



# Reducing Health Care Disparities: Collection and Use of Race, Ethnicity and Language Data

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## Equity of Care



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## Background

In 2011, the American College of Healthcare Executives, American Hospital Association, Association of American Medical Colleges, Catholic Health Association of the United States and America's Essential Hospitals stood together in a call to action to eliminate health care disparities. As national partners, these groups are working together to improve quality of care for every patient by disseminating best practices and resources for equitable care.

The Institute for Diversity in Health Management, an affiliate of the AHA, conducted a national survey in 2011 and found that only 18 percent of hospitals were collecting race, ethnicity and language preference (REAL) data at the first patient encounter and using it to assess gaps in care. As a result, the first goal set forth by the national partners is to increase the collection and use of REAL data to drive the elimination of disparities in care. This guide provides a road map to achieve this goal.

Two additional goals set forth by the national partners are to increase cultural competency training and increase diversity in health care governance and leadership. All three goals and designated milestones are outlined on the Equity of Care website at [www.equityofcare.org](http://www.equityofcare.org).

This guide is part of a continuing series that will support hospitals and care systems working to reduce health care disparities and promote equitable care. The partners in the national call to action intend for this series and other resources to markedly increase the percentage of hospitals committed to improving equity of health care in the coming years.

## Introduction

Racial and ethnic minorities are projected to account for a majority of the U.S. population by 2043, and the future market for health care services will inevitably reflect this change.<sup>1</sup> In addition, this next generation of health care consumers will be increasingly empowered to differentiate providers based on publicly available quality and satisfaction measures. As such, hospitals and care systems that can accommodate the unique needs of diverse populations will be well positioned for future success. One way to achieve this goal is to collect and use race, ethnicity and language (REAL) data in a meaningful way to understand and address health care disparities among various racial and ethnic groups.

REAL data also can drive success under new payment models that require hospitals and care systems to manage costs while improving the health of their patient populations. For example, both Massachusetts and Maryland have explored distributing incentive payments to hospitals and care systems based on performance metrics stratified by race and ethnicity.<sup>2,3</sup> Recent analysis suggests that 30 percent of direct medical costs for African-Americans, Hispanics and Asian-Americans are excess costs due to health inequities.<sup>4</sup> Using REAL data, hospitals and care systems can identify high-cost drivers, develop interventions to improve care for vulnerable populations and, as a result, appropriately deploy resources.

Given changing demographics, an empowered patient population and new reimbursement models, now is the time to develop thoughtful processes around the collection and use of REAL data. While studies show that most health care providers are collecting some REAL data, significant variation exists in how the data is collected.<sup>5</sup> Furthermore, as few as 14 percent to 25 percent of hospitals and care systems are actually using REAL data to assess variation in quality and health outcomes.<sup>6,7</sup>

This guide includes two sections, which will address both collection and use of REAL data. The first section provides a four-step approach on how to obtain an accurate and usable REAL data set. The second section discusses how hospitals and care systems can use REAL data to achieve clinical, operational, financial and population health benefits.

## Section I: Optimizing REAL Data Collection

Before hospitals and care systems begin using REAL data, they first should obtain a strong data set with which to work. Hospitals and care systems can adopt the four-step approach in Figure 1 to achieve a successful data collection effort.

Figure 1: Four-Step Approach to Ensure Successful REAL Data Collection



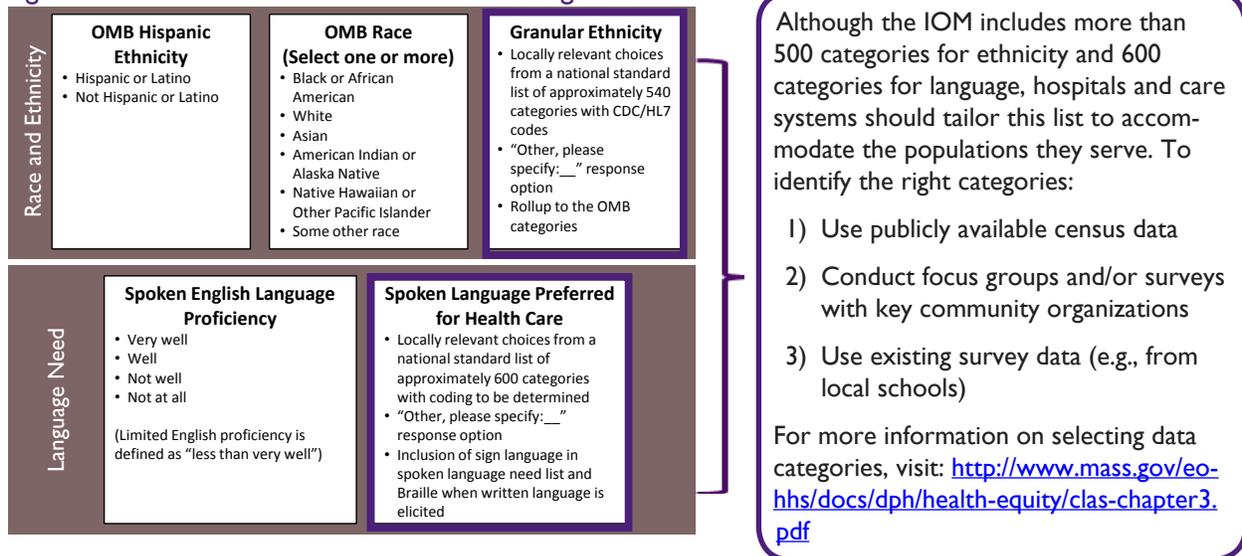
Source: American Hospital Association, 2013.

Step one is to develop a locally relevant and culturally appropriate set of REAL data categories that are standardized across the organization. Steps two through four consist of adopting an organizational process to ensure data integrity, accuracy and comprehensiveness.

### Step 1 Determine the appropriate data categories

To obtain a good data set, hospitals and care systems should first define the data categories that are appropriate for their patient populations. The U.S. Office of Management and Budget (OMB) originally defined standardized REAL data categories, and the Institute of Medicine (IOM) developed a 2009 report citing the need for more granular ethnicity categories. The IOM's recommendations are outlined in Figure 2.

Figure 2: IOM-Recommended REAL Data Categories



Sources: Institute of Medicine, 2009, "Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement"; American Hospital Association, 2013.

## Step 2 Develop a methodology for data collection

Next, hospitals and care systems will need to develop a methodology for collecting REAL data. Figure 3 outlines some questions to consider when designing this methodology.

Figure 3: Developing a Methodology for REAL Data Collection

Design Question	Options	Considerations / Suggested Method
<b>Who</b> should collect the data?	<ul style="list-style-type: none"> <li>Registration staff</li> <li>Medical assistant</li> <li>Registered nurse</li> </ul>	<ul style="list-style-type: none"> <li>Using registration staff has been proven to increase collection rates, although one study found patients preferred being asked in the exam room by nursing staff.<sup>8</sup> Providers should assess staffing levels and determine who is best suited to collect the data.</li> <li><b>Suggested: Registration staff</b></li> </ul>
<b>When</b> should the data be collected?	<ul style="list-style-type: none"> <li>At time of check-in</li> <li>Over the phone</li> <li>Pre-exam</li> </ul>	<ul style="list-style-type: none"> <li>Collecting preferred language data over the phone when a patient is scheduling an appointment can help in planning for interpretation services.</li> <li><b>Suggested: At check-in or over the phone</b></li> </ul>
<b>What format</b> should be used to collect the data?	<ul style="list-style-type: none"> <li>Paper format</li> <li>Electronic kiosks / tablets</li> <li>Verbal discussion</li> </ul>	<ul style="list-style-type: none"> <li>Paper forms, kiosks and tablets allow for patient privacy, although one study has shown that collection rates are highest when patients have the option to also report REAL data verbally.<sup>9</sup></li> <li>Paper forms, kiosks and tablets may pose a challenge for patients with limited literacy.</li> <li>Kiosks or tablets will eliminate the need for staff to transcribe data into the electronic medical record.</li> <li><b>Suggested: Provide options for a more private form of entry (paper form, kiosk or tablet) as well as verbal discussion</b></li> </ul>

Source: American Hospital Association, 2013.

Patient self-reporting of REAL data is the gold standard of data collection. Staff should never attempt to guess a patient's race, ethnicity or preferred language. While the suggested methods in Figure 3 have proved successful in the past, ultimately hospitals and care systems should choose the best path forward given the populations they serve. As an example, one hospital found that paper forms were often left incomplete in the waiting room, because of the low literacy rate and limited English proficiency of its patient population.<sup>10</sup>

## Step 3 Train staff members on methodology for data collection

Once a methodology for data collection is defined, hospitals and care systems should provide training to appropriate staff members. Training on standardized processes can increase compliance, ensure data integrity and improve patient buy-in. The Health Research & Educational Trust (HRET) developed a toolkit that provides REAL data collection training materials for hospitals and care systems and can be accessed free at <http://www.hretdisparities.org/>.

## Step

4

### Assign accountability and monitor progress of data collection efforts

Hospital leadership should assign accountability and monitor data collection efforts to ensure processes are working as planned. For example, registration staff can be held accountable for achieving certain metrics against a baseline, such as a decrease in the number of patients reported as “unknown” for race or ethnicity. Leveraging existing processes can save time and resources. One hospital used an existing post-discharge survey to determine whether or not REAL data was collected at registration.<sup>11</sup> No new costs were associated with this process, and the data helped to increase compliance with collection protocols.

Proper data collection will not be a quick process: it took one hospital several years to reduce the number of patients reported as “unknown” race to less than 1 percent. However, this four-step process gives hospitals and care systems a starting point to obtaining a strong REAL data set.

## Section 2: Making Good Use of REAL Data

After obtaining a robust REAL data set, hospitals and care systems will need to make several decisions, including which measures to look at, what to use as a reference point, whether any risk adjustments are needed and what sample size is appropriate. The Disparities Solution Center at Massachusetts General Hospital provides a toolkit with recommendations on how best to conduct REAL data analyses. The toolkit can be found at [http://www2.massgeneral.org/disparitiessolutions/z\\_files/Disparities%20Commissioned%20Paper.pdf](http://www2.massgeneral.org/disparitiessolutions/z_files/Disparities%20Commissioned%20Paper.pdf). After completing analyses, hospitals and care systems then can use the results in meaningful ways, as outlined in Figure 4.

Figure 4: Using REAL Data Effectively

How to Use REAL Data	Details
<b>Identify the measures where the greatest disparities exist and prioritize which initiatives to pursue.</b>	Given resource constraints, hospitals and care systems can use REAL data to prioritize their agenda for reducing disparities. For example, AnMed Health in Anderson, S.C., created a “Disparities Dashboard” and stratified patient satisfaction and inpatient quality indicators by race and ethnicity to identify disparities. The health system found that while some scores were fairly consistent across race categories, the 30-day readmission rate for acute myocardial infarction was significantly higher among African-Americans compared to other patients. In order to identify the root cause, the hospital dedicated a nurse to interview patients flagged to be at-risk for AMI readmissions. <sup>12</sup>
<b>Understand the demographic makeup of the patient population at a more granular level and develop tailored care plans.</b>	Using REAL data, clinicians can begin addressing disparities during patient visits. For example, studies have shown that breastfeeding rates vary significantly among different Asian ethnicities (91% among Indian women versus 35% among Cambodian women). <sup>13</sup> Using granular ethnicity data, obstetricians can include additional patient education for certain populations. As another example, clinicians at Hennepin County Medical Center in Minnesota will consider ordering vitamin D blood screens for Somali women, who are prone to vitamin D deficiencies. <sup>14, 15</sup>

<b>Develop patient-centered, community-based interventions to reduce disparities.</b>	REAL data can support the development of programs that influence behavior outside the exam room as well. Massachusetts General Hospital in Boston pursued a patient navigator program after finding a significant gap in colorectal cancer (CRC) screening rates between Latino and white populations. The hospital first interviewed a subset of Latino patients to understand common barriers to CRC screening, then trained patient navigators to provide patients with educational materials, emotional support and referral and scheduling services. <sup>16</sup>
<b>Drive board-level decision making on where to invest and deploy resources.</b>	Hospitals and care systems also can use REAL data for operational and strategic decision making. One study found that among providers using REAL data, 40% used it to “inform decisions about resource allocation (e.g., deciding where to build new clinics) and one-third used the data to look at trends in patient demographics for marketing and strategic planning.” <sup>17</sup> For example, Vidant Health, based in North Carolina, identified 45 different languages used by its patients. As a result, the health system created a patient-centered communications task force to improve language interpretation services among its 10 hospitals and 40 physician practices. <sup>18</sup>

For designing interventions, it is important to receive feedback from community members to drive program success. Hospitals and care systems can use focus groups, community surveys, advisory boards or other mechanisms to ensure interventions are patient-centered and effective.

Using REAL data can result in a number of benefits to hospitals and care systems, some of which are outlined in Figure 5.

Figure 5: Benefits of Using REAL Data

<b>Benefit</b>	<b>Example</b>
<b>Reduce costs</b>	After discovering high readmission rates among its African-American population, Methodist Le Bonheur Healthcare, based in Memphis, Tenn., implemented a program to help these patients transition from hospital to home. As a result, total health care costs for participants were roughly \$8,700 lower, on average, than for nonparticipants, and readmissions for patients with heart failure fell from 35% to 20%. <sup>19</sup>
<b>Reduce disparities in health outcomes</b>	Massachusetts General Hospital in Boston provided culturally tailored individual and group coaching sessions to Latino patients struggling with diabetes self-management. As a result, the gap in the percentage of Latinos compared with whites with uncontrolled diabetes decreased from 13% to 9%. <sup>20</sup>
<b>Reduce hospital readmissions</b>	AnMed Health, based in Anderson, S.C., used an EMR alert and patient navigator program to reduce disparities in readmission rates. The intervention reduced the 30-day AMI readmission rate among African-Americans by 20%, and the gap in readmission rates between African-Americans and other racial subgroups decreased by 16% within one year. <sup>21</sup>
<b>Receive incentive payments</b>	Hospitals and care systems may begin to receive incentive payments for reducing health care disparities. Massachusetts already has a Medicaid pay-for-performance program that provides hospital rate increases “contingent upon quality measures, including the reduction of racial and ethnic disparities in health care.” The program asks hospitals and care systems to report on a Clinical Disparities Composite Measure to determine eligibility for payment. <sup>22, 23</sup>
<b>Meet PCMH certification requirements</b>	Hospitals and care systems can meet Standard 6 of NCQA certification for patient-centered medical homes if data collected “is stratified by race and ethnicity,” and “the practice identifies areas of disparity among vulnerable populations, sets goals and acts to improve performance in these areas.” <sup>24, 25</sup>

## Conclusion

While the ultimate goal of collecting REAL data is to reduce health care disparities, the immediate focus for hospitals and care systems should be ensuring data is standardized and collected appropriately. By adopting a four-step approach—defining the right data categories, developing a methodology for collection, training staff, and assigning accountability / monitoring progress—hospitals and care systems will have a strong REAL data set for analysis. With this data, hospitals and care systems can stratify outcomes measures to understand where disparities exist, prioritize where to focus time and resources and develop patient-centered interventions. Effective collection and use of REAL data will position hospitals and care systems for success in an environment where regulators, payers, employers and, most importantly, patients are looking for more differentiated and individualized health care.

### Case Study: The Institute for Family Health, New York

The Institute for Family Health operates 17 sites that provide primary health care services to more than 90,000 patients in New York City and the Hudson Valley. In 2006, IFH attempted to assess quality measures stratified by race and ethnicity, only to discover deficiencies in the data sets. As a result, IFH became one of the first institutions to adopt the Institute of Medicine's 2009 recommendations for REAL data collection, with four goals in mind: 1) maximize data collection rates, 2) obtain self-reported data from patients, 3) obtain granular data and 4) create new tools for identifying and addressing health care disparities. IFH embarked on a five-stage process to achieve these goals, which consisted of designing the data collection process, updating the EMR, training staff members, monitoring their progress and using the data meaningfully. During the monitoring stage, IFH saw statistically significant improvements in the proportion of patients with race and granular ethnicity recorded across several sites—an increase of 13 percent in race fields completed and 24 percent in ethnicity fields completed. IFH also was able to use the REAL data sets to identify a need for hepatitis B screening among foreign-born patients from endemic geographies. Using an EMR alert, providers now know when to administer the screening.

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### Case Study: Wheaton Franciscan Healthcare, Wisconsin

Wheaton Franciscan Healthcare is a nonprofit, integrated health system serving nearly one quarter of southeast Wisconsin. WFHC recognizes the importance of attaining a strong REAL data set for analysis to reduce health care disparities. The health system not only trains staff on proper data collection techniques but also monitors progress by reviewing collection metrics on a quarterly basis. With support from the health system's executive strategy diversity team and the organization's CEO, WFHC uses REAL data to identify and reduce disparities in health outcomes. Recent analysis revealed a need to improve diabetes management for the hospital's African-American population. To develop a patient-centered intervention, the health system first conducted a series of focus groups to identify common barriers to diabetes self-management among African-Americans. The discussions revealed that traditional, structured diabetes education programs were overwhelming for patients, especially newly diagnosed diabetics. Given the findings, WFHC created an intervention program that uses a community health worker to provide diabetes education and support for participants. The CHW, who is a community member that patients can easily relate to, spends the majority of time engaging patients in both clinical and nonclinical settings. In addition, participants have the opportunity to attend peer support groups at the end of each educational session. The program started in March 2013, and WFHC is currently tracking patient progress on diabetes knowledge, A1C levels, body mass index, weight and blood pressure.

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## Resources

American Hospital Association (Producer). (2012). *Keeping it REal: An analysis of health care quality among priority patient populations* [Webinar]. Retrieved from <http://www.hpoe.org/resources/hpoe-live-webinars/684>

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health research and educational trust disparities toolkit*. Available from <http://www.hretdisparities.org/>

Massachusetts Department of Health and Human Services (2009). *Making CLAS happen, chapter 3: Collecting diversity data*. Retrieved from <http://www.mass.gov/eohhs/docs/dph/health-equity/clas-chapter3.pdf>

Ulmer C., McFadden B., Nerenz D.R. (2009). *Race, ethnicity, and language data: Standardization for health care quality improvement*. Retrieved from [http://books.nap.edu/openbook.php?record\\_id=12696](http://books.nap.edu/openbook.php?record_id=12696)

Weissman, J.S. et al. (2011, October 4). *Commissioned paper: Healthcare disparities measurement*. Retrieved from [http://www2.massgeneral.org/disparitiessolutions/z\\_files/Disparities%20Commissioned%20Paper.pdf](http://www2.massgeneral.org/disparitiessolutions/z_files/Disparities%20Commissioned%20Paper.pdf)

## Endnotes

- 1 U.S. Census Bureau. (2012, December 12). *U.S. Census Bureau projections show a slower growing, older, more diverse nation a half century from now*. Suitland, MD: Author. Retrieved July 9, 2013, from <http://www.census.gov/newsroom/releases/archives/population/cb12-243.html>
- 2 Weinick, R., et al. (2007, July). *Pay-for-performance to reduce racial and ethnic disparities in health care in the Massachusetts Medicaid program*. Roundtable conducted at the meeting of the Massachusetts Medicaid Policy Institute and Metrowest Community Health Care Foundation, Boston, MA.
- 3 State of Maryland, Maryland Health Quality and Cost Council. (2012, January). *Health disparities workgroup final report and recommendations*. Retrieved from <http://www.governor.maryland.gov/ltgovernor/documents/disparitiesreport120117.pdf>
- 4 The Kaiser Family Foundation. (2012, December). *Disparities in health and health care: Five key questions and answers* (Issue Brief No. 8396). Washington, DC: Author.
- 5 Bhalla, R., Youngue, B.G., Currie, B.P., (2012). Standardizing race, ethnicity, and preferred language data collection in hospital information systems: Results and implications for healthcare delivery and policy. *Journal for Healthcare Quality*, 34(2), 44-52. doi: 10.1111/j.1945-1474.2011.00180.x
- 6 Ibid.
- 7 Robert Wood Johnson Foundation. (2010, August). *Aligning forces to reduce racial and ethnic disparities*. Princeton, NJ: Author.
- 8 Wilson, G., Hasnain-Wynia, R., Hauser, D., Calman, N., (2013). Implementing Institute of Medicine recommendations on collection of patient race, ethnicity, and language data in a community health center. *Journal of Health Care for the Poor and Underserved*, 24(2), 875-884. doi: 10.1353/hpu.2013.0071
- 9 Ibid.
- 10 Ibid.
- 11 Robert Wood Johnson Foundation. (2010, September). *Ensuring REL data collection with the use of a post-discharge survey tool*. Princeton, NJ: Author.

- 12 American Hospital Association (Producer). (2012). *Keeping it REal: An analysis of health care quality among priority patient populations* [Webinar]. Retrieved from <http://www.hpoe.org/resources/hpoe-live-webinars/684>
- 13 Wilson, G. (2010, September). *Identifying and addressing health disparities* [PowerPoint slides]. Retrieved from <http://www.institute2000.org/2010/09/30/identifying-and-addressing-health-disparities/>
- 14 Grady, D. (2009, March 28). Foreign ways and war scars test hospital. *The New York Times*. Retrieved from <http://www.nytimes.com/2009/03/29/health/29immig.html?pagewanted=all>
- 15 C. Hill (personal communication, August 2013).
- 16 Green, A.R. (2008, September). Quality improvement for disparities reduction: The Chelsea community health center experience, the Disparities Solutions Center at Massachusetts General Hospital. *Sixth National Conference on Quality Health Care for Culturally Diverse Populations*. Conference conducted at the meeting of DiversityRx, Minneapolis, MN.
- 17 Robert Wood Johnson Foundation. (2010, August). *Aligning forces to reduce racial and ethnic disparities*. Princeton, NJ: Author.
- 18 S. Collier (personal communication, February, 2012)
- 19 U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality. (2012, March 14). *Church-health system partnership facilitates transitions from hospital to home for urban, low-income African Americans, reducing mortality, utilization, and costs*. Retrieved from <http://www.innovations.ahrq.gov/content.aspx?id=3354>
- 20 Green, A.R. (2008, September). Quality improvement for disparities reduction: The Chelsea community health center experience, the Disparities Solutions Center at Massachusetts General Hospital. *Sixth National Conference on Quality Health Care for Culturally Diverse Populations*. Conference conducted at the meeting of DiversityRx, Minneapolis, MN.
- 21 J. Slade (personal communication, July 1, 2013)
- 22 Weinick, R., et al. (2007, July). *Pay-for-performance to reduce racial and ethnic disparities in health care in the Massachusetts Medicaid program*. Roundtable conducted at the meeting of the Massachusetts Medicaid Policy Institute and Metrowest Community Health Care Foundation, Boston, MA.
- 23 Commonwealth of Massachusetts, Executive Office of Health Human Services, (2012, August 22). *Technical specifications manual for MassHealth acute hospital quality measures (version 6.0)*. Retrieved from <http://www.mass.gov/eohhs/docs/masshealth/acutehosp/ry2013-eohhs-technical-specifications-manual-masshealth-acute-hospital-measures-6-0.pdf>
- 24 National Committee for Quality Assurance. (2011). *NCQA standards workshop patient-centered medical home PCMH 2011*. Washington, DC: Author. Retrieved from [http://www.ncqa.org/Portals/0/Programs/Recognition/RPtraining/PCMH%202011%20standards%204-6%20%20workshop\(v2\).pdf](http://www.ncqa.org/Portals/0/Programs/Recognition/RPtraining/PCMH%202011%20standards%204-6%20%20workshop(v2).pdf)
- 25 Sloane, L.R. (2013, April). *Race, ethnicity, and language data (REL) collection standardization*. Paper presented at the Greater Cincinnati Health Council Meaningful Use Conference, Cincinnati, OH. Retrieved from <http://www.healthbridge.org/Portals/0/2013%20MU%20Conference/Improving%20Quality%20by%20Identifying%20and%20Resolving%20Disparities3.pdf>