



# HIGHLIGHTS

*of the report on  
Health Equity and  
Race and Ethnicity Data*

## *How Race and Ethnicity Data is Collected and Used*

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» Over the past few decades, the United States has become an increasingly multi-cultural country.<sup>1</sup> As the nation's demographics change, many health care organizations are finding that some of their biggest challenges to improving health care services are knowing the patient populations they serve and what they need.<sup>2</sup> Because of this, the collection of race and ethnicity data is considered crucial to providing quality health care for everyone.

The Colorado Trust report, *Health Equity and Race and Ethnicity Data*, examines a number of issues around collecting, analyzing, using and reporting race and ethnicity data to reduce and eliminate health disparities, including:

- The importance of collecting, analyzing, using and reporting these data
- Legal mandates and guidance for collecting and reporting race and ethnicity data
- Best practices health care organizations can adopt.

### **WHY COLLECT RACE AND ETHNICITY DATA?**

The prevalence of racial and ethnic health disparities has received heightened national and state visibility in the past decade. Improved data collection and reporting procedures could help health care organizations increase awareness of health and health care disparities, determine appropriate strategies for reducing disparities and gauge the effectiveness of efforts.<sup>3</sup> Race and ethnicity data can help health care organizations better understand whether racial and ethnic health disparities exist and, if so, if those disparities are increasing or decreasing. In addition, race and ethnicity data results can be used to validate the effectiveness of programs, demonstrate accountability, promote an organization's values and commitment to being inclusive and justify funding. Collecting race and ethnicity data not only is permitted under Title VI of the 1964 Civil Rights Act and the 2010 Patient Protection and Affordable Care Act (ACA), it also is required for recipients of federal funding to ensure compliance with many statutes.

### **CHALLENGES TO COLLECTING AND USING RACE AND ETHNICITY DATA**

Patients may be hesitant to provide race and ethnicity data because of concerns around privacy and discrimination.<sup>2</sup>

They may not understand why health professionals want race and ethnicity data, or they may believe that providing race and ethnicity data will result in discrimination or misuse of the data, such as using it to find undocumented immigrants.<sup>4</sup>

Staff of health care organizations also need a clear understanding of why it is important to collect race and ethnicity data. Without this, staff may feel burdened by the process or be uncomfortable soliciting this information from patients. Some staff may not believe there are disparities in their practice, while others may worry that if disparities are identified, they will be accused of discrimination.<sup>5,6</sup>

### **NATIONAL STANDARDS**

The federal Office of Minority Health has developed national standards on Culturally and Linguistically Appropriate Services (CLAS) to ensure that the practices of health care organizations are culturally and linguistically accessible to all communities. Most of the 14 CLAS standards are required for all recipients of federal funds or recommended for adoption as mandates by federal, state and national accrediting agencies. Six standards apply specifically to the collection, analysis, use and reporting of race and ethnicity data.

The ACA also provides guidance and standards for how health care organizations can collect, analyze, use and report patient demographic data. Section 4302 expands requirements for data collection and analysis by requiring standardization, collection, analysis and reporting of health disparities data.<sup>7</sup>

## BEST PRACTICES FOR SUCCESS

Health care organizations use best practices that range from explaining why race and ethnicity data are needed to using their findings to make changes in how they provide health care services to various populations. Those practices include:

- Increasing patients' comfort levels by asking them to self-identify their race and ethnicity and explaining that the data will be used to monitor quality of care.
- Increasing staff comfort levels by facilitating discussions and training on data collection, its legality and uses, and how to work with patients on data collection.
- Recording demographic data in a standard database linked to clinical data as well as other quality measures to provide a comprehensive picture of any disparities that exist.
- Reviewing and interpreting data results to identify how services can be modified and/or developed to address patient health disparities, assess the impact of culturally tailored and targeted services, and track changes in patient health disparities over time.
- Comparing patients' race and ethnicity data with outcomes data (e.g., health indicators, disease rates) and satisfaction data to better align services with patients' needs and preferences.
- Demonstrating leadership and supporting a culture that is open to self-reflection and growth.

## Organizations Using Data Collection

Two health care organizations taking part in The Colorado Trust's Equality in Health initiative have shared their experiences specific to race and ethnicity data collection:



### Metro Community Provider Network

Founded in 1989, the Metro Community Provider Network (MCPN), a nonprofit organization in the

Denver Metro area, provides medical and health education services to underserved communities through 10 sites and several community-based case management programs. With the goal of serving disparate populations, MCPN began collecting race and ethnicity data from patients receiving diabetes case management services. The diabetes program links patients' race and ethnicity data with their clinical data and assesses the results every six months. Through this analysis, MCPN learned that Hispanics and blacks have a higher prevalence of diabetes than other racial or ethnic groups among their patient population.

To better serve this population, the organization hired bicultural and bilingual staff to provide Spanish health education programs that integrate culturally appropriate recipes into the discussion about diabetes. Additionally, when the data comparison from pre- to post-tests showed that Hispanic patients did not fully understand blood glucose monitoring, MCPN expanded information about that in the Spanish health education programs.<sup>8</sup>



### NORTHSIDE CHILD HEALTH CENTER

The Northside Child Health Center (NCHC) is a school-based health center in Montrose, Colorado. When analysis of its race and ethnicity data revealed that 66

percent of patients seeking primary medical services were Hispanic, NCHC decided to make changes to its organization and services. Included were developing signs and print materials in Spanish, creating a bilingual telephone recording, providing opportunities for staff to learn about various cultural health beliefs among the Hispanic populations and providing more homeopathic treatment options.

The data also showed that the Hispanic community had a significantly lower rate of using mental health services compared to primary care services. NCHC increased its mental health outreach to the community's Hispanic families and sent letters to parents that not only informed them of the clinic's services but also addressed the stigma attached to mental health in Hispanic communities.<sup>9</sup>

## END NOTES

- <sup>1</sup> Brittingham A, De la Cruz GP. *Ancestry: 2000*. Washington, DC: U.S. Census Bureau; 2004.
- <sup>2</sup> U.S. Department of Health and Human Services Agency for Healthcare Research and Quality. *Race, Ethnicity, and Language Data: Standardization for Health Care Equality Improvement*. <http://www.ahrq.gov/research/iomracereport/reldata1.htm>. Accessed December 18, 2012.
- <sup>3</sup> U.S. Department of Health and Human Services. *Improving Data Collection to Reduce Health Disparities*. <http://www.healthcare.gov/news/factsheets/2011/06/disparities06292011a.html>. Accessed December 18, 2012.
- <sup>4</sup> Kandula N, Hasnain-Wynia R, Thompson J, Brown E, Baker D. Association between prior experiences of discrimination and patients' attitudes towards health care providers collecting information about race and ethnicity. *J Gen Intern Med*. 2009;24(7):789-94.
- <sup>5</sup> Hasnain-Wynia, R, Pierce D, Pittman M. *Who, When and How: The Current State of Race, Ethnicity and Primary Language Data Collection in Hospitals*. New York, NY: The Commonwealth Fund; 2004.
- <sup>6</sup> Weinick R, Flaherty K, Bristol S. *Creating Equity Reports: A Guide for Hospitals*. The Disparities Solution Center at Massachusetts General Hospital. Boston, MA; 2008.
- <sup>7</sup> U.S. Department of Health and Human Services. *Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*. <http://aspe.hhs.gov/datacncl/standards/ACA/4302/index.pdf>. Accessed December 27, 2012.
- <sup>8</sup> Metro Community Provider Network. <http://www.mcpn.org/en/index.html>. Accessed January 6, 2013.
- <sup>9</sup> The Colorado Trust. Northside Child Health Center in Montrose receives The Colorado Trust's Annual Leadership Award. <http://www.coloradotrust.org/news/news-releases/show-news-release?id=192>. Accessed January 6, 2013.