ISSUE BRIEF

COLLECTING RACE, ETHNICITY, AND PRIMARY LANGUAGE DATA:

Tools to Improve Quality of Care and Reduce Health Care Disparities

"It is a capital mistake to theorize before one has data. Insensibly one begins to twist facts to suit theories, instead of theories to suit facts."

— Sherlock Holmes

What Are Disparities in Health Care?

Disparities in health care are differences that remain after accounting for patients' needs and preferences and the availability of health care.[1] Disparities in *health care* differ from disparities in *health* (or *health status*). Though the two are interrelated, causes of disparities in health include differences in economic conditions across racial and ethnic groups, which "are likely to result in less access to health care, inability to afford higher-quality care, and greater exposure to harmful occupational and environmental factors. Differences in education may contribute to disparities in health, as may health-related behavior patterns (e.g., diet, exercise)."[2]

This issue brief focuses on disparities in health care. Health care disparities occur within a wide range of health care settings including hospitals, emergency departments, clinics, and doctors' offices, and across a broad range of conditions. Not surprisingly, these disparities in care are associated with higher mortality among racial and ethnic minorities.

Linking Disparities and Quality

Hundreds of articles have not only documented disparities in U.S. health care but also linked them to lower quality of care. The 2004 *National Healthcare Disparities Report (NHDR)* declared that disparities in quality "pervade the American health care system."[3] Furthermore, disparities and quality of care are "not isolated phenomena," according to the *NHDR* and its companion report, the *National Healthcare Quality Report (NHQR)*.[4] The Institute of Medicine's 2001 report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, describes a "chasm" that lies "between the health care that we now have and the health care that we could have." It reports that the "U.S. health care delivery system does not provide consistent, high-quality medical care to all people."[5]

These reports emphasize the interdependence of disparities and quality and underscore the need for targeted action to improve overall quality of care and reduce disparities for underserved populations. Disparities are a result of a number of factors including inequitable care, lack of insurance, poverty, language barriers, cultural barriers, and bias. The quality chasm is a result of ineffective, unsafe, untimely, inefficient care that is not patient-centered.[6]

What Causes Disparities in Health Care?

Though the presence of disparities in care is well documented, the causes of these disparities are not well understood.[7] A panel of experts convened by the National Academies found that disparities in health care may or may not be due to conscious or unconscious discrimination.[8] Disparities in care may be attributed to both organizational or *systems* factors as well as *individual* characteristics of practitioners and patients (see *Factors Contributing to Disparities in Health Care* table). Some factors occur at both the systems and individual levels.

Factors Contributing to Disparities in Health Care

Systems Level	Individual Level
• Fragmentation of care • Financial barriers • Physical barriers (e.g., excessive distance) • Information barriers (on part of providers and patients) • Differential access to high-quality hospitals and other facilities	• Communication barriers and lack of trust between practitioner and patient • Cultural barriers: little understanding of patients' health beliefs and behaviors • Problems with health literacy • Language barriers for patients with limited English proficiency • Bias and prejudice: stereotyping and biased decision making by providers and practitioners

Data Are the Building Blocks

Whatever factors contribute to creating health care disparities, collecting accurate data is of utmost importance—the basic foundation—in working toward eliminating such disparities and improving quality of care. Data collection has long been central to the quality assurance process. If data on race, ethnicity, and primary language are available, disparities in health care can be addressed through a quality of care framework.

Though disparities and quality are linked, there is an inherent tension in blending the two. Simply improving overall quality of care may not reduce disparities. As such, the data on patient race, ethnicity, and language become necessary.

Systems reform envisions quality improvement as an organizational responsibility. A systems reform approach to reducing racial and ethnic disparities requires performance data that stratify quality-of-care indicators according to patients' race and ethnicity.

According to Sidney Watson, "Performance data stratified by race and ethnicity could provide valuable information about the extent and impact of health care disparities. Moreover, this information could indicate which system's designs, training modules, and protocols reduce racial and ethnic disparities and which ones fail to do so."[9]

"Disparities in health and health care illuminate weaknesses in the health care and public health systems. Interest in better understanding the causes of these differences and formulating strategies to ensure the highest quality of care for everyone has generated significant attention to disparities across racial and ethnic groups."

Eliminating Health Disparities, National Research Council Panel on DHHS Collection of Race and Ethnicity Data

Collecting Accurate Data Efficiently: A Case Study

Though providers and practitioners recognize the need for accurate data, collecting and reporting such data is not common practice or done effectively. The Health Research and Educational Trust (HRET) and Northwestern Memorial Hospital (NMH) in Chicago collaborated on a research project that implemented new race, ethnicity, and language questions into the patient registration process at NMH. The project's goals included linking race and ethnicity data to quality of care and exploring any disparities, and examining the hospital's response to reporting quality measures by race and ethnicity.

In NMH's former system, hospital clerks did not routinely collect information on race and ethnicity nor did they ask patients to provide this information themselves. If clerks did collect this information, they often used their own observations to record patients' race and ethnicity—a widespread practice among many hospitals and health care settings.

In the current system, patients self-report their race and ethnicity, preferred language, and their ability to speak and understand English. NMH developed this explanation for clerks to use when asking for race/ethnicity data:

We want to make sure all our patients get the best care possible. We would like you to tell us your race or ethnic background so we can review the treatment patients receive and make sure everyone gets the highest quality of care. You can use general terms such as White or African American or more specific terms like Mexican or Korean. You can use more than one term.

In collaboration with NMH, HRET developed a toolkit for providers to use for the systematic collection of data on race, ethnicity, and primary language. Go to **www.hretdisparities.org** to access this toolkit.

Self-Reporting Reveals Greater Diversity

Using a uniform framework increased the accuracy and efficiency of data collection at NMH. In self-reporting, NMH patients used 150 different terms, revealing a wider diversity of race/ethnicity than had previously been documented at NMH. All these terms can be rolled up into broader categories for reporting purposes, but the granular information is available for providing patient-centered care and targeting quality improvement initiatives. The self-reporting at NMH also showed that approximately 8 percent of their patient population was Hispanic, a higher percentage than previously documented. In addition, 35 different primary languages were reported by patients.[10]

Using the Data on Race and Ethnicity

For providers and practitioners, collecting data on race, ethnicity, and primary language is necessary and useful for two main reasons: reporting to external sources and providing patient-centered care. The accompanying table, *Using Data on Race, Ethnicity, and Primary Language*, shows how providers and practitioners use the data for these purposes. By collecting the data, providers and practitioners can tailor care to each patient. They can also ensure that they are meeting the needs of the population in their community.

Using Data on Race, Ethnicity, and Primary Language

Reporting to External Sources

- Regulatory, Purchaser, Payer (Centers for Medicare and Medicaid Services)
- Legal (19 states have mandates to collect race/ethnicity data in hospitals; Health and Human Services Title IV regulations)
- Accreditation (Joint Commission on the Accreditation of Health Care Organizations, National Committee on Quality Assurance)

Systems Level

- Make language services available
- Understand patients' health beliefs and behaviors
- Know dietary needs
- Provide appropriate signage
- Plan for cultural competency training

Recommendations for Collecting, Standardizing, and Using Data on Race, Ethnicity, and Primary Language

Collecting the Data

Though the *National Healthcare Disparities Report* recommends collecting data on race and ethnicity using the Office of Management and Budget (OMB) standards, experts recognize that greater detail beyond the OMB's five race categories may be more useful for providers and practitioners. Here are our recommendations for collecting race and ethnicity information:

- Ask patients or designees to self-report, and collect data directly from them.
- Provide a rationale or reason to explain why the information is being collected.
- Address patients' questions and concerns about data collection and how data will be used.
- Use an open-ended format (if information systems allow for this level of detail) or provide subcategories (under broader categories) that best meet the needs of the community served.
- Allow patients to identify as multiracial/multiethnic and to select more than one category.
- Standardize the method for aggregating subcategories into broader categories for analytical purposes.

Standardizing Data Collection Practices

We offer the following recommendations to standardize data collection practices:[11]

- Decide who provides the information: patients or designees.
- Standardize when data are collected: upon admission or at patient registration to ensure all fields are completed.
- Establish how data are stored: storing in a standard format (preferably electronic) enables linkages to clinical measures.
- Provide ongoing staff training on collecting race, ethnicity, and language data from patients.
- Monitor and evaluate data collection practices and how data are used.

Using the Data

As discussed in this brief, information on racial and ethnic characteristics is needed to target quality improvement efforts, identify the nature and extent of disparities, and monitor progress. In addition, legal statutes and laws require reporting data by race and ethnicity to monitor discriminatory practices.

Efforts to stratify quality measurements by accurate race and ethnicity data will help the health system serve three critical functions:[12]

- Ensure the health of the population
- Ensure equitable access to care
- Ensure quality of care

"Most quality improvement in health care organizations goes on over relatively long periods of time. The important test of a QI initiative to reduce disparities is not whether it produces a statistically significant difference in one measurement cycle but rather whether it produces sustained reduction in, or elimination of, the target disparity over time."

David R. Nerenz, PhD
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Endnotes

1. Institute of Medicine, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2003).

2. National Research Council, *Eliminating Health Disparities: Measurement and Data Needs*, Panel on DHHS Collection of Race and Ethnicity Data, Michele Ver Ploeg and Edward Perrin, editors, Committee on National Statistics, Division of Behavioral and Social Sciences and Education (Washington, DC: National Academies Press, 2004), p. 22.

3. Agency for Healthcare Research and Quality, *National Healthcare Disparities Report* (Rockville, MD: Agency for Healthcare Research and Quality, 2004), p. 1.

4. Agency for Healthcare Research and Quality, *National Healthcare Quality Report* (Rockville, MD: Agency for Healthcare Research and Quality, 2004).

5. Institute of Medicine, Committee on the Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Washington, DC: National Academies Press, 2001), p. 1.

6. Helen Burstin, Agency for Healthcare Research and Quality, "Evidence-Based Research to Reduce Healthcare Disparities," slide presentation, March 1, 2005.

7. National Research Council, *Eliminating Health Disparities*.

8. Ibid.

9. Sidney Watson, *Equity Measures and Systems Reform as Tools for Reducing Racial and Ethnic Disparities in Health Care* (New York: The Commonwealth Fund, 2005).

10. David Baker, Kenzie A. Cameron, Joseph A. Feinglass, Patricia Georgas, Shawn Foster, Debra Pierce, Jason A. Thompson, and Romana Hasnain-Wynia, "Patients' Attitudes Toward Health Care Providers Collecting Information About Their Race and Ethnicity," *Journal of General Internal Medicine* 20, no. 10 (2005): 895-900.

11. Romana Hasnain-Wynia, Debra Pierce, and Mary A. Pittman, "Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals" (New York: The Commonwealth Fund, 2004).

12. National Research Council, *Eliminating Health Disparities*.

About HRET

Founded in 1944, HRET is a private, not-for-profit organization involved in research, education, and demonstration programs addressing health management and policy issues. HRET, an American Hospital Association affiliate, collaborates with health care, government, academic, business, and community organizations across the United States to conduct research and disseminate findings that will shape the future of health care.

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Related Research

HRET researchers are working on a number of projects that focus on collecting race, ethnicity, and language data. We are linking this information to clinical performance measures in both inpatient and out-patient settings to examine quality of care for specific population groups. The projects include:

- Developing a Uniform Framework for Collecting Race, Ethnicity, and Primary Language Data in Hospitals
- Improving Data Collection of Patients' Race, Ethnicity, and Language in California
- Linking Race and Ethnicity Data to Inpatient Quality of Care Measures
- Integrating Race, Ethnicity, and Language Data with National Clinical Performance Measures
- Expecting Success: Excellence in Cardiac Care (training 10 hospitals in a national learning collaborative to systematically collect race, ethnicity, and language data and link to cardiac care performance measures)
- Survey of Hospital Language Services

For more information about these projects, visit www.hret.org or e-mail rhasnain@aha.org.

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