

Improving Patient Race, Ethnicity and Language Data

Background & Previous Study Findings

Our country's population is very unique and diverse due to the racial and ethnic mix of its communities. New Jersey is one of the most racially and ethnically diverse states in the country, with residents representing more than 100 nationalities. In particular, U.S. Census data shows that from 1990 to 2000 the state's African American population has grown by 10 percent and the Asian population by 77 percent. The Hispanic population increased by 51 percent and foreign-born residents by 52 percent. In addition, about 875,000 of the state's population do not speak English well and 116,000 do not speak English at all. This increasing diversity has significant implications for the healthcare delivery system. Many studies have found healthcare disparities and persistent differences in access, healthcare utilization and health outcomes of different patient groups, mainly the vulnerable minority and underserved populations.

Recognizing the importance of this issue, the New Jersey Hospital Association has focused its efforts on improving measures of healthcare disparities, including collection of data on patient race, ethnicity and primary language. The major source for this patient data has been the UB-92 and currently UB-04 data set from the New Jersey Discharge Data Collection System, collected by hospitals at admission and during hospital stays. The accuracy of this data is critical in identifying racial and ethnic disparities in healthcare. It helps healthcare organizations assess the needs of patient groups and develop targeted programs and services that are culturally and linguistically appropriate and that ensure the quality of healthcare for all patients.

Previous Studies on This Issue

Several studies have identified quality issues with collected data on patient race and ethnicity, mainly due to flaws in the admitting process where the information may be assumed, may not have been asked appropriately or simply may not be solicited from patients. Below is a summary of some of these studies.

- In 1996, NJHA/HRET issued a report on its first study that examined the quality of race and ethnicity data collected as part of the hospital discharge dataset, using 1995 discharges. The study identified significant issues with collecting and coding practices. To address the issues, HRET developed resources and offered educational sessions in 1996 to assist hospitals with their race and ethnicity coding improvement efforts.
- A pilot study in 2003, conducted by the Rutgers Center for State Health Policy, reported barriers to proper collection of data on patient race and ethnicity that were identified by intake staff at healthcare facilities, including health departments, community clinics and hospitals.
- In 2004, HRET issued its second report that examined the reporting of race and ethnicity for all inpatients discharged from New Jersey acute care hospitals from 1995 through 2002, tracked changes in hospital practices over time and compared them with the population mix of the state and geographic areas each hospital serves.

- HRET conducted a series of surveys in 2005 that studied the current data collection practices of New Jersey acute care hospitals and federally qualified health centers and identified perceived barriers and needs.
- Studies have also focused on patient language needs and services in hospitals. American Hospital Association/HRET conducted a national survey in collaboration with the National Health Law Program to better understand the processes and resources available to hospitals in providing language services to patients with limited English proficiency.
- In 2007, the Joint Commission released the findings of a study, *Hospitals, Language, and Culture: A Snapshot of the Nation*. This study was designed to gather information about the activities hospitals nationwide are undertaking to address cultural and language needs among an increasingly diverse patient population.

In summary, the findings from these studies show:

- Wide variations in hospital data collection and reporting practices ;
- Persistent inconsistency in collection and coding practices leading to misclassification and underreporting of utilization of services for certain racial and ethnic categories, mainly Hispanics;
- Frequent reporting of patient race and ethnicity only based on observation of the patient's appearance;
- Staff barriers in collecting these data;
- Patient barriers and concerns in providing these data;
- Ongoing need for identifying patients' communication problems, storing information on their language needs in an electronic format and making it accessible to other departments and for future patient visits.

These identified barriers revealed a need to standardize the data collection processes and recommended a routine channel of communication and consistent training for registrars.

Education Campaign to Improve Data Collection Practices

In 2005, HRET initiated a two-year education program funded by a grant from the Robert Wood Johnson Foundation that aimed at improving the quality of data on patient race, ethnicity and primary language collected at hospitals and reported to the state. The program planned to develop standardized guidelines and processes for collection of this data, as well as a training curriculum and educational tools and resources to train hospital intake staff.

Standardized Categories & Guidelines

To address the identified barriers and needs, HRET worked closely with the New Jersey Department of Health and Senior Services to standardize the race and ethnicity categories and require the use of new categories based on a revised 2000 U.S. Census Bureau listing. In the new listing, some of the old race and ethnicity categories were reordered and redefined and new categories were added to reflect the state's diverse populations and specifically capture the race of multiracial residents. In addition, the Joint Commission released a new standard in 2007, recommending all healthcare organizations collect primary language data from their patients as the first step to identify patient communication needs and provide appropriate language services. Following this requirement, the state of New Jersey decided to add a new field to the registration

system for collection of primary language data as part of the state's conversion to a new National Uniform Billing System – UB04. This change became effective in January 2008. HRET worked with the state to identify appropriate language categories and codes that reflect the state population.

In addition to standardizing the race, ethnicity and primary language categories, HRET also developed a set of guidelines to assist hospitals with uniform collection and reporting of these data based on the Office of Management and Budget 15 (OMB15) recommendations and other federal and national guidelines as well as best practice models.

Training Curriculum

As part of the education component of the project, HRET developed a training curriculum including information on standard protocols for systematic data collection, adjusted race and ethnicity categories and new primary language categories released by DHSS. It also offered steps to follow during the patient interview and recommendations on how to handle complex situations and patient concerns during registration.