



## POLICY BRIEF 4

### PATIENT RACE AND ETHNICITY DATA AND QUALITY REPORTING: A LEGAL “ROADMAP” TO TRANSPARENCY

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#### I. SUMMARY OF FINDINGS

This analysis builds on a previous report issued by the Legal Barriers to Health Information Project that addressed the legality of *collecting* patient race and ethnicity data as part of a quality improvement program.<sup>1</sup> That brief concluded that neither federal nor state law creates legal barriers to the collection of such information by health care entities. The focus of that previous analysis was principally on the question of *collection*; thus, there was relatively limited discussion of how the data might be *used*, other than the broad observation that federal and state law promoted rather than discouraged uses aimed at enhancing the quality of care for all patients.

This Policy Brief further addresses issues of data collection by specifically focusing on three questions: *First*, what are the legal *uses* of race and ethnicity data as part of a health care quality performance program? *Second*, does the legal use of such data in health care quality improvement include transparent, public reporting of aggregated clinical quality performance according to the race and ethnicity of patients? *Third*, based on existing legal principles, what uses of race and ethnicity data would be permissible?

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<sup>1</sup> See Sara Rosenbaum, et al., *The Legality of Collecting and Disclosing Patient Race and Ethnicity Data* (The George Washington University for the Robert Wood Johnson Foundation, June 2006) available at, [http://healthinfolaw.org/uploads/racial\\_and\\_ethnic\\_data.pdf](http://healthinfolaw.org/uploads/racial_and_ethnic_data.pdf).

This analysis draws three conclusions: *First*, racial and ethnic patient characteristics have assumed an important role in quality improvement efforts, and therefore the use of such data in this context is fundamentally different from the use of such data to exclude or discriminate. *Second*, health care entities (including health plans or health care providers) may report aggregated and de-identified data related to patient race, ethnicity, and primary language as part of a broader, transparent, and readily understandable reporting system that is part of an effort to measure and report on health quality. Reporting would include documentation of racial, socioeconomic, and ethnic health patterns as well as the *effects of health care improvement strategies* aimed at patient sub-populations at heightened risk for poorer outcomes of care. *Third*, patient race, ethnicity and primary language data can be used to measure and inform, but may *not* be used for “red-lining”<sup>2</sup> certain health care providers on the basis of the racial, ethnic, or language characteristics of their patients; for “steering” patients to certain health care providers; or, as the basis for set-asides or quotas involving providers and patients.

## II. BACKGROUND AND OVERVIEW

### A. *The Need for Data Collection*

Decades of research have shown that racial and ethnic minorities in the United States, including persons whose primary language is not English, experience higher rates of mortality and morbidity than their non-minority counterparts.<sup>3</sup> Reports over the last 20 years consistently document the lower quality of health care services received by minorities as a general matter, regardless of their access to health insurance.<sup>4,5</sup> These disparities have been tied to poorer clinical outcomes at various stages of disease, as well as disease prognosis. The higher burden of disease and mortality among minorities has profound implications for all Americans because of its population health implications. The evidence also shows that interventions aimed

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<sup>2</sup> A term used to signify the illegal practice of discrimination against a particular racial group, originally defined as withholding home-loan funds or insurance from neighborhoods considered poor economic risks. Merriam-Webster’s Dictionary.

<sup>3</sup> See Institute of Medicine, *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business*, 15, 21 (2006).

<sup>4</sup> Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. (National Academies Press, Washington D.C., 2003); Agency for Healthcare Research and Quality, *National Healthcare Disparities Report 2005*, available at, <http://www.ahrq.gov/qual/Nhdr05/fullreport/> (visited November 2007).

<sup>5</sup> In certain specific circumstances minorities have been shown to receive “higher” quality care – at least according to current measurement strategies. See 2005 National Healthcare Disparities Report, U.S. Department of Health and Human Services, Agency for Healthcare Quality and Research, AHQR Publication No. 06-0017, page 3 (December 2005).

at improving the quality and timeliness of care can have a major impact on closing this health gap.<sup>6</sup>

Several studies have concluded that eliminating these inequities is essential to improving health care quality.<sup>7</sup> Further, the need to eliminate disparities in health and health care becomes more urgent as the nation's population becomes more racially and ethnically diverse. It is expected that the number of minority patients who use health care will equal that of the non-minority population majority by 2050.<sup>8</sup> As noted by disparity reduction studies, the evidence indicates that targeted quality measurement and improvement strategies may be able to reduce or even eliminate disparities as part of overall quality improvement.<sup>9</sup>

To address this goal of overall quality improvement, including disparities reduction, “[t]here have been clear calls to action to systematically document disparities and tailor interventions to improve the quality of care”<sup>10</sup> in both the public and private sectors.<sup>11</sup> Collecting data on race, ethnicity and primary language is the vital first step in meeting these goals.<sup>12</sup> Once collected, the data can then be used internally by plans and providers as part of health care quality performance programs, in order to understand the source or scope of disparities affecting minority patients, design targeted quality improvement activities, and monitor the effectiveness of these efforts. The public and transparent reporting of disparities data may also be an effective driver of quality improvement and disparities reduction.<sup>13</sup>

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<sup>6</sup> Bruce Siegel, Marsha Regenstein, and Karen Jones, *Enhancing Public Hospitals' Reporting of Data on Racial and Ethnic Disparities in Care* (The Commonwealth Fund, 2007); Marshall H. Chin, et al., *Interventions to Reduce Racial and Ethnic Disparities in Health Care*, *Med Care Res Rev*, 64; 7 (2007); Andrew M. Davis, et al., *Cardiovascular Health Disparities: A Systematic Review of Health Care Interventions*, *Med Care Res Rev*, 64: 29S -100S (2007); Cooper, L. A., et al., *Designing and Evaluating Interventions to Eliminate Racial and Ethnic Disparities in Health Care*, *Journal of General Internal Medicine*, 17 (6): 477–86 (2002).

<sup>7</sup> See *supra* note 3.

<sup>8</sup> Robert Wood Johnson Foundation, *Tracking Health Plan Enrollees' Race and Ethnicity*, September 23, 2004. <http://www.rwjf.org/pr/product.jsp?id=20853&topicid=1180&gsa=pt1180> (visited November 2007), see also *supra* note 3.

<sup>9</sup> See *supra* note 4.

<sup>10</sup> Romana Hasnain-Wynia & David W. Baker, *Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations: Current Challenges and Proposed Solutions*. *Health Services Research*, August, 41(4p1):1501–18 (2006).

<sup>11</sup> David R. Nerenz, *Health Care Organizations' Use of Race/Ethnicity Data to Address Quality Disparities*. *Health Affairs*. Vol. 24: 409-416 (March/April 2005).

<sup>12</sup> See *Health Insurance Plans Address Disparities in Care: Highlights of AHIP/Robert Wood Johnson Foundation Quantitative and Qualitative Research*. Available at: <http://www.vdh.virginia.gov/ohpp/clasact/researchresources2.asp>

<sup>13</sup> Siegel et al., *supra* note 6.

## B. *Legality of Race, Ethnicity and Language Data Collection*

Our previous analysis underscored the legality of collecting data on race, ethnicity and primary language as part of a broader program to improve quality by reducing disparities in health and health care. Existing law does not prohibit, and indeed encourages, such data collection by health care entities for these legitimate purposes. To put the current analysis in context, a brief summary of the legality of data collection follows. A more detailed discussion of the legality of collecting race and ethnicity data for health care quality purposes can be found in the prior brief in this series.<sup>14</sup>

Under federal law, no law or regulation prohibits the collection of race, ethnicity or language data for quality improvement programs, although a common misperception is that Title VI of the Civil Rights Act of 1964 inhibits the collection of such data.<sup>15</sup> Title VI and its implementing regulations prohibit discrimination on the basis of race, color or national origin in the provision of any services that are supported with federal funds. The law applies to a broad range of organizations including those that provide health services paid by federal programs such as Medicaid and Medicare.<sup>16</sup> The regulations prohibit both intentional as well as *de facto* discrimination (i.e., discrimination in effect), and they classify differential treatment in the provision of services as a prohibited form of discrimination.<sup>17,18</sup> The regulations also require affirmative steps be taken to overcome prior discrimination and permit such steps even in the absence of prior discrimination in order to overcome conditions which may have limited the participation of individuals of a particular race or ethnic group.

Neither the Civil Rights Act nor its implementing regulations require collection of race, ethnic or language data. However, the regulations include “racial and ethnic data” as an “example” of the type of information which recipients of federal funds should make available in order to demonstrate they are in compliance with the non-discrimination rules – thereby indicating that voluntary collection of such data is

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<sup>14</sup> Rosenbaum et al., *The Legality of Collecting*, *supra* note 1.

<sup>15</sup> America’s Health Insurance Plans, *Collection and Use of Race and Ethnicity Data for Quality Improvement: 2006 AHIP-RWJF Survey of Health Insurance Plans*, (“AHIP 2006 Survey”) (Funded by Robert Wood Johnson Foundation 2006) at 5. Available at, <http://www.ahip.org/healthandmedicine/diversityandculturalcompetency>.

<sup>16</sup> Rosenbaum et al., *The Legality of Collecting*, *supra* note 1. Physicians who receive only Medicare Part B payments on a fee for service basis are considered not to be recipients of federal financial assistance.

<sup>17</sup> *Id.* (citing Sara Rosenbaum and Joel Teitelbaum, *Civil Rights Enforcement in the Modern Health Care System: Reinventing the Role of the Federal Government in the Aftermath of Alexander V. Sandoval*, 3 YALE JOURNAL OF HEALTH POLICY LAW AND ETHICS, 215-290 (2003)).

<sup>18</sup> 45 C.F.R. § 80.3.

acceptable.<sup>19</sup> Thus, Title VI encourages the collection of race and ethnicity data, and federal officials have the authority under Title VI and the implementing regulations to require the collection of racial and ethnic data.

Other federal laws authorizing the collection of race and ethnicity data include Title VII of the Civil Rights Act of 1964, which prohibits employers from discriminating against individuals with respect to the terms and conditions of employment. Under Title VII, covered employers are *required* to collect and report data on the race, ethnicity and gender of their employees, so that conditions of employment can be viewed by race and ethnicity.

The regulations issued under the Health Insurance Portability and Accountability Act of 1996 (the HIPAA Privacy Rule) restrict the use and disclosure of identifiable health information without the individual's permission in many circumstances. However, the privacy regulation does not restrict the collection of race and ethnicity data for quality improvement purposes.

Overall, experts have consistently determined that neither Title VI, nor any other federal law or regulation,<sup>20</sup> prohibit the collection of race and ethnicity data for the purpose of improving health care quality.<sup>21</sup> To the contrary, collecting such data is permissible, enhances the goals of Title VI, and supports compliance efforts. In the Title VII context, collecting such data is required.

At a state level, previous research has found no evidence of state laws that prohibit providers from collecting race and ethnicity data.<sup>22</sup> On the contrary, 22 states require hospitals to collect data on race and ethnicity.<sup>23</sup> Even some cities have regulations addressing this issue. Boston, for example, has recently begun to require all hospitals and community health centers in the city to collect demographic

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<sup>19</sup> See *Madison-Hughes v. Shalala*, 80 F.3d 1121 (6<sup>th</sup> Cir. 1996) (where the court found no statutory or regulatory requirements pursuant to Title VI that racial and ethnic data be collected, but rather that such data collection is within the discretion of the Department of health and Human Services).

<sup>20</sup> See America's Health Insurance Plans, *Tools to Address Disparities in Health: Data as Building Blocks for Change* ("AHIP Tools") (2005) at 6-7. Available at, <http://www.vdh.virginia.gov/ohpp/clasact/documents/CLASact/research/default.pdf>

<sup>21</sup> See Rosenbaum et al., *The Legality of Collecting*, *supra* note 1, Gilliam K. SteelFisher, *Addressing Unequal Treatment: Disparities in Health Care* (The Commonwealth Fund, Nov. 2004). Available at, [http://www.commonwealthfund.org/usr\\_doc/SteelFisher\\_unequaltreatment\\_cong2004\\_709.pdf?section=4039](http://www.commonwealthfund.org/usr_doc/SteelFisher_unequaltreatment_cong2004_709.pdf?section=4039);

AHIP Tools, *supra* note 20; Ruth T. Perot and Mara Youdelman, *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices* (The Commonwealth Fund 2001); Karen Llanos and Lindsay Palmer, *Using Data on Race and Ethnicity to Improve Health Care Quality for Medicaid Beneficiaries* (Center for Health Care Strategies June 2006).

<sup>22</sup> Rosenbaum et al., *The Legality of Collecting*, *supra* note 1 at 17.

<sup>23</sup> Nerenz, *supra* note 11 at 410.

information for all patients including, race, ethnicity, preferred language, and education.<sup>24</sup> Although a few states have laws or regulations placing restrictions on health insurance plans in collecting data on race and ethnicity, these laws have limited applicability. The restrictions do not apply outside the insurance application process, allowing the subsequent collection of race and ethnicity data through voluntary participation in disease management programs or questionnaires. In addition, these state laws generally do not apply to ERISA-governed employer sponsored plans.<sup>25</sup> Collecting race and ethnicity data is therefore not prohibited by either federal or state law. In fact, many public and private programs encourage these collection activities.

Accrediting bodies also are moving toward requiring race and ethnicity data collection. For example, The Joint Commission on Accreditation in Healthcare (JCAH) recently issued a report recommending targeted strategies to address language and cultural issues that are increasingly inhibiting the ability of hospitals to deliver quality health care to diverse populations.<sup>26</sup> The Report recommended, among other things, that hospitals implement a uniform framework for collecting data on race, ethnicity and language, and use the data collected to develop a host of quality measures.

### III. COLLECTING RACE, ETHNICITY AND LANGUAGE DATA: CURRENT PRACTICE

While most physicians are not yet collecting race and ethnicity data,<sup>27</sup> many federal programs, health care organizations, and health plans are doing so.<sup>28</sup> HHS collects data on race, ethnicity and primary language in a number of health care programs either as a matter of custom or law. For example, all federally funded health centers must collect and report race and ethnicity data, as must grantees under the Maternal and Child Health Services block grant program.<sup>29</sup> Similar reporting requirements exist for grantees under the Substance Abuse and Mental Health

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<sup>24</sup> Available at, <http://www.bphc.org/programs/initiative.asp?i=271&p=202&b=7&d>.

<sup>25</sup> AHIP 2006 Survey, *supra* note 15 at 8.

<sup>26</sup> Hospitals, Language and Culture, A Snapshot of the Nation, available at, [http://www.jointcommission.org/PatientSafety/HLC/compiled\\_list.htm](http://www.jointcommission.org/PatientSafety/HLC/compiled_list.htm).

<sup>27</sup> AHIP 2006 Survey, *supra* note 15; see also David R. Nernez, et al., *Developing a Health Plan Report Card on Quality of Care for Minority Populations*, The Commonwealth Fund, 2002 (noting that 75 percent of medical groups responding to one survey did not collect race and ethnicity data).

<sup>28</sup> See Mara Youdelman with Steve Hitov, *Racial, Ethnic and Primary Language Data Collection: An Assessment of Federal Policies, Practices and Perceptions*, The Commonwealth Fund (October 2001); Marsha Regenstein and Donna Sickler, *Race, Ethnicity, and Language of Patients: Hospital Practices Regarding Collection of Information to Address Disparities in Health Care* (National Public Health and Hospital Institute funded by The Robert Wood Johnson Foundation 2006). Available at, <http://www.rwjf.org/pr/product.jsp?id=15189> (visited December 2007); and AHIP 2006 Survey, *supra* note 15.

<sup>29</sup> Rosenbaum et al., *The Legality of Collecting*, *supra* note 1 at 11, citing Perot and Youdelman *supra* note 21.

Services Administration, states providing care to families under the State Children's Health Insurance Plan, and states operating HIV/AIDS programs under the Ryan White Care Act.<sup>30</sup> The Medicare program has collected data on race from the program's inception, and its special data bases have yielded some of the most important disparities studies to be found in the literature.<sup>31</sup> The Office for Civil Rights (OCR) at the Department of Health and Human Services examines cases focusing on the effects of provider policies and practices on health care access among persons with limited English proficiency. OCR frequently enters into compliance agreements in which providers agree to collect data pertaining to primary language of the patient or client population.

An increasing number of public and private health insurers also collect race and ethnicity data on enrollees. All state Medicaid agencies collect some form of data on race and ethnicity.<sup>32</sup> On a broader scale, a 2006 survey conducted by America's Health Insurance Plans (AHIP) with funding by the Robert Wood Johnson Foundation reported the number of health insurance plans (weighted by enrollment) that collect race and ethnicity data increased 500 percent since 2001.<sup>33</sup> In 2006, 67% of the respondents' enrollees were covered by plans collecting race and ethnicity data.<sup>34</sup> The plans obtained race and ethnicity data directly from enrollees on a voluntary basis, as well as indirectly by using other existing information about enrollees to infer their race and ethnicity (such as using a person's surname to identify race or relying on geocoding).

A recent survey revealed a significant portion of hospitals now also are collecting race and ethnicity data. As of 2005, more than three-quarters of non-federal acute care hospitals in the United States collected information on the race of their patients and half collected information on patient ethnicity and language.<sup>35</sup> In a subsequent survey of safety net hospitals, virtually all of the respondents reported collecting data on race and ethnicity.<sup>36</sup> Nearly all of the hospitals collecting race and ethnicity information do so at the point of registration for both inpatient and outpatient services provided on the hospital campus.<sup>37</sup> Further, many published works discuss the legality of collecting data, as well as set forth the proper methods for

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<sup>30</sup> *Id.*

<sup>31</sup> Rosenbaum et al., *The Legality of Collecting*, *supra* note 1 at 11.

<sup>32</sup> Llanos and Palmer, *supra* note 21.

<sup>33</sup> AHIP 2006 Survey, *supra* note 15 at 3.

<sup>34</sup> *Id.*

<sup>35</sup> Regenstein and Sickler, *supra* note 28 at 5.

<sup>36</sup> *Id.* at 19.

<sup>37</sup> *Id.* at 8, 24.

doing so.<sup>38</sup> An increasing number of health insurance plans collect race and ethnicity data of enrollees. Sixty percent of the health insurers that responded to a 2006 survey conducted by AHIP in conjunction with RWJ reported collecting such data.<sup>39</sup> The methodologies for collecting data can vary; however, obtaining information directly from patients seems to be the most frequently used process. One of the rationales for collecting data directly from patients is that third parties are not good judges of race and ethnicity and, thus, inaccurate information can result.<sup>40</sup> An alternative (although perhaps not as specific) method is indirect data collection, which entails using proxy information, such as surname or geocoding, to create information on health care use by race and ethnicity.<sup>41</sup>

Although collection of race, ethnicity and primary language data is becoming more prevalent, much work remains to be done even with respect to this initial step. Many in the health care system still do not collect such data.<sup>42</sup> Among those who do, challenges surrounding collection methodology and data quality remain.<sup>43</sup>

National health plans, hospital and physician organizations, and accreditation bodies have begun initiatives to address these issues. Both AHIP and the Health Research and Educational Trust (HRET), the education and research affiliate of the American Hospital Association, have developed toolkits designed to encourage and provide guidance on collecting and analyzing data on race, ethnicity, and primary language to health professionals at health insurance plans and health care organizations.<sup>44</sup> Nine of the major health insurers, in partnership with public and private funders and investigators, have formed the National Health Plan

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<sup>38</sup> *Collection and Use of Race and Ethnicity Data for Quality Improvement*, America's Health Insurance Plans (Funding Provided by Robert Wood Johnson Foundation) (2006). *Tools to Address Disparities in Health: Data as Building Blocks for Change, America's Health Insurance Plans* (Funding Provided by Pfizer) (2005); Ruth T. Perot and Mara Youdelman, *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices* (Funding Provided by the Commonwealth Fund) (2001); Romana Hasnain-Wynia, et al., *Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals* (Funding Provided by the Commonwealth Fund) (2004).

<sup>39</sup> AHIP 2006 Survey, *supra* note 15 at 2.

<sup>40</sup> Hasnain-Wynia, Romana, and Baker, David W., *Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations: Current Challenges and Proposed Solutions*. Health Services Research, 1501-1518. 41:4, Part I (August 2006).

<sup>41</sup> *Id.*

<sup>42</sup> American Medical Association, *Data on Race and Ethnicity: How and Why it Should be Collected in Medical Practice*. Available at, [http://www.bigshouldersdubs.com/clients/ama/compilation/ama\\_11.html](http://www.bigshouldersdubs.com/clients/ama/compilation/ama_11.html) (visited December 2007); AHIP 2006 Survey, *supra* note 15 at 4 (almost 30 million enrollees represented in survey were in plans that do not collect race and ethnicity data); Regenstein and Sickler, *supra* note 28 at 5.

<sup>43</sup> Siegel et al., *supra* note 6 at 18-19, 21; Regenstein and Sickler, *supra* note 28 at 38-39; AHIP 2006 Survey, *supra* note 15 at 4.

<sup>44</sup> See AHIP Tools, *supra* note 20. Romana Hasnain-Wynia, et al., *Health Research and Education Trust: A Toolkit for Collecting Race, Ethnicity, and Primary Language Information from Patients* (2007). Available at, <http://www.hretdisparities.org/> (visited December 2007). See Appendix for further information on toolkits.

Collaborative, aimed at reducing racial and ethnic disparities and improving the overall care in the U.S. health care system.<sup>45</sup>

The American Medical Association (AMA), in conjunction with the national Medical Association and the National Hispanic Medical Association, established the Commission to End Health Care Disparities in 2004 with the goal of eliminating health care disparities.<sup>46</sup> The report issued by the Joint Commission on Accreditation of Healthcare Organizations documents how 60 hospitals across the country are providing care to culturally and linguistically diverse patient populations.<sup>47</sup> The Report highlighted the need for a uniform framework for the collection of data on race, ethnicity and language. Most recently, the AMA has released a series of training videos intended to educate physicians about health care disparities,<sup>48</sup> including one focused on the benefits and methods of race and ethnicity data collection.<sup>49</sup>

#### IV. USING RACE, ETHNICITY AND LANGUAGE DATA IN QUALITY IMPROVEMENT

The case for the legality and sound policy underpinnings of collecting race, ethnicity and language data in the health care context is well established. However, collecting such data, while necessary, is insufficient in truly tackling disparities challenges. Experts in the field believe it is time to focus discussions on the pressing issue of *use* of this data.<sup>50</sup> Major health insurers have only recently begun to develop and pilot ways to use race, ethnicity and language data in their quality improvement efforts.<sup>51</sup> Similarly, only a small percentage of hospitals report using the data they collect for such purposes.<sup>52</sup> This Brief addresses two key issues central to fostering further use of race and ethnicity data for quality improvement: *First*, what are the legal *uses* of race, ethnicity and language data as part of a health care quality performance program? *Second*, does the legal use of race and ethnicity data in health care quality improvement include transparent public reporting of clinical quality

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<sup>45</sup> National Health Plan Collaborative. *National Health Plan Collaborative: Phase One Summary Report* (November 2006). Available at, <http://www.rwjf.org/files/publications/other/NHPCSummaryReport2006.pdf> (visited November 2007).

<sup>46</sup> American Medical Association Commission to End Health Care Disparities, <http://www.ama-assn.org/ama/pub/category/12809.html> (visited November 2007).

<sup>47</sup> Amy Wilson-Stronks and Erica Galvez, *Hospitals, Language and Culture, A Snapshot of the Nation* (2007). Available at, <http://www.jointcommission.org>.

<sup>48</sup> American Medical Association, *Educating Physicians on Controversies and Challenges in Health: Health Care Disparities Among Racial-Ethnic Minority Patients*. Available at, <http://www.ama-assn.org/ama/pub/category/18151.html> (visited December 2007).

<sup>49</sup> American Medical Association, *Data on Race and Ethnicity*, *supra* note 42.

<sup>50</sup> Regenstein and Sickler, *supra* note 28 at 38-39; AHIP 2006 Survey, *supra* note 15 at 8.

<sup>51</sup> National Health Plan Collaborative, *supra* note 45 at 3.

<sup>52</sup> Rosenbaum et al., *The Legality of Collecting*, *supra* note 1.

performance according to the race and ethnicity of patients?

*A. Background Surrounding Use of Race, Ethnicity and Language Data in Quality Improvement and Civil Rights Compliance Programs*

As discussed in the preceding section, it is well settled that it is legal to collect race, ethnicity and language data. In early January 2001, the Surgeon General and the Director of the Office for Civil Rights at the U.S. Department of Health and Human Services sent letters to over 30 prominent healthcare stakeholders, including accrediting bodies, health plans, and associations of health care providers, reiterating the importance and legality of data collection.<sup>53</sup> These letters reaffirmed collection of such data is permissible under Title VI. In addition, the letter outlined a number of potential uses of such data, including:

- Helping providers focus prevention, health education, and treatment efforts for specific demographic groups on health conditions prevalent in those groups;
- Helping providers identify and track similarities and differences in quality of care among various groups, and evaluate programs and health plan performance;
- Facilitating the provision of culturally and linguistically appropriate health care; and
- Alerting providers to potential Title VI issues before they arise.

These are by no means the only permissible uses of race and ethnicity data. This section outlines examples of health care stakeholders who are using race, ethnicity and language data for quality improvement purposes, and also outlines impermissible uses of such data. Health care providers, health plans, accreditation bodies, and other health care stakeholders are increasingly recognizing the importance of using race, ethnicity and language data for quality improvement and civil rights compliance purposes. These health care stakeholders have taken critical data, and used it to implement a host of innovative programs to combat racial and ethnic disparities.<sup>54</sup> The link between quality improvement and civil rights compliance is very important; indeed, regulations implementing Title VI establish legal authority to collect such data.

Title VI regulations explicitly refer to the Secretary's power to require health

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<sup>53</sup> Letters to Various Healthcare Care Stakeholders on Data Collection from Surgeon General David Satcher and OCR Director Thomas Perez, January 19, 2001, on file at George Washington School of Public Health.

<sup>54</sup> See *supra* notes 10, 11, and 15.

and human service providers who are recipients of federal financial assistance to collect racial and ethnic data “showing the extent to which members of minority groups are beneficiaries of and participants in federally-assisted programs.”<sup>55</sup> The regulations also require affirmative steps be taken to overcome prior discrimination. Designing and implementing evidence and data based quality improvement programs can enable a covered entity under Title VI to demonstrate racial and ethnic minorities are meaningful beneficiaries of the program.

The propriety of using such data can also be inferred from numerous governmental sources, such as federal guidelines related to health care and human services to persons with Limited English Proficiency (LEP).<sup>56</sup> The LEP guidance calls for an individualized assessment that includes, among other things, determining the number or proportion of LEP persons eligible to be served or likely to be encountered by the program or grantee and determining the frequency with which LEP individuals come in contact with the program.<sup>57</sup>

The language assessment required under federal guidelines constitutes evidence that Title VI permits not only the collection of data but its active use to improve the quality of care for patients. Indeed, the guidelines underscore the importance under Title VI of not only collecting but using data, in view of the obligation of federal recipients to assure compliance. In other words, covered entities are expected to not only collect relevant information but use it to actually implement changes calculated to be beneficial.

### *B. Examples of Appropriate Uses of Race and Ethnicity Data for Quality Improvement*

The mere collection of race and ethnicity data is not enough; analysis and use of such data is the key to improving health care quality. HHS encourages combining race and ethnicity data with data on other variables, such as cultural background and socioeconomic status, which may be useful in assessing and improving the health and well-being of minority populations and the provision of needed health and social services.<sup>58</sup> Analyzing these data can help identify the characteristics of patients and

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<sup>55</sup> 45 CFR § 80.6(b).

<sup>56</sup> United States Department of Health and Human Services, *Guidance to Federal Financial Assistance Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons*. Available at, <http://www.hhs.gov/ocr/lep/revisedlep.html>.

<sup>57</sup> *Id.*

<sup>58</sup> HHS, “Policy Statement on Inclusion of Race and Ethnicity in DHHS Data Collection Activities,” (Oct. 24, 1997). Available at, <http://aspe.hhs.gov/datacncl/inclusn.htm>.

enrollees as well as potential health disparities. The information can then be used in initiatives designed to eliminate such disparities and improve health care quality.

This section first sets out a brief list of appropriate uses of race and ethnicity data for quality improvement. It then gives some examples of health care plans and health care organizations that have utilized these methods, mostly in combination, in their quality improvement initiatives.

### *Analyzing Race and Ethnicity Data*

Collection of race and ethnicity data lends itself to numerous permissible uses. As an initial step, race, ethnicity and primary language data can be used to:

- *Understand patient/enrollee composition by*
  - Identifying the composition of enrollee or patient populations; and
  - Identifying the primary languages spoken by patients.
- *Identify disparities in health*
  - Race and ethnicity data can be combined with diagnoses to identify differences in health care status among patients in different population subgroups (such as higher incidence of diabetes or asthma).
- *Identify disparities in access or utilization by*
  - Measuring patient access to specific types of care stratified by race or ethnicity (e.g., percent of women with a mammogram stratified by racial or ethnic subgroups);
  - Measuring patient satisfaction according to race/ethnicity/primary language, which may reveal cultural competence issues; and
  - Comparing these separate measures to determine whether statistically significant differences exist.

### *Using Race and Ethnicity Data to Improve Care*

Once data have been analyzed, information can be used to design interventions that enhance services and improve access to care. Some of the interventions designed to improve quality of care and to reduce or eliminate health disparities include:

- *Culturally and linguistically appropriate outreach to targeted members to encourage testing and screening;*
- *Targeted member health education;*
- *Developing partnerships with community organizations to reach people who might not otherwise seek care and to promote behavioral change;*
- *Designing and providing cultural and linguistically appropriate materials;*
- *Conducting cultural competency training for providers;*
- *Targeting physician education based on disparities;*
- *Providing member-directed incentives; and*
- *Assess impacts of efforts.*

The following examples are but a few of the initiatives that show how these interventions can be, and often are, used in combination to remedy identified disparities.

#### *National Health Plan Collaborative*

As part of the National Health Plan Collaborative, the effort by major health insurers to reduce racial and ethnic disparities (described above). Members not only collect data but are also pilot testing interventions designed to reduce disparities in care.<sup>59</sup> For example, one member of the collaborative, Aetna, has been collecting members' racial and ethnic data on a voluntary basis since 2002 (approximately 4 million plan members have shared their information).<sup>60</sup> Data is being used in Aetna's breast care management program, African-American

<p>National Health Plan Collaborative Some interventions:</p> <ul style="list-style-type: none"><li>• Voluntary collection of race/ethnicity data</li><li>• Staff cultural sensitivity training</li><li>• Outreach to targeted patient subgroups</li></ul>
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pre-term delivery program, and diabetes disease-management program. Specifically, Aetna intensified outreach to targeted members and their physicians, developed a cultural sensitivity training module for all staff, and implemented a nursing education-training program. Another member, CIGNA, collects data (racial, ethnic, and primary-language) on a voluntary basis through health risk assessments and disease management programs. CIGNA has implemented cultural competency training with its formal disease management nurse coaches and is equipping its disease management clinical staff with tools to communicate effectively. The insurer

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<sup>59</sup> National Health Care Collaborative, *supra* note 45. In its 2006 first year report, the collaborative gives brief examples of some of the quality improvement interventions undertaken to date by all nine of its members. *Id.*

<sup>60</sup> *Id.*

is also training call center nurses in culturally appropriate ways to encourage medication use and is trying to improve health literacy.<sup>61</sup>

### *Medicaid Managed Care Demonstration Projects*

In 2003, the Health Resources and Services Administration (HRSA) sponsored a series of 12 demonstration projects in 6 states designed to determine whether managed care plans can obtain data on race/ethnicities of enrollees from state Medicaid program and use that data to identify and reduce or eliminate disparities in quality of care.<sup>62</sup> Oregon's Medicaid diabetes care project is an example of the multi-faceted approach of these demonstration projects. A group of health plans serving Oregon Medicaid managed care beneficiaries, together with the state Medicaid agency, formed a partnership with the African-American Health Coalition, a local community organization, to work together to reduce health care disparities among African-American plan members.<sup>63</sup> The Medicaid agency pulled administrative data, including race/ethnicity information, which was merged with Health Plan Employer Data Information Set (HEDIS) data files to produce quality of care reports stratified by race/ethnicity.

#### *Oregon Medicaid Diabetes Care*

##### Interventions:

- Analysis of stratified data
- Identification of health disparities
- Partnership with minority community organization
- Using culturally appropriate materials
- Targeted mailings
- Assessment of effectiveness of intervention

The reports produced by the project showed significant disparities in rates for diabetes and diabetes care between African-Americans and whites. The partnership developed a health plan intervention to improve testing for diabetes management that was comprised of targeted mailings designed, tested, and distributed by the coalition. The plan also collaborated with a local university to conduct a survey of members who received the preventive health mailings to examine the impact of mailings on outcomes including health care use. As a result of the informational mailings, the

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<sup>61</sup> See AHIP Tools, *supra* note 20. A health insurance plan in Washington state analyzed its HEDIS measures stratified by race/ethnicity and discovered some disparities between Hispanic and non-Hispanic children in the areas of immunizations and well-child visits for very young children. To remedy the disparities, the plan developed and disseminated culturally sensitive, Spanish language reminders for mothers of newborns. As a result, improvements in both immunizations and well-child visit rates occurred within a year following the start of intervention. *Id.*

<sup>62</sup> HHS, Health Resources and Services Administration (HRSA), *Addressing Racial and Ethnic Disparities in the Context of Medicaid Managed Care: A Six-State Demonstration Project* (November 2004) (describing all 12 projects). Available at, <http://ftp.hrsa.gov/financeMC/HRSA-Disparities-in-MC-Report.pdf>. This report contains descriptions of the data analysis and interventions undertaken by all 12 projects.

<sup>63</sup> *Id.* at 33-37.

health plans measured an increase in the number of H<sub>v</sub>A1c and LDL tests (used in diabetes management) in the target population.<sup>64</sup>

### *Boston Disparities Project*

Even though not a widespread practice, hospitals and clinics are beginning to use race and ethnicity data to target specific groups for interventions designed to improve quality of care. One excellent example is in Boston, the first city in the United States to establish a blueprint for addressing racial and ethnic disparities in health.<sup>65</sup> As part of the city's multifaceted Disparities Project, Boston hospitals and community health centers have begun to collect demographic information for all patients, including race, ethnicity, preferred language, and education. The project entails various approaches to eliminating disparities including assessment of patient needs and health care organization practices, cultural competency training for health care employees, targeted patient health education, and patient disparities education, including information on how to communicate with providers when English is not the patient's primary language.

The Disparities Project makes a concerted effort to engage people outside the health care sector in the process. For example, to better understand barriers to care and potentially discriminatory practices, one health center conducted focus groups on the issues of Haitian, Vietnamese, Cape Verdean, African- American and Latino patients, engaging over 70 people in the process. It identified a number of quality improvement concerns, including limited Vietnamese and Haitian Creole translation services, lengthy clinic wait times, lack of culturally and linguistically appropriate patient education materials, and English-only after hours phone services.<sup>66</sup>

Another example is a program entitled Expecting Success<sup>67</sup> – a multi-hospital collaborative focused on reducing disparities. The program is helping 10 hospitals measure the quality of cardiac treatment they provide to patients based on race, ethnicity, and primary language. The hospitals are tracking data to identify if there are disparities so that they can then make efforts to fix them.<sup>68</sup>

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<sup>64</sup> Llanos and Palmer, *supra* note 21.

<sup>65</sup> Boston Public Health Commission, *Disparities Project - Year One Report* (2007). Available at, [http://www.bphc.org/director/pdfs/disp\\_year1report.pdf](http://www.bphc.org/director/pdfs/disp_year1report.pdf).

<sup>66</sup> *Id.*

<sup>67</sup> Available at, <http://www.expectingsuccess.org/>.

<sup>68</sup> Other examples include Denver Health, which is looking at utilization of services and health outcomes by race and ethnicity. These include utilization of preventative services such as pap smears, tests for glycemic control for persons with diabetes, mammograms, and management of lipid levels and hypertension. Broadlawns Medical Center uses information on languages to determine whether it has the appropriate number and mix of interpreters on staff. See

Health plans also have elevated the profile of health care disparities transparency and reporting. A 2007 study conducted by the National Committee for Quality Assurance (NCQA) investigated racial and gender differences in cardiovascular disease prevention and treatment based on national health care quality data from commercial health care plans.<sup>69</sup> The study concluded that both race and gender disparities in the management and outcomes of cardiovascular disease exist among patients in commercial managed care plans despite similar access to care.<sup>70</sup> The investigation of health care disparities both within plans and across plans is achieved through the linked analysis of claims and patient data, stratified by race, ethnicity and gender. In its contribution to understanding about racial differences in health care quality even within single plans, the study represents an important contribution.

While there are indeed a number of contexts in which race, ethnicity and language data is being used for quality improvement purposes, the reality is that too few health care providers and health plans do so. The Joint Commission on Accreditation in Healthcare Report discussed above points out, “[i]t is worth noting that only a few of the study hospitals reported that they use data on race, ethnicity and primary language to improve the quality of care they provide.”<sup>71</sup>

### C. *Impermissible Health-related Uses of Race and Ethnicity Data*

While Title VI encourages the collection and use of race and ethnicity data for quality improvement purposes, it prohibits the collection and use of such information for discriminatory purposes. For example, a managed care group that accepts Medicaid cannot identify a racial subgroup as having a disproportionately high incidence of asthma and diabetes and then “reduce” the disparity by limiting acceptance of new patients based on their race. Such discriminatory use of race and ethnicity data is clearly barred by Title VI and its implementing regulations.

Medical redlining is another example of an impermissible use of race and ethnicity data. A health plan that serves a certain geographic market but bypasses census tracts containing high concentrations of people of color may be in violation of Title VI. The Office for Civil Rights has investigated a number of cases of so-called

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*Race, Ethnicity, and Language of Patients: Hospital Practices Regarding Collection of Information to Address Disparities in Health Care.* National Public Health and Hospital Institute (2003).

<sup>69</sup> Ann F. Chou, et al., *Gender Disparities in the Quality of Cardiovascular Disease Care in Private Managed Care Plans*, Women’s Health Issues. Volume 17, Issue 3, Pages 120-130 (May-June 2007).

<sup>70</sup> *Id.*

<sup>71</sup> The Joint Commission, *Hospitals, Language and Culture, A Snapshot of the Nation*, at p. 7. Available at, [http://www.jointcommission.org/PatientSafety/HLC/compiled\\_list.htm](http://www.jointcommission.org/PatientSafety/HLC/compiled_list.htm).

“medical redlining,” where health plans bypassed zip codes containing high minority populations.

There is no federal guidance or case law on the impermissible collection or use of race and ethnicity data in the quality improvement context; however, some restrictions can be inferred from other areas. Were information on race, ethnicity, and primary language to be used to, for example, auto-assign patients to primary care providers or to select providers for network participation, such a practice would arguably entail an impermissible use. For example, with respect to home insurance, courts have indicated that the practice of excluding a community or purchasing group from coverage because they represent a high risk or are otherwise undesirable, known as redlining, is actionable as a violation of the Civil Rights Act.<sup>72</sup> Providers and/or plans cannot use race/ethnicity/language data as a basis for discrimination, (e.g., “racial profiling” with the purpose of denying or limiting health care).

The selection of participating providers based on the race or ethnicity of their patients could be viewed as a discriminatory or exclusionary attempt to create patient quotas based on impermissible criteria. In these contexts, the effects of data use would be to control access based on prohibited criteria rather than to improve the quality. True quality improvement efforts do not use race/ethnicity data in the selection of providers for network participation or to auto-assign patients to certain primary care providers.

It is possible that Title VI could impose limits even on well-intentioned efforts to reduce disparities, particularly in the case of quota systems. While there are no court cases addressing the use of race and ethnicity data to remedy health disparities, the issue of how to remedy racially discriminatory practices has been addressed by the courts in the education context. Those cases make clear the use of strict quota systems based on race is not an appropriate remedial strategy.<sup>73</sup> It is reasonable to conclude such quota systems would also be found improper in the health care context. For example, a health care organization that accepts Medicaid payments which determines its patient population is 30% Hispanic, cannot set a 30% quota for Hispanic doctors on staff, even if it believes this might address cultural awareness. It would be appropriate, however, for the organization to use race/ethnicity and language proficiency of staff as one of many factors in a well-designed hiring process

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<sup>72</sup> See *Mackey v. Nationwide Ins. Companies*, 724 F.2d 419 (4<sup>th</sup> Cir. 1984); *N.A.A.C.P. v. American Family Mut. Ins. Co.*, 978 F.2d 287 (7<sup>th</sup> Cir. 1992).

<sup>73</sup> See *Gratz v. Bollinger*, 539 U.S. 244, 326 (2003) where the Court held the University of Michigan’s use of a race-based quota system in its freshman admissions policy violated the Equal Protection Clause of the Fourteenth Amendment.

where every applicant received significant individual scrutiny.<sup>74</sup> Thus, while it is perfectly legitimate to consider race as a factor to ensure a work place can provide racially and culturally appropriate services, race may not be *the sole* determining factor in the decision.<sup>75</sup>

#### *D. Privacy and confidentiality standards*

Some have questioned whether HIPAA and the medical records privacy framework present any barriers to the use of race, ethnicity or language data. Federal health privacy and confidentiality standards allow the use of identifiable health information for quality improvement programs in many circumstances. For example, the HIPAA Privacy Rule governs the manner in which health plans and most health care providers may use individually identifiable health information they maintain (called “protected health information”).<sup>76</sup>

Health plans and health care providers covered by HIPAA are permitted to use and disclose protected health information without patient consent to carry out their *own* treatment, payment, or health care operations activities, which expressly include quality improvement activities.<sup>77</sup> They are also permitted to disclose protected health information to another covered health plan or health care provider for the recipient’s quality improvement activities so long as both parties have or have had a relationship with the individual whose information they are sharing.<sup>78</sup> This means, for example, that a health plan can share an enrollee’s protected health information, including race and ethnicity data, with the enrollee’s physician for the physician’s quality improvement program. Likewise, a physician or hospital can share a patient’s protected health information with the patient’s health insurer for the plan’s quality improvement activities.<sup>79</sup> It is clear that the HIPAA Privacy Rule allows the use of protected health information, including race and ethnicity data, for quality improvement programs.

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<sup>74</sup> *Grutter v. Bollinger*, 539 U.S. 306, 353 (2003); *Gratz*, 539 U.S. at 326.

<sup>75</sup> *Id.*

<sup>76</sup> See generally 45 CFR Parts 160 and 164, subpart A and E, and 45 CFR § 160.103 (defining “individually identifiable health information” and “protected health information.”)

<sup>77</sup> See 45 CFR § 164.501 (which defines “health care operations” as meaning activities related to “Conducting quality assessment and improvement activities, including . . . population based activities relating to improving health or reducing health care costs, protocol development, case management and care coordination...”) and § 164.506 (permitting the use of personal health information for health care operations without consent).

<sup>78</sup> See 45 CFR § 164.506(c)(4).

<sup>79</sup> See Office for Civil Rights, U.S. Department of Health and Human Services, *Guidance on Uses and Disclosures for Treatment, Payment and Health Care Operations* (April 3, 2003). Available at, <http://www.hhs.gov/ocr/hipaa/guidelines/sharingfortpo.pdf> (last visited December 2007).

## V. PUBLIC REPORTING OF RACE AND ETHNICITY DATA

Collecting race, ethnicity and language data is the first step in a three step process of reducing racial and ethnic health care disparities. Step two, described in the preceding section, involves making meaningful use of such data in a host of quality improvement initiatives. The third step involves providing for the transparent reporting of quality data, stratified for race and ethnicity and (if available) socioeconomic status. Public reporting of quality data has spurred providers, particularly hospitals, to initiate quality improvement efforts.<sup>80</sup> Reporting racial and ethnic disparities could be an effective driver of quality improvement and disparities reduction.<sup>81</sup> A few initiatives publicly report racial and ethnicity disparity data and their quality improvement targets.<sup>82</sup> However, such efforts are rare and many health care organizations do not place a high priority on beginning such an initiative.<sup>83</sup>

In order to appreciate the importance of having mechanisms for the public reporting of data, it is useful to look at the evolution of data collection requirements in the home mortgage and employment settings, both of which offer private context parallels for public performance reporting, stratified by race and ethnicity.

### A. *Data Collection in Mortgage Lending- The Home Mortgage Disclosure Act*

The historical debate surrounding the role of discrimination in mortgage lending is quite similar to the current debate in health care. Communities of color had difficulty obtaining mortgages, and many groups were concerned about redlining. To put it slightly differently, widespread concerns existed about whether there were racial disparities in the rate of denial of applications, and whether these disparities, if any, were a function of discrimination, or some other non-discriminatory factor.

In 1968, Congress had passed the Fair Housing Act, which contained an explicit anti-redlining provision. However, problems of discrimination in housing persisted, and Congress in 1975 passed the Home Mortgage Disclosure Act

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<sup>80</sup> Siegel et al., *supra* note 6 at 1.

<sup>81</sup> *Id.*

<sup>82</sup> See Llanos and Palmer, *supra* note 21 (describing how Oregon shared the results of its targeted effort to reduce diabetes disparities in its publicly distributed Minority Report Card) and Boston Public Health Commission, *supra* note 65 at 14 (describing Massachusetts General Hospital's plans to release its racial and ethnicity quality improvement targets and associated progress reports).

<sup>83</sup> Siegel et al., *supra* note 6 at 17.

(HMDA).<sup>84</sup> HMDA illustrates how federal regulations mandating data collection can serve as a powerful tool for social and policy change to improve the lives of marginalized and disenfranchised minority populations. The stated purposes of HMDA are:

- (i) To help determine whether financial institutions are serving the housing needs of their communities;
- (ii) To assist public officials in distributing public sector investments so as to attract private investment to areas where it is needed; and
- (iii) To assist in identifying possible discriminatory lending patterns and enforcing anti-discrimination statutes.

HMDA is a pure data collection statute. There is no private right of action under HMDA, meaning that the enforcement of HMDA is entirely dependent upon federal regulators. HMDA data itself is insufficient to state a civil rights claim under the Fair Housing Act or any other federal provision. However, HMDA data frequently gives a broad snapshot of trends that allows investigators to determine whether additional investigation is warranted.

A number of federal agencies are involved in the data collection effort, including the Federal Reserve, the Federal Deposit Insurance Corporation, the National Credit Union Administration, the Comptroller of the Currency, and the Office of Thrift Supervision. Collectively, these agencies comprise an interagency entity called the Federal Financial Institutions Examination Council (FFIEC). Financial institutions must comply with HMDA, and the term “financial institution” is broadly defined to include banks, savings associations, credit union and mortgage lending institutions, as well as their subsidiaries. They are required to report a variety of information on their mortgage lending practices to the FFIEC, including but not limited to information relating to the race and ethnicity of applicants for mortgages.

From 1975 to 1989, HMDA was in place but had little effect on lending practices. According to one expert, it had little effect because the data was collected but was not widely publicized or collected in a publicly accessible format.<sup>85</sup> In 1989, HMDA was amended to make the data public for the first time, although the specific identity of particular individuals was protected. Once data were publicly disseminated, community based organizations and other advocacy groups were

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<sup>84</sup> 12 USC § 2801.

<sup>85</sup> Interview with Kenneth Zimmerman, Executive Director, New Jersey Institute for Social Justice, Newark, New Jersey.

empowered because they could use the HMDA data to compare data on area lenders and put pressure to bear on lenders that appeared to have problematic data.

It was not until the sunshine amendments of 1989 that social science studies could be undertaken in order to examine the potential role of various explanatory factors, including but not limited to discriminatory practices. These analyses allowed policymakers to answer, for the first time, a critical question: the role played by discriminatory practices in producing disparate results. The findings flowing from these studies supported settlements aimed at reducing such practices when they were identified.<sup>86</sup>

### *The Lessons of HMDA*

A host of lessons can be gleaned from the HMDA experience. First, HMDA has given meaning to the adage that “knowledge is power” because it has assisted in answering critical questions about the role of discrimination. Knowledge can also be powerful in the health care context.

Second, HMDA illustrates that it is not simply important to collect data; rather, it is important to collect the right data. In the health context, stakeholders can and must develop consensus on standard data collections methods, as well as the types of data that should be collected. Otherwise, it becomes difficult to compare and analyze data. Perhaps data collection will differ between geographic areas. However, it is important to develop a commonly accepted language of data collection.

Third, it is also important to periodically reevaluate data collection. In the HMDA context, for instance, there currently is no data being collected by race and ethnicity on the interest rate that is being charged. With the emergence of predatory lending as a formidable civil rights challenge, the absence of this data is problematic. Similarly, in the health care settings, it is important to reexamine data collection protocols regularly and adjust to meet emerging concerns.

Finally, and perhaps most significantly, it is not simply important to collect data. It is also essential to report data, and ensure that data is accessible to the public at large. The 1989 sunshine amendment marked a critical turning point under HMDA. Similarly, allowing public access to data will enable policymakers and the public at

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<sup>86</sup> *U.S. v Albank FSB*, Case No. 97-CV-1206 (N.D.N.Y. 1997).

Available at, <http://www.usdoj.gov/crt/housing/documents/albanksettle.htm>. See also *U.S. v Decatur Federal Savings* Case No. 1 92-CV-2198-CAM (N.D. Ga. 1992).

available at, <http://www.usdoj.gov/crt/housing/documents/decaturcomp.htm>.

large to have a better handle on critical questions and potential trends. In so doing, it is important to be mindful of considerations of medical records privacy. However, it is possible to obtain basic necessary information without running afoul of the privacy regulation. Allowing wider access to this data can be a useful accountability tool, although it will undoubtedly be unsettling to some.

*B. Title VII of the Civil Rights Act of 1964*

Title VII of the Civil Rights Act of 1964 prohibits discrimination in the terms and conditions of employment on a number of bases, including race, ethnicity and gender. Data collection and dissemination is vital component of the Title VII enforcement framework. Covered employers are required to submit data on the race, ethnicity and gender of the workforce, including data disaggregated by the type of job being held (e.g., supervisory, non-supervisory). These data are used for a variety of purposes, including enforcement, self assessment by employers, and research.<sup>87</sup> Although the data is confidential, aggregated EEO data is available to the public. In the employment setting, mandatory race, ethnicity and gender data collection is a critical component of the effort to ensure a level playing field for women and people of color. The public reporting of aggregated EEO data is a critical accountability tool, and is used by government, employers, community stakeholders, and others to hold employers accountable.

*C. HIPAA Permits Publicly Reporting Racial and Ethnicity Data*

There is much confusion about the scope of activities allowed and prohibited under the HIPAA Privacy Rule, which protects the confidentiality of individually identifiable health information maintained by covered health care providers and plans (protected health information). In many circumstances, HIPAA requires the individual's permission to disclose protected health information. The Privacy Rule does not apply, however, to de-identified information. HIPAA considers information to be de-identified if it has had all 18 identifiers such as name, address, and social security number removed. As a general rule, HIPAA does not require the removal of race and ethnicity for information to be de-identified and permits the disclosure of aggregate data.<sup>88</sup> In addition, the HIPAA Privacy Rule permits the aggregate public reporting of racial and ethnicity data. For example, hospitals generally can report their outcomes data stratified by race.<sup>89</sup> Such reporting may be problematic only

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<sup>87</sup> EEO Surveys, [www.eeoc.gov](http://www.eeoc.gov).

<sup>88</sup> See 45 CFR § 164.514(b).

<sup>89</sup> See 45 C.F.R. § 164.514(b)(2)(ii).

where the population of the racial subgroups is so small that it would readily allow the identification of the individuals who are the subject of the information.<sup>90</sup>

## CONCLUSION

Information is power. Data on race, ethnicity and primary language can serve as a catalyst for the development and implementation of effective and innovative strategies to improve access to quality care for vulnerable populations. Ensuring data leads to meaningful innovation requires three related steps. Health care entities must (1) collect the right data; (2) analyze and use such data to design quality improvement and related programs, and (3) provide mechanisms for transparent reporting of such data. There is ample legal authority to move forward with all three steps, and there is a compelling policy and health care imperative for doing so. This Brief has outlined a roadmap for implementing these three steps, and has demonstrated that many plans and providers are already taking steps to collect such data and use it to solve disparities they have identified. It is imperative that plans continue to do so. This effort will lead to more transparency in the health system and provide us with information necessary to close the gap that currently exists.

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<sup>90</sup> See 45 CFR § 164.514(b)(ii) (which provides that information is not de-identified if the covered entity has “actual knowledge that the information could be used alone or in combination with other information to identify an individual who is the subject of the information”).

## Appendix

### Data Collection and Use Toolkits

#### **Health Research and Education Trust: A Toolkit for Collecting Race, Ethnicity, and Primary Language Information from Patients.**

Available at <http://www.hretdisparities.org/index.php>

“Designed to help hospitals, health systems, community health centers, health plans, and other potential users understand the importance of accurate data collection, assess organizational capacity to do so, and implement a framework designed specifically for obtaining information from patients/enrollees about their race, ethnicity, and primary language efficiently, effectively, and respectfully.” Includes sections on: Making the Case, Collecting the Data, Using the Data, Legal Issues, Privacy/Confidentiality, Staff Training, and Improvement Tools.

#### **American Health Insurance Plan: Tools to Address Disparities in Health: Data as Building Blocks for Change.**

Available at <http://www.ahip.org/content/default.aspx?docid=10761>

This Toolkit is geared for health professionals at health insurance plans and health care organizations. The first four components provide rationale for, and highlight the importance of, collecting and analyzing data on race, ethnicity, and primary care. These sections also include an overview of laws and regulations relating to data collection. The next three components provide information on how to collect, analyze, and use data. The last component includes resources and publications. AHIP plans to identify and build a clearinghouse of health insurance plan collection practices that can serve as innovative models to address disparities in health and health care within the industry.

#### **Center for Medicare and Medicaid Services: Planning Culturally and Linguistically Appropriate Services, Guide for Managed Care Plans**

Available at <http://www.ahcpr.gov/about/cods/planclas.htm>

This guide offers health plans an approach to defining the needs of multi-ethnic members and developing culturally and linguistically appropriate services for them. The guide helps plans address shifting demographic trends by offering an approach to defining the oral linguistic needs of members and developing strategies to meet their communication needs.

**Boston Public Health Commission: Disparities Project Tools**

Available at [http://www.bphc.org/director/disp\\_toolkit.asp](http://www.bphc.org/director/disp_toolkit.asp)

Hospital Working Group Online Toolkit: A reference and resource guide to the Hospital Working Group report recommendations. This Toolkit includes information and articles on the collection of data, and measurement of disparities.

Cultural Competency Assessment Toolkit: Designed in three sections, the Cultural Competence Assessment Tool offers health care organizations a framework for assessing the delivery of culturally and linguistically appropriate services.

Data Collection Toolkit: Example of intake tools that can be used by hospital and health center registration staff and community organizations to collect demographic information on patients and clients.

**Center for Health Care Strategies, Inc.: Reducing Racial and Ethnic Disparities: A Quality Improvement Initiative in Medicaid Managed Care**

Available at [http://www.chcs.org/usr\\_doc/Racial\\_&\\_Ethnic\\_Health\\_Disparities.pdf](http://www.chcs.org/usr_doc/Racial_&_Ethnic_Health_Disparities.pdf)

This toolkit details the experiences of a collaborative workgroup of Medicaid managed care organizations. From 2004 to 2006, 10 Medicaid health plans and one state primary care case management program worked together to develop new ways to identify members of racial and ethnic subgroups in their enrolled populations, to measure the gaps in their care, and to explore ways to reduce disparities and improve overall health care quality. The toolkit provides an overview of the kinds of problems workgroup members identified, their strategies for addressing barriers to care specific to racial and ethnic minorities, and the results of their efforts.