

**POLICY BRIEF**

**Measuring Racial and  
Ethnic Disparities in  
Health Care: Efforts to  
Improve Data Collection**

*May 2009*

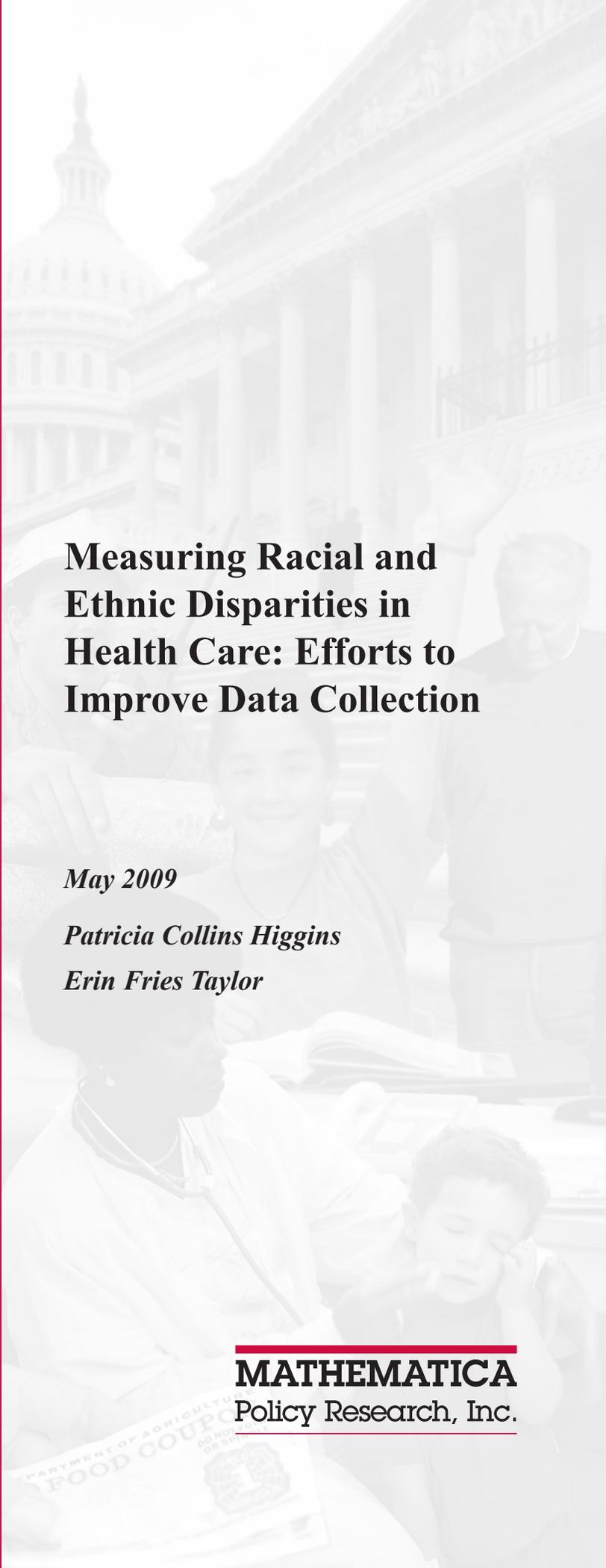
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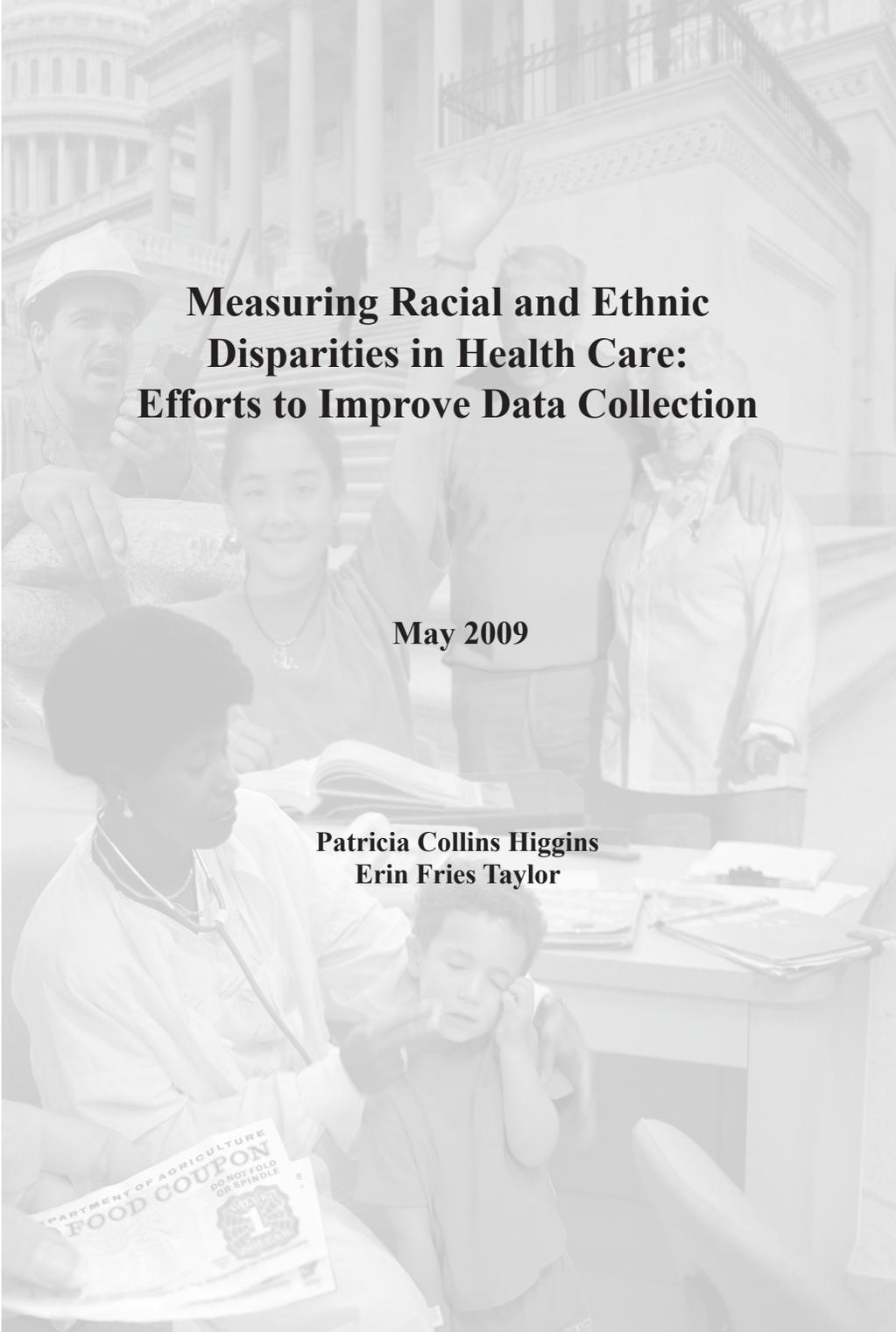
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## **Measuring Racial and Ethnic Disparities in Health Care: Efforts to Improve Data Collection**

**May 2009**

**Patricia Collins Higgins  
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## *Measuring Racial and Ethnic Disparities in Health Care: Efforts to Improve Data Collection*

Policy attention to racial and ethnic health care disparities has grown substantially in the past decade. However, a standardized, coordinated approach to measuring disparities across the public and private sectors does not yet exist. This brief assesses emerging federal and state activities aimed at strengthening collection of data on race, ethnicity, and primary language. Our focus is on data collection related to health care services.<sup>1</sup> We highlight the work of three states—Massachusetts, California, and New Jersey—that have implemented laws and regulations guiding data collection activities by hospitals, health plans, and government agencies. Early lessons learned by these forerunners may influence other states' efforts to improve data collection and ultimately reduce disparities.

### Issues at a Glance

- Government agencies, academic institutions, and other organizations have highlighted the existence of health care disparities and have called for improved data as a first step in identifying disparities and developing strategies to eliminate them.<sup>2</sup>
- Yet the lack of valid and reliable data continues to hamper collective understanding of racial and ethnic disparities (Billheimer and Sisk 2008; Lurie et al. 2008b; Lurie 2005).
- Data collection policies and regulations across public and private entities lack coordination and standardization.
- Pockets of activity are emerging at the national and state levels, to strengthen collection of data on race, ethnicity, and primary language (r/e/l).

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### Early Initiatives

Disparities in health and health care are now viewed not only as an issue of justice, but also as one of quality. Reflecting priorities expressed by several federal agencies, *Healthy People 2010*—released by the Department of Health and Human Services (HHS) in January 2000—cited the elimination of disparities as one of two overarching goals for the nation. Soon afterwards, the Institute of Medicine released *Unequal Treatment*, its influential report on disparities in the U.S. health care system (Institute of Medicine 2002). The Agency for Healthcare Research and Quality (AHRQ) issued its first *National Healthcare Disparities Report* in 2003. This report, released annually in conjunction with the *National Healthcare Quality Report*, provides “a full and comprehensive expansion of the equity dimension” of quality of care, as defined by the Institute of Medicine (AHRQ 2003, p.5). These federal reports all contain recommendations for improved r/e/l health care data collection in both the public and private sectors as a first step in reducing racial and ethnic health disparities in the health care system.

One early federally sponsored initiative that focused attention on the importance of race and ethnicity (r/e) data collection was the Health Disparities Collaborative of the Health Resources and Services Administration (HRSA). Launched in 1998, the Health Disparities Collaborative’s mission was to improve access to high quality, culturally and linguistically competent primary and preventive care for underserved, uninsured, and underinsured Americans via quality improvement initiatives in federally qualified health centers (HRSA HDC website 2008). Evaluations of the collaborative’s impact suggest there have been significant improvements in measures of quality of

care in health centers subsequent to their participation (see, for example, Chin et al. 2007; Landon et al. 2007). Its impact on reducing r/e disparities, however, is unclear since disparities have not been measured directly (by either health centers or evaluators).

National attention to disparities also caught the interest of the U.S. health care industry. In 2002, Aetna emerged as an industry leader in collecting r/e/l data when it formed its Task Force on Racial and Ethnic Disparities in Health Care (Hassett 2005). Other health plans have since responded by developing similar initiatives. To support and leverage their individual work, the National Health Plan Collaborative (NHPC)—a public-private partnership originally sponsored by AHRQ and the Robert Wood Johnson Foundation—was formed in late 2004. The NHPC, which now consists of 11 national and regional managed care firms with 87 million beneficiaries, has convened periodically to share strategies related to data collection and interventions to eliminate racial and ethnic health disparities. (For more information, see [www.nationalhealthplancollaborative.org](http://www.nationalhealthplancollaborative.org); Lurie et al. 2008a; Gold et al. 2006.)

These health plan initiatives complement others addressing similar issues within the provider community. For instance, the Health Research and Educational Trust (HRET) Disparities Toolkit provides information and resources for the systematic collection of race, ethnicity, and primary language data from patients (see [www.hretdisparities.org](http://www.hretdisparities.org)). Generating better r/e/l data and acting on them also is an important component of the Robert Wood Johnson Foundation's Aligning Forces for Quality initiative, a large, multi-stakeholder quality improvement effort operating in 14 locales (see [www.rwjf.org/qualityequality/af4q/index.jsp](http://www.rwjf.org/qualityequality/af4q/index.jsp)).

### Recent Federal Activity

The federal government has a strong interest in the health of the U.S. population as whole. This interest is reflected in *Healthy People 2010*, the *National Healthcare Quality Reports*, and the *National Healthcare Disparities Reports*. In addition, the federal government has an important stake in the health of a number of subgroups—including minorities—because it often pays directly for their care. In fact, half of the U.S. minority population receives health care through federal programs (Lurie et al. 2005).<sup>3</sup> For this reason, the federal government has a core interest in the accessibility, quality, cost, and equity of care provided to racial and ethnic minorities. Moreover, interventions aimed at reducing disparities in large public programs have the potential to drive private sector change.

Although the Office of Management and Budget (OMB) released standards for r/e data collection in 1997, researchers and others have identified multiple shortcomings of these standards.

- Lack of widespread knowledge and understanding of the standards
- Lack of compliance with the standards on the part of several federal agencies
- Insufficiency of r/e categories reflected in the standards (particularly given the wide variations of subgroups that exist within ethnicities). As Lurie et al. (2005) note, “it is increasingly clear that the field would benefit from clearer guidance for how ethnic subgroup data should be collected by various entities.”

AHRQ recently commissioned the Institute of Medicine to study this subject. This study will recommend appropriate r/e categories and may promote standardization in data collection. The results of this study are expected in mid-2009.

Although there has been little federal legislative or regulatory action that provides guidance or mandates regarding the collection of r/e/l data, two recent pieces of federal legislation (one

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passed and one proposed) have the potential to affect collection of such data. They reflect a growing recognition by policymakers of the importance of r/e/l data, although the scope of their possible impact remains uncertain.

**Medicare Improvements for Patients and Providers Act of 2008 (MIPPA).** On July 15, 2008, Congress overrode a presidential veto to enact the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, PL-110-275). The Act's content is broad, but some provisions relate to improving methods for collection of data on health disparities in the Medicare program. Sections 183 and 185 direct the Secretary of HHS to evaluate and report to Congress on approaches "for the collection of data that allow for the ongoing, accurate, and timely collection and evaluation of data on disparities in health care services and performance on the basis of race, ethnicity, and gender" within Medicare (Congressional Research Service Summary, HR 6331).<sup>4</sup> MIPPA also charges the Secretary with the implementation of the most effective approaches to data collection. While the impact of this legislation remains unclear until its regulations are issued, it could have important implications for health plans and other interested parties. However, the time frame for reporting on the results of this work is relatively lengthy, with a recommendation report to Congress due within four years of enactment.

**The Proposed Health Equity and Accountability Act.** The Health Equity and Accountability Act (HR 3014) was proposed in the 110th Congress, but did not make it to a floor vote. It is unknown whether the bill will be reintroduced in the 111th Congress, but interest in the bill was strong, as indicated by its 114 cosponsors. The bill included multiple provisions related to r/e/l data collection, cultural competency, and workforce diversity (Congressional Research Service Summary, HR 3014). Provisions included the establishment of a technical clearinghouse on health workforce diversity, as well as regional minority centers of excellence programs.

The bill further directed all health-related programs of HHS to collect r/e/l data. In addition, each HHS agency would be required to create a division to address minority health issues.<sup>5</sup> The Secretary of HHS would be responsible for establishing an Office of Health Disparities within the Office of Civil Rights, placing civil rights compliance officers in each HHS agency that administers health programs, establishing a center for cultural and linguistic competence in health care, and creating a Rural Health Quality Advisory Commission (Congressional Research Service Summary, HR 3014).

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### State-Level Activity

Most states have not been active legislatively in the area of disparities reduction, but a few have emerged recently as leaders in efforts to improve r/e/l health data collection. Massachusetts and California have been forerunners and a few other states—such as New Jersey—also have been active. These states have adopted policies and regulations to improve collection of r/e/l health data by government agencies, hospitals, and health plans.

**Massachusetts.** Massachusetts is unique in its legislative and regulatory efforts to begin mandating and standardizing r/e data collection by hospitals and health plans. Three such efforts within the state are: (1) the work of the Health Care Quality and Cost Council, which will establish standards for collection of r/e data by health plans; (2) the establishment of regulations

for hospitals to collect r/e patient data; and (3) the creation of the Office of Health Equity, which will monitor r/e data collection across state agencies and coordinate state-level disparities work.

- *Health plans will soon be required to report members' r/e data.* Chapter 58, the 2006 Massachusetts law that aims to achieve near-universal health care coverage, includes provisions related to the reduction of health disparities and the collection of r/e health data by health plans (Smedley et al. 2008).<sup>6</sup> Chapter 58 created a Health Care Quality and Cost Council (HCQCC), which was directed to “establish statewide goals for improving health care quality, containing health care costs, and reducing racial and ethnic disparities in health care” (General Laws of Massachusetts, Chapter 6A). As part of this mandate, the HCQCC has been working with The Brookings Institution to establish standards that health plans will use to collect and report data on the race and ethnicity of members. Eventually, the HCQCC will use data from health plans to report on several measures of health care quality and costs in the state, stratified by race and ethnicity.<sup>7</sup>

Health plans are required to begin reporting r/e data to the HCQCC by July 2009. To help develop plans for this work, the HCQCC and Brookings staff have partnered on various activities, including conducting baseline surveys of health plans to identify plans for r/e data collection, holding multiple consumer focus groups comprised of participants of diverse races and ethnicities to discuss issues of trust and self-reporting of race/ethnicity, and convening an expert panel to build consensus on statewide standards for health plan r/e data collection.<sup>8</sup>

- *Hospitals already are collecting r/e patient data.* Hospitals in Massachusetts have been collecting and reporting patient r/e data to the state since 2007, as required by the Massachusetts Division of Healthcare Finance and Policy (2006). Hospitals are required to collect data only for inpatient hospitalizations, observation unit stays, or emergency department visits, but most are collecting r/e data for patients seeking other services as well (Weinick et al. 2007). Typically, these data are collected during patient registration. As discussed in the NHPC toolkit (2008), collecting data during the intake process provides an opportunity for patients to inquire why these data are being collected. With properly trained staff, this process can be both effective in collecting data and educational for patients. On the other hand, if providers or office staff simply record their “best guess” of patients’ r/e data without directly asking patients for this information, many inaccuracies may occur (NHPC toolkit 2008).
- *Office of health equity will coordinate statewide r/e data collection.* The latest legislative development related to r/e health data collection in Massachusetts is the creation of the Office of Health Equity via an Act Eliminating Racial and Ethnic Health Disparities in the Commonwealth (H. 2234), passed in April 2008. This office will coordinate and lead state disparities reduction work, including r/e data collection (Smedley et al. 2008). The extent to which the Office of Health Equity will partner with the HCQCC on r/e data collection work remains to be determined, but there is potential for the two entities to learn from and bolster each other. As a first step, the new leader of the Office of Health Equity is a member of the expert panel guiding implementation of the new HCQCC regulations.

As health plans implement the HCQCC requirements, hospitals and federally qualified health centers (FQHCs), which already collect patient r/e data, may be able to impart lessons learned or even to share data. For example, FQHCs are required by HRSA to collect patient r/e data, and some health centers in Massachusetts share these data with at least

one health plan.<sup>9</sup> While sharing data in this way is not yet a widespread practice, discussion of this possibility has begun in Massachusetts.

**California.** California also has taken legislative action mandating r/e/l data collection by health plans. Senate Bill 853, signed into law in 2003, requires that all California health plans provide language assistance services to members with limited English proficiency. The focus of SB 853 to date has been appropriate provision of translation and interpretation services.<sup>10</sup> However, regulations specify that health plans must collect demographic profiles of their members, including “preferred spoken and written language, race, and ethnicity” (CA Code of Regulations). As of January 2009, health plans are required to have established and implemented a language assistance program, including the collection of r/e/l data.

- *State, plans, and others work together on data collection, though barriers remain.* In developing the regulations and guiding the implementation of SB 853, California’s Department of Managed Health Care and the Department of Insurance have worked closely with advocacy groups and health plans to identify potential barriers and suggest strategies to overcome them. To this end, California’s Health Industry Collaboration Effort (ICE), a nonprofit, volunteer work group of health care industry stakeholders, has worked with health plans on training staff and establishing coding schemes for r/e/l data based on the HRET toolkit and the recommendations of several health plans participating in the NHPC (ICE website 2008).

Despite this work to facilitate health plans’ implementation of the new regulations, health plans, particularly commercial-only plans, have identified significant technical and financial challenges to their attempts to collect r/e/l data.<sup>11</sup> For instance, health plans face barriers in the modification of IT systems to accommodate new data fields. It also is challenging to identify the best means of collecting r/e/l data. Health plans perceive that members often are unwilling to provide information on race and ethnicity in response to surveys, and are uncertain whether other methods of data collection (for example, pre-enrollment forms) would be more acceptable to members. According to several organizations involved in California’s efforts, some health plans are turning to indirect methods of data collection (such as geocoding and surname analysis), due to low response rates to direct methods. Although self-reported, directly collected r/e data remains the gold standard, such methods are not always feasible. Indirect methods are becoming increasingly sophisticated and, when used correctly, provide a workable alternative or supplement to direct data collection.

- *Requirements for data collection provide flexibility.* Health plans in California are required to survey enrollees to collect language information, but the regulations give plans leeway in determining how to collect r/e data. For example, plans may use data collected directly from members, data on members collected from third parties (such as employers or hospitals), or Census data that approximate r/e by geographic area. In addition, plans themselves may determine which categories of race and ethnicity to collect, although the Department of Managed Health Care has stated that health plans should consider race and ethnicity as two separate demographic characteristics (California DMHC website 2008). This strategy reduces the potential to compare data across plans, but allows plans to tailor data collection to fit their technical capabilities. In theory, the lack of standardization also allows plans to choose more specific r/e categories that reflect their particular membership, although whether this will occur in practice remains to be seen.

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**New Jersey.** The state government of New Jersey, in partnership with the New Jersey Hospital Association (NJHA), has improved r/e/l data collection in hospitals and government agencies.

- *State standardized r/e/l data collection across the Department of Health and Senior Services (DHSS).* In the spring of 2007, New Jersey released a Strategic Plan to Eliminate Health Disparities, which identified strengthening the state's infrastructure for collection of r/e/l data as a major area of focus (NJ DHSS 2007b). In response to the goals established by this Strategic Plan, the state's Office of Minority and Multicultural Health partnered with the state's Center for Health Statistics to field a survey of all program directors in the DHSS. This survey assessed whether and how r/e/l health data were collected by the programs in the department. Using the results of the survey, the DHSS developed Race and Ethnicity Coding Guidelines, a resource that helps to ensure every program within the department collects data uniformly (2007a).
- *Hospitals are pursuing standardized r/e data collection.* Another major initiative in New Jersey is NJHA's work with hospitals, state agencies, and academics to standardize and improve statewide r/e data collection by hospitals. For many years, hospitals in New Jersey have been mandated by state law to report patients' race and ethnicity as part of discharge data reporting requirements. However, these data have not always been collected in a standardized manner.<sup>12</sup> Using the results of a survey of hospitals and FQHCs, the NJHA and an advisory board developed a list of revised codes for all hospitals to use in their data collection and reporting.<sup>13</sup>

The NJHA also helped hospitals implement the new data collection and reporting requirements. Most critically, the NJHA's Management Information Systems department worked with the seven information system vendors operating hospital data collection systems in the state to ensure the new categories were taken into account in every type of system used by New Jersey hospitals. In addition, the NJHA has developed patient education materials, staff training sessions, and a toolkit modeled on HRET's work to facilitate implementation.

**Other State Activity.** While most states have not undertaken significant activities to improve r/e/l data collection, state attention to minority health issues has increased in the past decade. Forty-six states now have an Office of Minority Health (or similar office), and the remaining states have committees or other bodies working on minority health issues (NCSL 2007). The duties of these offices vary substantially from state to state, although they typically play an advisory role within states' health departments.

The National Association of State Offices of Minority Health (NASOMH) was formed about a year ago to help shape the work of individual state offices of minority health and act as a liaison between these offices and the federal Office of Minority Health.<sup>14</sup> According to NASOMH staff, the goals of the organization include establishing core competencies and providing technical assistance for minority health, as well as influencing policy development on minority health. NASOMH staff suggest there is a growing consensus among states that they lack accurate data on racial and ethnic origins, which they need to understand the extent of disparities. While few state offices of minority health are directly involved with data collection, more may become involved with it in the future, especially in light of possible state regulations.

**Data Collection Activity on the Horizon.** Although understanding the data collection efforts in forerunner states is useful, this work raises two important questions: (1) will similar data collection activities emerge elsewhere? and, if so, (2) will the locus of such activity be at the

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state or federal level? At most organizations, staff with whom we spoke expected that collection of r/e data will continue to increase and expand, but were unsure whether state or federal entities will take the lead. In addition, some experts noted that several states are waiting to see how initiatives in Massachusetts and California play out before moving forward with their own.

### Lessons Learned

While policy interest in disparities reduction has grown considerably in the past decade, federal and state activities on r/e/l data collection are still evolving. The experiences of Massachusetts, California, and New Jersey underscore the power of legislation and regulation in influencing health plans, hospitals, and state agencies to collect r/e/l data. As one contact noted, “Without a law in place, [r/e/l data collection by health plans] wouldn’t have happened.” Moreover, representatives from several organizations suggested that other states are watching these forerunners before deciding what they should do.

#### Lessons at a Glance

State activities have a significant impact on the collection of r/e/l data.

- As demonstrated by the Massachusetts experience, carefully crafted and thoughtfully implemented legislation and regulation provide the motivation for health plans and hospitals to overcome some of the barriers to r/e/l data collection.
- Moreover, as evidenced by the three states discussed in this brief, state agencies, advocacy organizations, and other groups skilled in technical assistance can facilitate collection of r/e/l data (for example, through standardization of r/e/l categories, staff training, and patient education).

Another important catalyst is the involvement of organizations capable of rallying stakeholders to participate and collaborate with one another.

- In Massachusetts, the Brookings Institution is coordinating the rollout of the new r/e regulations by consulting with and disseminating information across health plans, consumers, providers, and representatives of the state government.
- In California, ICE plays this role, facilitating the sharing of information and strategies across health plans.
- In New Jersey, the state hospital association has been instrumental in the successful standardization of r/e/l data collection in hospitals.

While the most significant policy activity directly related to r/e/l data collection by health plans has occurred at the state level, contacts emphasized that national leadership in this area is also important. In particular, as more states join the movement towards policy development and implementation of r/e/l data collection, a standard set of r/e/l categories, promoted by the federal government, could be used nationwide. This issue is of particular concern to national health plans, which will face different sets of regulations and standards in different states. The recently commissioned IOM study on r/e data collection may provide important recommendations, thereby allowing for a more uniform approach that promotes best practices in r/e data collection and facilitates comparative measurement.

Movement on the collection of r/e/l health data across the public and private sectors is a crucial first step towards reducing health disparities. But to what ends will these data be used? As

*... data collection is a necessary but insufficient step towards disparities reduction.*

Weinick and colleagues argue, “measurement by itself will do nothing to reduce systematic inequalities in health care” (2007, p. 1300). In other words, data collection is a necessary but insufficient step towards disparities reduction. Developing strategies to reduce r/e disparities will become the next goal for states like Massachusetts, which soon will have a large amount of data on which to base targeted initiatives. Continuing to track the activities of innovative states will inform other states’ work on r/e/l data collection and disparities reduction.

### Endnotes

1. Analogous work is underway to integrate such data into health status assessment, recognizing that the causes of disparities are diverse and that multiple strategies are required to address them. See Bilheimer and Sisk (2008) for an analysis of national gaps and Gold et al. (2008) for an analysis of gaps at the federal and state level. See the National Quality Forum Issue Brief (2008) for an analysis of the causes of disparities and strategies to address them.
2. For example, see Healthy People 2010 2008; Institute of Medicine 2002; Agency for Healthcare Research and Quality 2003.
3. These programs include Medicare, Medicaid, the VA health care system, the Military Health System (Department of Defense), and federal employee health plans.
4. For a thorough discussion of current deficiencies and suggestions to improve the quality of Medicare r/e data, see McBean (2006).
5. The potentially duplicative nature of these provisions was questioned at a House Energy and Commerce Health Subcommittee meeting on June 24, 2008.
6. There are no current plans to collect data on primary language, but this field could be added in the future.
7. According to HCQCC staff, these r/e data will be added to a Health Care Claims Dataset, which is modeled after similar data sets established in Maine and New Hampshire.
8. The expert panel includes physicians, academicians, health plan representatives, the Executive Director of the HCQCC, representatives from the Department of Public Health, the Director of the Massachusetts Office of Health Equity, and an advisor to the Secretary of the Massachusetts Executive Office of Health and Human Services.
9. One Massachusetts health plan, which works closely with FQHCs, successfully negotiated with these clinics to obtain patients’ r/e data for purposes of improving care.
10. A separate Mathematica brief explores language access in depth. See Au et al. (2009).
11. According to one quality expert, most health plans had some experience with this type of work, due to involvement with Medi-Cal. However, commercial-only plans have faced significant struggles.
12. As of January 2008, hospitals also are required by the NJ DHSS to collect primary language data (personal communication with NJHA staff).
13. This advisory board was composed of representatives of hospitals, state agencies, and academics.
14. For general information on NASOMH, see <http://mih.ohio.gov/NASOMH%20ad%2012%2016%2005.pdf>.

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This work was developed as part of a larger project funded by the Agency for Healthcare Research and Quality in which Mathematica evaluated the second phase of the National Health Plan Collaborative to reduce racial and ethnic disparities. We gratefully acknowledge the insights provided by national experts and representatives from federal and state organizations contacted for this study. We also thank Marsha Gold and Judith Wooldridge at Mathematica for valuable input.

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