inequities cannot be monitored. To support policymaking that will advance health equity, data collection has to be sufficiently detailed, supported by adequate financing, and coordinated across the federal government.

WHAT DOES IT MEAN TO COLLECT SUFFICIENTLY DETAILED DATA?

- Data should capture the experiences and needs of minoritized racial, ethnic, and tribal populations. Lack of data disaggregation reflects norms, values, and practices rooted in racism, xenophobia, colonialism, and imperialism. This antiquated approach views and treats racially and ethnically minoritized populations as monoliths and erases the complexity, nuances, and specificities of their social positions and lived experiences. Recognizing and capturing intra-group complexity via data disaggregation is critical for understanding the needs of all minoritized racial and ethnic groups, for drawing evidence-based conclusions, and for taking action (see Conclusion 2–2 and Recommendation 6 in the report). Failing to appreciate this diversity can obscure significant within-group health inequities and hamper efforts to mitigate health inequities more broadly. In addition to expanding the scope of data collection, survey design should also be updated. A lack of appropriate options may lead respondents to select a racial or ethnic category that does not reflect their lived experience, erasing their identity and potentially obscuring outcomes for other populations.
• **Minoritized racial and ethnic groups should be adequately represented in data collection.** Smaller minoritized racial, ethnic, and tribal groups—especially American Indian, Alaska Native, Native Hawaiian, and Pacific Islander populations—are often underrepresented or entirely missing from national survey datasets. Inadequate sampling of these groups makes them effectively invisible when these data are used for federal decision making. This invisibility may prevent these groups from receiving the resources they need, further perpetuating already deep and persistent health inequities. Standard and equitable data collection processes (including sampling frames and methods) should be developed for all racial and ethnic groups to ensure accurate and representative datasets (see Recommendation 5 in the report).

• **Data collection should include appropriate social and environmental context, including the impact of racism.** Without appropriate context, health disparities may be incorrectly blamed on individual-level factors. For example, poor health outcomes among Black populations are often inaccurately attributed to socioeconomic inequities alone, when analyses that incorporate more detailed data often show interpersonal, institutional, and structural racism as key drivers of these poor outcomes. A complete and nuanced understanding of health inequities and their context requires the development and use of common measures on social determinants of racial, ethnic, and tribal health inequities, including racism and other forms of discrimination (see Recommendation 7 in the report). Increased funding from Congress will be needed for federal agencies to collect these data (see Recommendation 8 in the report).

**IMPORTANCE OF UNDERSTANDING MINORITIZED RACIAL AND ETHNIC GROUP COMPLEXITY**

There are many examples of how a lack of representative and disaggregated data masks inequities. Disaggregated data, in general, show that people from Puerto Rico have worse health outcomes than every other Latino/a group in the United States. The Asian population is one of the most diverse U.S. populations, spanning more than 37 ethnocultural groups. The Asian population also has the largest within-group wealth gap; the lowest income levels show the least growth 1970–2016 compared to other racial and ethnic groups. This heterogeneity applies to other population groups as well and affects all measures of health. Intra-group inequities such as these can be masked when complexities are not adequately captured, and incorrect conclusions can be drawn from overly generalized data (see Conclusion 2–1 in the report).

**DATA COLLECTION FOR AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS**

American Indian and Alaska Native populations have been historically excluded from data collection, concealing their experiences and needs. When such data are collected, they are often undersampled and generalized; misclassified if not a member of a federally recognized Tribal Nation; or relegated to a racial category of “other,” which lumps multiple minoritized groups together and is therefore unusable for tailoring health interventions. This history of exclusion, coupled with these groups’ disproportionately poor health outcomes, demands additional attention to ensure that data are collected accurately and sensitively.
NECESSARY FINANCIAL SUPPORTS

The additional data collection required to oversample and target groups that have been historically overlooked will be costly, as will efforts to protect data confidentiality when disaggregating and examining these data. However, this level of detail is necessary to identify solutions that will improve overall equity in health and socioeconomic outcomes.

ENSURING LONG-TERM FEDERAL INTERAGENCY COORDINATION ON DATA EQUITY LONG-TERM

To make the work of the existing Equitable Data Working Group more enduring, the federal government should make interagency coordination on data equity a permanent feature across statistical agencies. The president of the United States should convert the Equitable Data Working Group into an Office of Data Equity under the Office of Management and Budget with representation from the Domestic Policy Council. This work should emphasize small and underrepresented populations and include a scientific and community advisory commission.

Learn more about the report and its recommendations at www.nationalacademies.org/health-equity-policies.

Health and Medicine Division