

LESSONS IN THE ACQUISITION OF RACE, ETHNICITY, AND LANGUAGE DATA BY HEALTH PLANS

Introduction

The quality of health care in America varies significantly depending on a number of factors, including the racial and ethnic backgrounds of patients. In the past decade, hundreds of research studies have confirmed that patients from specific racial and ethnic backgrounds experience lower quality care than other groups. According to the Agency for Healthcare Research and Quality, which tracks the quality of health care for minority groups through an annual research report, patients identified as African-American or Hispanic/Latino fared worse on getting effective care for a number of conditions, including cancer, diabetes, and heart disease.¹

A necessary first step to increasing health care quality for all Americans is to assess disparities in treatment and outcomes for the most vulnerable patients, including the poor, disabled, children, elderly, and racial/ethnic minorities. Since 2001, The Institute of Medicine has attempted to address racial/ethnic health care disparities by urging health care organizations to collect, report, and monitor critical patient-care data. Information about patients' race, ethnicity, and primary language (r/e/l) could help to document gaps in care for specific patients, develop targeted interventions, and improve care for all.

Hospitals have taken the lead in collecting r/e/l data. According to two hospital surveys conducted by the Commonwealth Fund and the American Hospital Association, almost 80 percent of hospitals are collecting race/ethnicity data and 60 percent are collecting language data. In fact, 22 states have requirements for hospitals to collect race/ethnicity data.²

Unlike state requirements for hospitals, only two states, California and Massachusetts, have required the collection and/or reporting of race/ethnicity and/or language data by health plans. Further, although 61

Reducing Disparities through High-Value Health Care

The High-Value Health Care Project is working to make valid, timely, and consistent information about the quality and cost of health care widely available in the United States. One part of this effort, the Racial/Ethnic Health Care Equity Initiative, focuses on promoting equity in health care quality. The initiative engages stakeholders from across the public and private sectors in developing standards and models for collecting and reporting r/e/l data and ensuring that performance measures are stratified accordingly. The High-Value Health Care Project is supported by the Robert Wood Johnson Foundation and directed by the Engelberg Center for Health Care Reform at Brookings.

percent of commercial health plans report voluntarily collecting this information, few have produced response rates robust enough to measure and address disparities.³ For example, among commercial health plans, Aetna has led the way with data collection efforts since 2002, but has been able to acquire race/ethnicity data on only approximately 30 percent of actively enrolled members.⁴ Limited data collection methods, cost prohibitive storage and maintenance processes, and membership turnover continue to challenge health plans in effectively acquiring and utilizing r/e/l information.

Massachusetts: Addressing the Need

In July 2008, the Massachusetts Health Care Quality and Cost Council (QCC) established a requirement for health plans to report r/e/l data as part of their uniform reporting system for health care claims data sets.⁵ The Engelberg Center for Health Care Reform at Brookings provided technical support for the development of consistent data collection and reporting protocols for

all health plans in Massachusetts. The effort, conducted through the High-Value Health Care Project, included interviews with health plan employees to identify the current procedures and strategies for collecting and reporting r/e/l data, as well as to highlight the challenges they faced. In addition, consumer focus groups were held to assess perceptions and concerns about r/e/l data collection by health plans, as well as preferences for racial and ethnic categories. The findings were used to develop a training program for health plan representatives across the state to aid in addressing the challenges associated with acquiring r/e/l data.

This brief identifies significant challenges faced by the QCC in collecting r/e/l data from health plans, but also presents strategies that could be used to advance r/e/l data collection by health plans across the country.

Challenges and Potential Strategies for Reporting Race, Ethnicity, and Language Data

Interviews with Massachusetts health plans helped identify the various challenges faced by the plans in acquiring data, which resulted in the development of specific strategies for improving self-reported acquisition of r/e/l health plan member data.

I. Restrictive, Inconsistent, and Costly IT Systems

Challenges: Restrictive, inconsistent, and costly IT systems present significant challenges for health plans to store, maintain, and effectively use r/e/l information. Updating IT systems, reconciling data capture from multiple sources, and reducing costs to make IT modifications are necessary to enable plans to effectively acquire and utilize r/e/l data.

Many health plans capture member data using legacy systems lacking the functionality to collect r/e/l data.

- Older systems are often no longer supported by vendors, which makes it challenging for health plans to receive assistance with any necessary changes.
- Adding r/e/l fields to legacy systems may be cost prohibitive.

Health plans typically store data using multiple databases.

- Multiple sources may prevent health plans from linking or merging data. Without data integration capabilities, it is difficult for health plans to use r/e/l data for quality improvement purposes.

Costs pose a significant challenge to plans attempting to make changes to their IT systems.

- Massachusetts plans determined that a range of \$1-11 million would be necessary to change IT systems to accommodate state requirements for r/e/l data reporting.

Strategies and Solutions: If a health plan currently has one race field in its data system, and is unable to add another field to capture more specific ethnicities, the health plan can “repurpose” the existing race field by changing the categories (i.e., adding as many ethnicity categories as needed) in that field to enable the collection of r/e/l data. This approach can also reduce the costs associated with modifying IT systems.

- Many health plans are currently using, or are in the process of developing, data warehouses that will allow data from multiple sources to be stored in one central location. This allows plans to address the drawbacks of legacy systems.
- Integration and analysis of data from multiple sources enables the use of r/e/l data for a more complete picture of quality.

II. Multiple Methods of Data Collection

Challenges: While hospitals have face-to-face contact with each patient during administration, facilitating the collection of race/ethnicity information, health plans have few direct interfaces with health plan members, limiting their abilities to acquire race/ethnicity information. Thus, health plans employ a variety of methods to acquire such information, including: enrollment forms; incoming and outgoing customer service calls; disease/care/case management; health risk appraisals and health needs assessments; member surveys; providers or hospitals; Web portals; and interactive voice response.

- Plans may have r/e/l data on a single member from three or four different sources that use different r/e/l categories than those used by the health plan.
- No standards or incentives currently exist for third parties to share collected data with health plans.

Strategies and Solutions: Mapping sets may represent one unique solution for reconciling r/e/l data collected through multiple methods. These are coding schemes by which ethnicity categories collected at the local level can be “rolled-up” in a standard way to comply with broader requirements for reporting.

- Health plans can reconcile data collected from multiple sources, which are contained in different code sets, by creating a hierarchical map that includes all of the possible r/e/l categories from sources using the various code sets.
- This creates a mapping scheme that allows the health plan to map granular ethnicity categories in a standard way. Thus, organizations may incorporate coding sets used by the federal government and others into their own coding scheme.

III. Consumer Skepticism

Challenges: National research suggests that consumers may be significantly less trusting of their health plans than they are of their health care providers.⁶ Recent assessments of consumer perspectives in Massachusetts suggest weakened consumer trust in health plans’ collection and use of r/e/l data.⁷ These assessments also suggest that:

- Consumers worry whether health plans will be forthcoming in how information will and will not be used.
- Lack of trust affects consumers’ willingness to respond to r/e/l questions from plans.

Strategies and Solutions: Broader consumer education on the importance of r/e/l data is imperative for increasing response rates. Message testing revealed important information about consumers, as well as ways to reduce skepticism and improve anticipation about data collection.

- Consumers want to know that the information they share with plans will be used to increase quality of care.
- Consumers want to know that this information will not be used to set premiums or determine benefit packages.
- Consumers want to be presented with easy-to-read categories that reflect their race and ethnicity backgrounds.

IV. Membership Turnover/Portability

Challenges: Increasing the number of members from whom health plans have collected r/e/l data has proven to be extremely difficult due in part to high membership turnover rates. While plans may be able to collect r/e/l data on a member now, the same member may belong to another health plan in two years.

- Since 2002, for example, Aetna has collected r/e/l data for over 60 million members; however, in 2008, Aetna had data for only 5 million actively enrolled members.⁸
- Turnover greatly reduces health plans’ ability to use data to track long-term quality improvement.

Strategies and Solutions: Encouraging the use of data exchange and transfer protocols between third party sources and health plans and developing model contract language for use by all insurers may increase the amount of data health plans have and could use in reducing disparities.

- Since hospitals and providers collect and exchange r/e/l data using multiple file layouts and formats, developing a common standard would facilitate data exchange.
- Exchange and transfer protocols will assist health plans in obtaining data on members that switch health plans and reduce the effects of turnover on plans’ ability to collect r/e/l data.
- Model contracts should discuss data access and protection policies.

V. Overarching Strategies and Solutions to Address Challenges in Race/Ethnicity Data Collection

To help overcome challenges associated with direct data collection, indirect methods to estimate race and ethnicity have proved promising as an interim strategy. Newer methodologies, combining surname analyses, and geocoding have proved sufficiently accurate in allowing plans that lack r/e/l data to quickly assess and begin acting on disparities, even at the local community- and provider group-levels.

The National Impact of Better Race, Ethnicity, and Language Data

The challenges of acquiring r/e/l data identified by health plans in Massachusetts illustrate the many obstacles facing health plans who wish to collect consistent, reliable r/e/l data in other states and regions. The development of standardized r/e/l categories that take into account regional variation in ethnic groups will ease much of the burden in acquiring and storing such data.

Standard processes and protocols to facilitate data transfer from employers and providers to plans will increase the availability of r/e/l data and minimize the problems associated with membership turnover. IT software with standard, multiple r/e/l fields will simplify health plans' abilities to collect and report these data.

Consistent r/e/l data is critical in efforts to identify disparities and design interventions that can appropriately and consistently increase health care quality for all Americans.

Gaining Attention at the National Level

For health plans across the United States, the lack of standard categories presents a challenge to consistent, useful data.

- Some health plans currently have no dedicated fields for r/e/l data.
- Those that do utilize a varying number of categories to capture r/e/l data.
- IT systems often lack the capacity for adding fields or categories.
- Doing so would also require changes to downstream and upstream systems, creating a significant constraint on health plans' time and resources.

Strategies and Solutions: On August 31, 2009, the Institute of Medicine (IOM) released guidance on standard race/ethnicity categories for use in federal programs and other health care organizations wishing to assess and report on quality of care across varying race/ethnicity groups. These recommendations have been developed through input from a variety of stakeholders, including HVHC project staff. The adoption of these standards will reduce the burden on national health plans as more states adopt similar requirements to acquire and report r/e/l data.

1. Agency for Healthcare Research and Quality. 2008 National Healthcare Disparities Report (March 2009): AHRQ Pub. No. 09-0002.
2. Hasnain-Wynia R, Pierce D, and Pittman MA. "Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals," The Commonwealth Fund (2004).
3. "Collection and Use of Race and Ethnicity Data for Quality Improvement," AHIP-RWJF Survey of Health Insurance Plans (2006).
4. Hassett P. "Taking on Racial and Ethnic Disparities in Health Care: The Experience at Aetna," Health Affairs (2005): Millwood 24(2):417-20.
5. For more information on the Massachusetts Health Care Quality and Cost Council's Uniform Reporting System, see: http://www.mass.gov/lhccc/docs/regs/129_2_Adopted_2009_07_17.pdf
6. Hasnain-Wynia, R, Baker, DW. "Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations Current Challenges and Proposed Solutions." Special Section on Race and Ethnicity, Health Services Research (August 2006).
7. Hasnain-Wynia R, Taylor-Clark K and Anise A. "Perceptions of Race/Ethnicity Data Collection of Health Plan Members in Massachusetts" (2009).
8. Toolkit to Reduce Racial/Ethnic Disparities in Health Care, National Health Plan Collaborative, (2008).

Other Resources

Several resources exist within the race, ethnicity, and language data arena that detail challenges and best practices in collecting such information. While some of these resources do not specifically relate to health plans, they offer useful context and provide a clear picture of efforts to reduce disparities and ultimately promote health care equity.

Expecting Success Toolkit

This toolkit features summaries of innovations that work to collect race, ethnicity, and language data, raise awareness and improve quality; and downloadable tools hospitals can use. It was produced as part of a RWJF-funded hospital learning collaborative to improve quality and reduce disparities.

<http://www.rwjf.org/pr/product.jsp?id=28433>

Health Research and Educational Trust Disparities Toolkit

A web-based tool that provides hospitals, health systems, clinics, and health plans information and resources for systematically collecting race, ethnicity, and primary language data from patients.

<http://www.hretdisparities.org/>

IOM Report - Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement

Report from the IOM subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement.

<http://www.iom.edu/en/Reports/2009/RaceEthnicityData.aspx>.

National Quality Forum - National Voluntary Consensus Standards for Ambulatory Care: Measuring Healthcare Disparities

The report contains 36 disparities-sensitive consensus standards that address all levels of measurement, including practitioner practices, large and small groups, and health plans.

http://www.qualityforum.org/Publications/2008/03/National_Voluntary_Consensus_Standards_for_Ambulatory_Care—Measuring_Healthcare_Disparities.aspx

The National Health Plan Collaborative Toolkit

Toolkit of resources, lessons, best practices, and case studies to help health plans join the effort to reduce disparities.

<http://www.rwjf.org/pr/product.jsp?id=33960>

Creating Equity Reports: A Guide for Hospitals

This guide provides a framework for hospitals to implement equity reporting, sharing lessons learned from experiences with creating and using such reports and talking about the importance of the issue.

<http://www.rwjf.org/files/research/050608hospital-equityreport.pdf>

Legality of Collecting and Disclosing Patient Race and Ethnicity Data

The George Washington University School of Public Health and Health Sciences developed this policy brief to explain that the collection of patient data by race or ethnicity, as part of a program of quality improvement, complies with the law.

<http://www.rwjf.org/files/publications/other/RaceEthnicDisparitiesData06222006.pdf>