In the Literature

OBTAINING DATA ON PATIENT RACE, ETHNICITY, AND PRIMARY LANGUAGE IN HEALTH CARE ORGANIZATIONS: CURRENT CHALLENGES AND PROPOSED SOLUTIONS

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Hospitals and health care organizations that collect data on patients' race, ethnicity, and primary language are more likely than those without such information to examine disparities in care and design targeted programs to address them. Yet, a new Fund-supported study finds data collection efforts are inconsistent across health care organizations, hampered by a widespread lack of understanding about the most effective strategies.

In "Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations: Current Challenges and Proposed Solutions" (*Health Services Research,* Aug. 2006), Romana Hasnain-Wynia, Ph.D., of the Health Research and Educational Trust, and David W. Baker, M.D., M.P.H., of Northwestern University's Feinberg School of Medicine, argue that health care organizations should collect race, ethnicity, and language information directly from patients or their family members, and propose solutions for many commonly reported barriers.

Current Practices

The capacity to monitor the quality of care provided in hospitals and other health care organizations rests on the ability to measure quality in general and to conduct similar measurements across different racial and ethnic groups. Some health care organizations mistakenly believe that it is illegal to collect race and ethnicity data from patients. In fact, there are no federal statues prohibiting this practice, and the Centers for Medicare and Medicaid Services and other government agencies may soon begin requiring it.

Among organizations that do collect data, many rely on staff observation—a practice known to be prone to error. Most observers will accurately identify individuals as white or black but inaccurately identify Hispanic, Asian, or multiracial individuals.

Research has shown that asking patients to identify their own race or ethnicity yields the most reliable data. In addition, patients often give specific responses that provide more detailed information than is captured through broad, standardized categories. When patients identify themselves as being from a certain group, they may also have beliefs, health care use patterns, and perspectives common to that community. For example, knowing that a patient is Polish and not just white, or Cuban and not just Hispanic, can lead to more informed interactions and enable providers to offer more patient–centered care.

Overcoming Barriers to Data Collection

Still, there are obstacles to asking patients to identify their own race, ethnicity, and primary language. Some patients may be concerned about how the information collected will be used. In a survey conducted by the authors among patients in one Chicago hospital, nearly half of respondents said they were somewhat or very concerned that race or ethnicity data might be used to discriminate against patients.

The authors suggest that it is possible to alleviate such concerns by explaining the reasons for collecting race and ethnicity information and clarifying how it will be used. Given a range of explanations, respondents felt most comfortable when told that the information would be used "to monitor care to ensure that all patients get the best care possible."

Interviews with hospital staff revealed that they, too, often feel uncomfortable asking patients about their race or ethnicity, and did not have a consistent strategy for doing so. To overcome these barriers, the authors suggest that health care organizations invest in education and training to help staff implement a systematic method for collecting information from patients. In particular, the researchers suggest staff follow a script that outlines the rationale for collecting the information and describes how the information will and will not be used. Staff should also be given case examples that address patients' potential concerns and methods for recording and coding patient information.

In addition to discomfort on the part of patients and staff, many health care organizations point to the lack of appropriate categories as a barrier to data collection. The current race and ethnicity categories used by the Office of Management and Budget (OMB) are the recommended standard. But these categories are often vague, failing to capture the granular detail needed to provide truly patient-centered care. For instance, people of Middle Eastern or Arab ancestry are often categorized as "white." The authors suggest that health care organizations collect specific, self-reported information to inform their own quality improvement initiatives and then aggregate this information according to the OMB categories for reporting purposes.

Uniform Framework

To help hospitals meet these challenges, the authors offer a uniform framework for collecting race, ethnicity, and primary language data (see sidebar). By using such a framework to gather accurate information about their patient populations, hospitals and other health care organizations can develop appropriate interpreter services, educational materials, and cultural competency training for staff. They can also identify differences in health care and undertake targeted quality improvement efforts.

Proposed Elements of a Uniform Framework

1. A rationale for why the patient is being asked to provide information about race, ethnicity, and language.

2. A script for staff to use so that questions are asked in a uniform fashion.

3. A method for allowing patients to self-identify race, ethnicity, and language using their own words rather than a pre-established set of categories.

4. A standardized approach for "rolling up" granular responses to the Office of Management and Budget categories for analytical and reporting purposes.

5. Assurances that the data will be held confidential and a limited number of people will have access to the data, as well as a mechanism to guarantee this claim.