Collecting and Analyzing Race and Ethnicity Data in Highly Diverse Communities: Challenges and Strategies for Healthcare Systems

Ranjani K. Paradise, PhD1, Adriana Bearse, MS2, Linda Cundiff, RN, MSN3

1 The Institute for Community Health, Malden, MA; 2 Rescue Social Change Group, San Diego, CA; 3 Cambridge Health Alliance, Somerville, MA

**The Cambridge Health Alliance (CHA)**

**Background**
- Academic community health care system comprising 3 hospitals, 12 primary care clinics, and several other clinics and programs targeted at specific populations
- Robust community health programming led by the Department of Community Health Improvement
- Primarily serves the cities of Cambridge, Somerville, Everett, Malden, and Revere
- **Highly diverse patient population**
  - Many immigrant populations, particularly from Brazil, Haiti, Central America, and South Asia
  - Emerging populations from Nepal and Middle Eastern countries
  - 42% of primary care patients are Limited English Proficient
  - Over 65 languages and over 125 ethnicities represented in the primary care patient population

**ETHNICITY**
- Hispanic or Latino
- Not Hispanic or Latino

**RACE**
- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

**Challenges with national standards**
- Broad categories don’t capture cultural diversity within groups
  - Example: a black patient could be African American, Haitian, Ethiopian, Jamaican → these are very different cultures with different factors that may affect health
- Looking at broad categories alone can mask disparities
  - Example: Overweight/obesity rate for CHA adult primary care patients is 65%
  - Rate for Asian patients: 50%
  - Rate for Pakistani patients: 73%
- Some populations do not identify with any of the standard race categories, leading to a high percentage choosing “Other” race.
  - The resulting data is not useful for identifying disparities or improving services to better meet patients’ needs.

**Data collection**
- CHA collects race and Hispanic/Latino ethnicity according to OMB standards
- CHA also collects detailed ethnicity from all patients
  - The electronic medical record (EMR) has more than 130 options for detailed ethnicity, and this list is periodically updated
- Detailed ethnicity is a required field in the CHA’s EMR (must be populated)
- Patients can choose more than one ethnicity
- All registration staff are trained on how to collect REL data and how to respond to common questions/concerns

**Zero Disparities Committee**
- Working group comprised primarily of members from the CHA Department of Community Health Improvement and the Institute for Community Health
- Works to ensure accurate and comprehensive race, ethnicity, and language (REL) data collection for CHA patients so that CHA can:
  - Understand the populations served and ensure that services are culturally and linguistically appropriate
  - Meet state and federal mandates
- Dedicated to using REL data to identify and promote awareness of health disparities at CHA

**Benefits to this approach**
- More inclusive
- More nuanced information about populations served
- Deeper understanding of health disparities

**Challenges to this approach**
- Detailed data collection requires resources and extensive staff training
- Simple sizes for some ethnicities are very small; some level of rolling up is necessary
- Categorizing patients with multiple ethnicities

**Data analysis**
- The Zero Disparities Committee developed a tiered categorization system that enables drilling down and rolling up of ethnicities.

- This framework is used to identify disparities within and across ethnicity categories for key clinical and quality measures.