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The Legality of Collecting and Disclosing Patient Race and Ethnicity Data

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Robert Wood Johnson Foundation

Policy Brief

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SUMMARY OF FINDINGS

This Policy Brief, prepared for the Robert Wood Johnson Foundation, analyzes the following question: Whether the collection of patient data by race or ethnicity, as part of a program of quality improvement, violates the law.

First, Title VI of the 1964 Civil Rights Act (which prohibits discrimination on the basis of race or national origin by recipients of federal assistance) creates no legal liability for health care providers who collect and report health care quality data by race and ethnicity, when such an effort is undertaken as part of an overall program of quality improvement and not as a subterfuge for an impermissible purpose under the law. Experts in quality improvement – including the federal government – consider the evaluation of patient quality by race and ethnicity as an essential element of overall health care quality improvement. For this reason, the collection and disclosure of patient data by race and ethnicity in a quality improvement context advances the purposes of Title VI. Such practices would be entirely consistent with the regulations and would operate as evidence of compliance with the law rather than as a violation of it.

Second, the United States Department of Health and Human Services (HHS) could spur race and ethnicity patient data collection and disclosure by developing guidelines that set forth permissible data collection and disclosure practices as part of health care quality improvement. When followed, such guidelines would operate as evidence of compliance with applicable legal standards. Indeed, both the Bush and Clinton Administrations have used a similar approach under Title VI in outlining compliance guidelines for the health care industry with respect to language services for persons with limited English proficiency.

Third, the development of such guidance is essential in our view. Where race and ethnicity data collection are concerned, the health care industry lags notably behind comparable private sector industries, in particular housing, banking and lending. Furthermore, because health care services are not considered a public accommodation under the 1964 Civil Rights Act, as is the case under the Americans with Disabilities Act (ADA), voluntary reporting as part of cross-payer quality improvement effectively becomes the central means of ensuring system-wide quality improvement for all patients. In this respect, Title VI guidelines would guide health care data collection and reporting for the entire health care industry, even if legally applicable only to certain sectors. This industry-wide approach to race and ethnicity collection and disclosure standards presumably will benefit greatly by advances in health information technology and the creation of a national health information network operating in accordance with common standards.

Fourth, to the extent that health care providers may be concerned that race and ethnicity data could be used to pursue state-based medical liability theories, we believe that, just as with claims of discriminatory practices, the collection and disclosure of health disparities data showing disparities as part of quality improvement would operate as evidence of a professionally appropriate standard of care rather than negligence. To guard against the untoward use of such data, states could enact legislation treating race and ethnicity data collected for quality improvement purposes as evidence of professionally appropriate care.

Finally, the federal government could use its authority under the recently enacted Patient Safety Quality Improvement Act to incentivize the collection and reporting of such data.

1. THE EVOLUTION OF RACE AND ETHNICITY DATA COLLECTION AS PART OF HEALTH CARE QUALITY IMPROVEMENT

Information plays a critical role in the health care system. Recent attention has focused on the importance of health care information to quality improvement and medical error reduction,¹ as well as to the effective operation of the market for health services.² In discussing the data collection effort considered integral to the functioning of a high-performing health care system, experts stress the importance of systems that include the collection of patient data by race and ethnicity:

Standardized data collection is critically important in efforts to understand and eliminate racial and ethnic disparities in health care. Data on patient and provider race and ethnicity would allow researchers to better disentangle factors that are associated with health care disparities, help health plans to monitor performance, ensure accountability to enrolled members and payers, improve patient choice, allow for evaluation of intervention programs, and help identify discriminatory practices The challenges to data collection should be addressed, as the costs of failing to assess racial and ethnic disparities in care may outweigh new burdens imposed by data collection and analysis efforts.³

This expert opinion regarding the extent to which race and ethnicity data are intrinsic to overall health care quality measurement is echoed throughout federal agencies involved in health care quality measurement and improvement. The Agency for Health Care Research and Quality (AHRQ), the federal agency within HHS with overall responsibility for health care quality improvement, routinely links the collection of data on race and ethnicity to health care quality improvement.⁴ Data generated through computerized statistical systems maintained by the Centers for Medicare and Medicaid Services and the Veterans Administration have been used extensively to document differences in health care quality and patient outcome by race and ethnicity.⁵

¹ Institute of Medicine, *Crossing the Quality Chasm* (National Academy Press, Washington D.C., 2000)

² Federal Trade Commission, *A Dose of Competition* (Washington D.C. 2003)

³ Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, March 20, 2002, available at http://www.amsa.org/advocacy/IOM_Unequal_HCP.pdf at 6.

⁴ The AHRQ website is replete with reports and studies that link the examination and reduction of racial and ethnic disparities in health care to an overall quality improvement program. See, e.g., *Second National Reports on Quality and Disparities Find Improvements in Health Care Quality, Although Disparities Remain*. Available at <http://www.ahrq.gov/news/press/pr2005/nhqdr04pr.htm> (Accessed May 21, 2006); *Health Plans can work toward eliminating racial and ethnic health disparities by developing better data*, available at <http://www.ahrq.gov/research/jun02/0602RA26.htm#head5> (Accessed May 21, 2006); *Researchers examine racial and ethnic disparities in emergency care*, available at <http://www.ahrq.gov/research/apr04/0404RA4.htm> (Accessed May 21, 2006); AHRQ initiatives focus on understanding and reducing racial/ethnic disparities in health and health care (reporting on the agency's 5-year, \$45 million initiative to fund excellence centers to eliminate racial and ethnic disparities). Available at <http://www.ahrq.gov/research/jul02/0702RA21.htm> (Accessed May 21, 2006).

⁵ Much of this literature can be reviewed in the landmark study from the Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (National Academy Press, 2003). A

Evidence also suggests that states are similarly involved in efforts to add race and ethnicity data to public reporting standards for health care institutions. For example, in May 2006, the Massachusetts Division of Health Care Finance and Policy proposed amendments to expand hospital data submission requirements to include race and ethnicity data collected in accordance with the United States Office of Management and Budget (OMB) reporting standards.⁶ The proposed change notes that such data collection is “consistent with federal and EOHHS [state’s non-discrimination statute] standards.”⁷

An increasing emphasis on race and ethnicity data as basic elements of a comprehensive health care quality improvement strategy is not confined to government; collection of racial and ethnic health care data as part of quality improvement plays an increasing role in industry custom and practice. A 2004 study conducted by America’s Health Insurance Plans found that half of all responding entities collected race and ethnicity data, and at least one national health care accreditation organization has proposed to make the collection of racial and ethnic data part of its accreditation standards.⁸ Certain clinical practice providers, such as community health centers, routinely collect and evaluate race and ethnicity data as part of collaboratives to reduce health disparities in health care and outcomes.

Despite the large amount of evidence of evolving industry practices and government policy regarding race and ethnicity data collection in quality improvement, questions continue to linger regarding the legality – and the legal exposure created by – such collection efforts, particularly where collection is accompanied by a high degree of transparency through disclosure of system performance by patient race and ethnicity. It is never easy to talk about race, particularly because discrimination has been such a prominent feature of the history of U.S. medicine and health care.⁹ It is not surprising

compilation of studies also can be found in U.S. Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality* (Sept. 1999).

⁶ Memorandum from Judy Parlato to Interested Parties, dated May 11, 2006, “Summary of Proposed Amendments to 114.1 CMR 17.00: Requirements for the Submission of Hospital Case Mix and Charge Data.” (Commonwealth of Massachusetts, Executive office of Health and Human Services, Division of Health Care Finance and Policy).

⁷ *Id.* at 1.

⁸ America’s Health Insurance Plans, *Racial and Ethnic Data by Health Plans to Address Disparities: Final Summary Report*, Robert Wood Johnson Foundation, July 2004, available at <http://www.rwjf.org/files/research/080504AHIPFinalSummary.pdf> at 2, hereinafter [America’s Health Insurance Plans]; Robert Wood Johnson Foundation, *More Health Plans Addressing Gaps in Health Care Experienced by Minorities* (Princeton N.J., 2004), available at <http://www.rwjf.org/newsroom/newsreleasesdetail.jsp?id=10309>; Romana Hasain-Wynia, *Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data in Hospitals*, Commonwealth Fund, May 2004 at 4. In December 2004, the Joint Commission on Accreditation of Health Care Organizations proposed to make race and ethnicity data collection a requirement of accreditation. Although JCAHO subsequently decided not to include mandatory race and ethnicity data collection as a requirement for accreditation, the proposal itself underscores the degree to which the collection of such data is approaching the level of national industry practice. *Joint Commission on Accreditation of Healthcare Organizations Proposed Standards Language, Elements for Performance for IM.6.20*. (Dec. 2004).

⁹ This history is so extensively documented that it needs no further analysis. See e.g., *Unequal Treatment*, *supra*, n. 5; *The Health Care Challenge*, *supra*, n. 5. Perhaps the most definitive documented study of race

perhaps that the health care industry would be sensitive to any perception regarding less than equal treatment among patients of different racial and ethnic backgrounds, even if such differential treatment were unintentional.

These concerns on the part of the health care industry are perhaps even more understandable given the lack of federal guidance on the subject of collection of racial and ethnic data. Despite extensive federal standards issued by the OMB on data collection practices,¹⁰ as well as nearly a decade of focus on racial disparities as part of an overall approach to quality improvement across two Presidential Administrations, no federal agency has ever issued comprehensive guidelines regarding collection and disclosure of race and ethnicity data in health care quality improvement. The propriety of such collection and reporting can be inferred, of course, from numerous governmental sources, in particular, federal guidelines related to health care and human services to persons with Limited English Proficiency (LEP),¹¹ which calls for extensive self analysis as part of compliance:

Recipients should first examine their prior experiences with LEP encounters and determine the breadth and scope of language services that were needed. In certain circumstances, it is important in conducting this analysis to include language minority populations that are eligible for their programs or activities but may be underserved because of existing language barriers. . . . Recipients should assess, as accurately as possible, the frequency with which they have or should have contact with an LEP individual from different language groups seeking assistance. The more frequent the contact with a particular language group, the more likely that enhanced language services in that language are needed. . . . But even recipients that serve LEP persons on an unpredictable or infrequent basis should use this balancing analysis to determine what to do if an LEP individual seeks services under the program in question.¹²

and health care in the U.S. can be found in W. Michael Byrd, and Linda A. Clayton, *An American Health Dilemma: Race, Medicine, Health Care in the United States* (Routledge, NY, 2001). A particularly compelling study of physician interaction with patients and the racially identifiable results that may follow is found in Kevin A. Schulman, et al., *The Effect of Race and Sex on Physicians' Recommendations for Cardiac Catheterization*, 340 N.E. J. MED. 618 (1999). See also M. Gregg Bloche, *Race and Discretion in American Medicine*, 1 YALE J. HEALTH L. POL'Y & ETHICS 103.

¹⁰ The 1997 Office of Management and Budget Directive 15 required reporting of federal health statistics using five race categories and one ethnicity category. [Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity, 62 Fed. Reg. 58,782 \(Oct. 30, 1997\)](#). Federal agencies had until 2003 to comply with federal guidelines on race and ethnicity data collection practices that added a "Native Hawaiian and other Pacific Islander" category and allowed respondents to choose more than one race.

¹¹ HHS, *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/reviselep.html> (Accessed May 27, 2006). The guidance offers a range of compliance options, all of which begin with a detailed self-assessment by covered entities of the use of their facilities and services by protected individuals.

¹² *Id.*

But the implicit authority to examine racial and ethnic patterns is different from explicit and definitive federal guidance. This uncertainty is compounded by a fair degree of confusion regarding the reach of federal civil rights laws,¹³ as well as the possibility of state human rights laws applicable to the health care industry.¹⁴ Part of this confusion might stem from state laws that prohibit the use of racial data by insurers as a basis for actuarial calculations of risk.¹⁵ But these laws have no applicability in the context of data collection as part of quality improvement in health care. Whatever the basis, doubts remain.¹⁶

PATIENT RACE AND ETHNICITY DATA COLLECTION AND DISCLOSURE IN HEALTH CARE QUALITY IMPROVEMENT: THE ROLE OF TITLE VI OF THE 1964 CIVIL RIGHTS ACT

The Civil Rights Act of 1964 represents one of the great landmarks in civil rights legislation. The Act is comprised of a series of separate components each of which is aimed at remedying certain types of discriminatory practices. Title II reaches “public accommodations,” private enterprises such as transportation, restaurants, and hotels, that are not federally funded but that operate with a public purpose. Unlike the Americans with Disabilities Act, the 1964 Civil Rights Act does not classify health care as a public accommodation.¹⁷ As a result, health services providers are covered by the Act’s prohibitions only in an employment context under Title VII or as recipients of federal financial participation under Title VI.

¹³ Youdelman, M. et al., *Racial Ethnic and Primary Language Data Collection: An Assessment of Federal Policies, Practices and Perceptions*, National Health Law Program and The Commonwealth Fund (2001) available at http://www.cmwf.org/usr_doc/perot_raceethnic_492.pdf at v; National Health Law Program and the Office of Minority Health, *Assessment of State Laws, Regulations and Practices Affecting the Collection and Reporting of Racial and Ethnic Data by Health Insurers and Managed Care Plans* (2001) available at <http://www.omhrc.gov/omh/sidebar/datastats13.htm#reports>. Sidney D. Watson, *Reforming Civil Rights With Systems Reform: Health Care Disparities, Translation Services, & Safe Harbors*, 9 *WAS. & LEE RACE & ETHNIC AN. L. J.* 13, 17 (2003).

¹⁴ Several studies have examined state laws applicable to the health care industry. See National Health Law Program and the Office of Minority Health, *Assessment of State Laws, Regulations and Practices Affecting the Collection and Reporting of Racial and Ethnic Data by Health Insurers and Managed Care Plans* (2001) available at <http://www.omhrc.gov/omh/sidebar/datastats13.htm#reports>; Joel Teitelbaum and Sara Rosenbaum, *Medical Care as a Public Accommodation: Moving the Discussion to Race*, 29 *Am. J. L. and Medicine* 381 (2003).

¹⁵ California, Maryland, New Hampshire, and New Jersey currently prohibit collecting this information, and Connecticut, Iowa, Minnesota, South Dakota, and Washington will closely scrutinize proposed insurance application forms that include a race/ethnicity field. See National Research Council of the National Academies, 2004, *Eliminating Health Disparities: Measurement And Data Needs*, Chapter 6 “Private-Sector Collection of Data on Race, Ethnicity, Socioeconomic Position, and Acculturation and Language Use” (National Academies Press, Washington, DC).

¹⁶ Indeed, over the course of developing this analysis, one of the authors had a discussion with a colleague who is a highly experienced and able lawyer representing a large group medical practice. When she asked the lawyer about his client’s data collection practices in the area of race and ethnicity, his immediate response was that the practice could not do this without exposing itself to legal liability.

¹⁷ *Medical Care as Public Accommodation*, *supra* n. 14.

The Reach of Title VI

Title VI reaches entities that are considered “recipients” of federal funding. Title VI, whose authority rests on the Spending Clause, advances several underlying federal policies: a unified means of correcting all federal Spending Clause statutes enacted prior to *Brown v. Board of Education* that permitted “separate but equal” treatment;¹⁸ a means of authorizing federal agencies to prohibit discrimination and to act in a uniform way toward the problem of discrimination;¹⁹ and to establish an efficient alternative to litigation, permitting the federal government to seek change through intervention and corrective action;²⁰ and finally, as a means of reaching federally assisted private conduct otherwise exempt from Constitutional claims.²¹

That federally assisted health care was the subject of Title VI was readily evident during the Congressional debate over enactment. During the Senate debate, Senator Pastore, in a now-famous passage, made clear Congressional intent to eliminate segregation and exclusion in hospitals:

That is why we need Title VI of the Civil Rights Act, H.R. 7152 - to prevent such discrimination where federal funds are involved. . . . Title VI is sound; it is morally right; it is legally right; it is constitutionally right. . . . What will it accomplish? It will guarantee that the money collected by colorblind tax collectors will be distributed by federal and State administrators who are equally colorblind. Let me say it again: The title has a simple purpose - to eliminate discrimination in federally financed programs.²²

Because Title VI attaches to health care through Congress’ spending powers, it applies only to health care entities that are treated as receiving “federal financial assistance” within the meaning of the law.²³ Federal regulations promulgated in 1966 in the wake of enactment – and that remain essentially unchanged today – interpret the term “financial assistance” to include grants, training, equipment, donations of surplus property and other assistance.²⁴ The definition also reaches federal Medicare payments in all contexts other than direct fee-for-service payments made to physicians under the traditional Medicare Part B program. The definition of federal financial assistance also encompasses Medicaid and the State Children’s Health Insurance Program (SCHIP) payments.

¹⁸ *Reforming Civil Rights With Systems Reform: Health Care Disparities, Translation Services, & Safe Harbor*, *supra*, n. 13.

¹⁹ *Id.*

²⁰ *Id.*

²¹ *Id.*

²² *Id.* (citing 110 Cong. Rec. 7054 (1964) (Statement by Sen. Pastore)).

²³ *Id.*

²⁴ 68 Fed. Reg. 47311, 47313.

Federal assistance does not lose its character because it reaches health care providers as contractors²⁵ through broader intermediary payment systems, such as Medicare Advantage, Medicare Part D prescription drug coverage or Medicaid or SCHIP managed care organizations. Thus, health care professionals who receive payments as part of participating in a broader federally assisted health care system would be covered by Title VI.

There are two important exceptions to the meaning of “federal financial assistance,” only one of which is statutory. The first exception is “contract[s] of insurance or guaranty,”²⁶ which exempts from the meaning of the law indirect federal supports such as crop or flood insurance. In this respect, although Medicare Part A and Medicaid operate in the manner of health insurance, both programs historically have been treated as federal funding for Title VI purposes.²⁷

The second exception extends to physicians whose federal financial participation is limited to direct payment under the traditional Medicare Part B program. This exemption is an artifice of the history of Medicare and its interaction with Title VI. Lacking a statutory basis, the exemption is the result of a compromise between the Senate and the Johnson Administration in 1965 to prevent Medicare’s defeat in the face of widespread physician opposition.²⁸ The exemption originally rested on Medicare’s initial legal structure, under which Part B operated as an indemnification insurer, with no direct funding flowing to physicians. Although indemnification is now virtually a dead letter (direct payments to physician assignment have long since replaced indemnification as the principal means of Part B physician financing), every Administration has continued to adhere to the exemption.²⁹

²⁵ In one case interpreting the applicability of Title VI to health care, the Fifth Circuit held that a contractor’s direct role or “financial nexus” to the amount of Medicare and Medicaid funds paid to the hospital qualified the contractor as a primary recipient of federal funds, and hence obligated to abide by Title VI. *Frazier v. Bd. of Trustees of Northwest Mississippi Regional Medical Ctr.*, 765 F.2d 1278, 1290 n.29 (5th Cir. 1986).

²⁶ “Nothing in this subchapter shall add to or detract from any existing authority with respect to any program or activity under which federal financial assistance is extended by way of a contract of insurance or guaranty.” 42 U.S.C. § 2000d-4 (2000). Although Medicare Advantage and Part D involve risk contracts, both types of payments to participating organizations involve payment of governmental funds in various formats: risk contracts, direct subsidies for low income members, and stabilization funds.

²⁷ See, e.g., *United States v. Baylor Univ. Med. Ctr.*, 736 F.2d 1039, 1042 (5th Cir. 1984) (stating that Medicaid and Medicare funds constitute federal financial assistance).

²⁸ David Barton Smith, *A Nation Divided* (University of Michigan Press, 1994). In its 2000 LEP guidance the Clinton Administration eliminated the exemption, finding no legal basis for its continuation. The exemption was restored in the reissued LEP guidelines in 2003.

²⁹ See e.g., HHS guidelines for persons with limited English proficiency, *supra*, n. 11.

The Title VI Regulations

Congress delegated authority to federal agencies to implement Title VI, while at the same time maintaining legislative oversight powers to temper agency enforcement powers.³⁰ Federal agencies have the power to set standards, require the submission of data and take steps to terminate program funding where compliance problems are found and documented through review and hearing.³¹ The federal power includes an obligation to afford a suspected violator the right to voluntarily comply, as well as the duty to notify and report to Congress prior to taking fund withholding action following a finding of non-compliance.³²

Where data collection and reporting are concerned, the regulations do not require data collection by federal recipients, and legal action to compel collection has failed.³³ Given the tempered enforcement authority and the absence of compulsory data collection, the law can be said to rest in great part on the willingness of recipients of federal funds to voluntarily conform to the fundamental goal of Title VI: to end exclusion, segregation and discrimination in federally assisted programs. The regulations aim for achieving this goal through two key provisions that have remained untouched over four decades:

*A broad sweep to the concept of non-discrimination.*³⁴ In broad language, the rules prohibit discrimination on account of race, color or national origin. The rules are not restricted to intentional discrimination but reach *de facto* discrimination (i.e., discrimination in effect) as well.³⁵ They are explicit in their concept of what it means to discriminate: the outright denial of service; subjecting individuals to segregation or

³⁰ “Each federal department and agency which is empowered to extend federal financial assistance to any program or activity . . . is authorized and directed to effectuate the provisions of section 2000d of this title . . . by issuing rules, regulations, or orders of general applicability which shall be consistent with achievement of the objectives of the statute No such rule, regulation, or order shall become effective unless and until approved by the President.” 42 U.S.C. § 2000d-1, Pub. L. 88-352, title VI, Sec. 602, July 2, 1964, 78 Stat. 252. 45 C.F.R. §80.1.

³¹ “Compliance with any requirement adopted pursuant to this section may be effected (1) by the termination of or refusal to grant or to continue assistance under such program or activity to any recipient as to whom there has been an express finding on the record, after opportunity for hearing, of a failure to comply with such requirement, . . . or (2) by any other means authorized by law.” *Id.*

³² “[N]o such action shall be taken until the department or agency concerned has advised the appropriate person or persons of the failure to comply with the requirement and has determined that compliance cannot be secured by voluntary means. In the case of any action terminating, or refusing to grant or continue, assistance because of failure to comply with a requirement imposed pursuant to this section, the head of the federal department or agency shall file with the committees of the House and Senate having legislative jurisdiction over the program or activity involved a full written report of the circumstances and the grounds for such action. No such action shall become effective until thirty days have elapsed after the filing of such report.” *Id.*

³³ *Madison-Hughes v. Shalala*, 80 F.3d 1121, 1123 (6th Cir. 1996). See Bureau of National Affairs, *HHS Not Required To Amass Race Data To Comply With Civil Rights Act Rules*, 5 BNA HEALTH L. REP., Apr. 25, 1996.

³⁴ 45 C.F.R. §80.3.

³⁵ 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 Health Policy Law and Ethics 215-290 (2003).

separate treatment; or restricting individuals in any way, or treating individuals differently from others in determining admission, enrollment, quota, membership or other requirements or conditions that individuals must meet in order to be provided any service, financial aid or other benefit. Most significantly in the context of this analysis, the regulations classify differential treatment in the provision of services as a prohibited form of discrimination.³⁶

*A regulatory scheme that contemplates ongoing self-examination and preventive efforts to avert potential discrimination.*³⁷ The regulations require recipients of federal funds to take affirmative steps to overcome prior discrimination. More importantly, *even absent evidence of prior discrimination*, the rules authorize recipients to take affirmative steps to overcome the effects of conditions that might in some way be discriminatory.³⁸ In other words, the regulations serve a preventive purpose and encourage ongoing private conduct aimed at deterring results that could be adverse to individuals who receive services under the program. It is this regulatory emphasis on ongoing and preventive engagement that gives Title VI the potential to be both dynamic and evolutionary to changing circumstances. In health care this is critical, given the dramatic transformation of health care organization and financing since the passage of Title VI. Were the law tied strictly to federal financing as it existed in 1964 and to evidence of past discrimination, it would lack the preventive thrust that Congress envisioned in its effort to ensure that federal funds no longer would be used in a discriminatory manner.

In short, Title VI regulations establish a broad standard of non-discrimination, coupled with an emphasis on self-analysis and active encouragement of such assessments on a *preventive basis*. In crucial ways, this framework critically juxtaposes civil rights law against the preventive, transparency and self-assessment nature of health care quality improvement. In a health care context, these two sets of goals – the elimination of disparities and the improvement of quality – join together within an overall approach to health care quality improvement that simultaneously lifts quality while achieving the highest purpose of Title VI – the prevention of disparities. Put another way, the prevention of health care disparities emerges as legally intrinsic to the overall goal of quality improvement. The act of examining disparities as part of quality improvement becomes the highest form of civil rights compliance; in effect, the goal of health care quality improvement simply cannot be realized without addressing equality in the rendering of health care treatment.

If anything, this juxtaposition of civil rights law and quality improvement systems has become more important as a result of the United States Supreme Court's 2001 decision in *Alexander v Sandoval*,³⁹ which held the *de facto* discrimination rule to be privately unenforceable and ruled that only federal agencies had the power to enforce this standard through administrative interventions. Because *Sandoval* limits private enforcement to acts of intentional discrimination – in all likelihood a rarity today – it is

³⁶ 45 C.F.R. § 80.3.

³⁷ 45 C.F.R. §80.3(b)(6).

³⁸ 45 C.F.R. § 80.3(b)(6).

³⁹ 532 U.S. 275 (2001).

the sole responsibility of federal agencies to advance compliance with the *de facto* standard through guidance and active engagement in efforts to promote equality.⁴⁰

Although the legality of voluntary conduct related to the examination of performance has never been explicitly addressed by the courts, its propriety can be implied. Indeed, it was precisely this type of active self-engagement through the use of information about performance that underlay efforts on the part of the University of Michigan to ensure high quality of the student educational experience.⁴¹ Although the precise means by which federally assisted entities might achieve equality (i.e., the use of quotas) became the subject of scrutiny by the United States Supreme Court, the fundamental notion that self-assessment through the collection and analysis of information is critical in its own right went unchallenged. In other words, even though certain remedial approaches might be open to question in certain contexts, the act of self-examination is not.

The notion that the law encourages – rather than prohibits – the collection of race and ethnicity data as part of an overall program of quality improvement is bolstered by the enactment of the Minority Health and Health Disparities Research and Education Act of 2000 (MHHDREA).⁴² Among other matters, the legislation required the National Academy of Sciences to study HHS’ existing data collection reporting systems and practices and report to Congress on the range of data necessary to support an effective response to racial and ethnic disparities:

The National Academy of Sciences shall conduct a comprehensive study of the Department of Health and Human Services' data collection systems and practices, and any data collection or reporting systems required under any of the programs or activities of the Department, relating to the collection of data on race or ethnicity, including other Federal data collection systems (such as the Social Security Administration) with which the Department interacts to collect relevant data on race and ethnicity. . . . [T]he National Academy of Sciences shall prepare and submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Commerce of the House of Representatives, a report that. . . . identifies the data needed to support efforts to evaluate the effects of socioeconomic status, race and ethnicity on access to health care and other services and on disparity in health and other social outcomes and the data needed to enforce existing protections for equal access to health care.⁴³

The legislation underscores Congressional policy regarding the importance of race and ethnicity data collection as part of health care.⁴⁴

⁴⁰ *Civil Rights in the Modern Health Care System*, *supra*, n. 35.

⁴¹ *Gruter v Bollinger* 539 U.S. 982 (2003); *Gratz v Bollinger* 539 U.S. 244 (2003).

⁴² PL 106-525 (S 1880) November 22, 2000.

⁴³ *Id.* at sec. 301.

⁴⁴ In 2004 the Institute of Medicine published *Eliminating Health Disparities: Measurement and Data Needs* (National Academy Press, Washington D.C.) The report states that “disparities in health and health

Congressional intent underlying the appropriateness of race and ethnicity data collection mirrors public opinion on this matter, as evidenced by the defeat of a ballot initiative to make such data collection unlawful. California's recent debate over Proposition 54 represents the most prominent example of the level of popular support for efforts to understand and address disparities in health care. Proposition 54 was an outgrowth of Proposition 209, a successful California voter initiative to prohibit the state from granting preferential treatment to women and people of color in public education, contracting and employment.⁴⁵ Proposition 54 was rejected however,⁴⁶ despite the fact that it targeted the same three areas addressed in Proposition 209 (public education, public contracting and public employment), in part because of public perception regarding the impact of the initiative on basic health care quality and safety; proponents went so far as to exempt racial classification for purposes of medical research and clinical treatment in order to gain support.⁴⁷ In the wake of its defeat, the Proposition's chief proponent underscored the need for language that "would protect health care" because "the voters generally embrace the ideas of Prop. 54, but the opposition very, very effectively raised doubts about the health issue."⁴⁸

Potential Federal Action to Spur Race and Ethnicity Data Collection in Health Care Quality

In their emphasis on proactive engagement to avoid disparities, the federal regulations contemplate the voluntary and active collection of race and ethnicity data among federal assistance recipients. Although HHS has never set forth guidelines governing race and ethnicity data collection by Title VI-covered health care entities as part of quality improvement, one might presume that a reasonable approach in a health care context would incorporate the following elements:

- A clear stated purpose that race and ethnicity data collection is part of an overall quality improvement program and not as a subterfuge to achieve an impermissible purpose under the law;⁴⁹

care across racial, ethnic, and socioeconomic backgrounds in the United States are well documented [but] [t]he reasons for these disparities are, however, not well understood. Current data available on race, ethnicity, SEP, and accumulation and language use are severely limited." The report makes extensive recommendations regarding improvements in data collection. To date, Congress has not acted on these findings.

⁴⁵ See Chris Chambers Goodman, *Redacting Race in the Quest for Colorblind Justice: How Racial Privacy Legislation Subverts Antidiscrimination Laws*, 88 MARQ. L. REV. 299 (2004).

⁴⁶ *Id.*

⁴⁷ See California Health Care Foundation, *Racial and Ethnic Data Collection and Use in Health Care: Examples of Projects That Might be Affected by Proposition 54*, 3 (2003) available at <http://www.chcf.org/documents/policy/RacialAndEthnicDataCollection.pdf>.

⁴⁸ Tanya Schevitz, *Prop. 54 Defeated Soundly; State Initiative On Racial Privacy Raised Issues About Health, Education*, S.F. CHRON. Oct. 8, 2003 available at <http://sfgate.com/cgi-bin/article.cgi?f=c/a/2003/10/08/MN215579.DTL>.

⁴⁹ The assurance that lawful operational activities not be used as a subterfuge to mask unlawful conduct is common in health care. See e.g., ERISA Title V (prohibiting the use of actuarial data as a subterfuge);

- Uniformity of collection scope, so that all persons using health care services participate in the same type of collection activity;
- Collection at points other than the point of service (e.g., at time of plan enrollment or patient registry) in order to minimize disruption of the process of clinical care;
- Utilization of appropriate collection standards and methodologies (e.g. self-reporting in secure environments using OMB guidelines applicable to the collection of race and ethnicity data); and
- Compliance with patient privacy and security safeguards both in the collection phase and in public reporting of results.

In our view, were the federal government to develop such guidelines, this action would help pave the way for race and ethnicity data collection and disclosure as part of a broader program of health care quality improvement. The operation of such a quality improvement program – built first and foremost on self-assessment – becomes central evidence of compliance with Title VI, just as corporate compliance with the LEP guidelines is considered evidence of compliance with federal law.

THE HEALTH CARE LAG IN RACE/ETHNICITY DATA COLLECTION

A strong reason to spur the broad and transparent collection and disclosure of race and ethnicity data as a basic component of health care quality has to do with the extent to which such collection efforts have lagged behind other sectors as a matter of federal policy. To be sure, HHS collects data on race and ethnicity in health care programs either as a matter of custom or law. For example, all federally funded health centers must report race and ethnicity data, as must grantees under the Maternal and Child Health Services Block grant program.⁵⁰ Similar reporting requirements exist for grantees under the Substance Abuse and Mental Health 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.⁵¹ As noted previously, the Medicare program has collected data on race from the program’s inception, and its special databases have yielded some of the most important disparities studies to be found in the literature.⁵²

federal EMTALA regulations permitting the discharge of patients admitted for stabilization if the admission is not a subterfuge to avoid ERISA stabilization requirements. 42 C.F.R. 484.24.

⁵⁰ *Racial Ethnic and Primary Language Data Collection: An Assessment of Federal Policies, Practices and Perceptions*, *supra* n. 13 at 3.

⁵¹ *Id.* at 4.

⁵² The Centers for Medicare and Medicaid Services (CMS) obtains racial and ethnic data about Medicare beneficiaries through the Social Security Administration (SSA). The SSA permits enrollees to self-identify their race as part of their SSA application. CMS has established a number of Medicare databases that include information on both Medicare fee-for-service (FFS) and Medicare managed care (Medicare Plus Choice) plans. The “Enrollment DataBase” is CMS’ basic database for Medicare beneficiaries, while CMS surveys, such as the Current Beneficiary Survey, provide the means to assess Medicare patient service

Despite this set of activities, health care lacks the type of broad systemic approach to race and ethnicity data collection and measurement found in other sectors of the private economy. Were health services to be classified as a public accommodation for purposes of race and ethnicity, as is the case for purposes of disability under the ADA, this systemic lag might have abated over time. But where racial and ethnic data are concerned, civil rights law tends to operate in a “Balkanized” fashion, with collection standards and rules varying from program to program. As the nation moves toward health system interoperability through health information, some of this Balkanization might abate. For purposes of thinking about how to use clarifying civil rights standards to “lift” quality performance across the health care system, not merely for federally assisted programs, it is instructive to review other federal policies regarding systemic private sector data performance in the areas of race and ethnicity. Several striking examples exist.

Compulsory Racial Data Collection: Housing, Lending & Employment

Housing and Lending

Title VIII of the Civil Rights Act of 1968, also known as the Fair Housing Act (FHA), prohibits discrimination in the sale or rental of housing on the basis of race, religion, sex, family status, national origin or the existence of a disability.⁵³ The Act requires the Secretary of Housing and Urban Development (HUD), who is responsible for administration, to annually report to Congress and make available to the public “data on race, color, religion, sex, national origin, age, handicap, and family characteristics of persons and households who are applicants for, participants in, or beneficiaries or potential beneficiaries of programs administered by the Department.”⁵⁴ The regulations give the Secretary discretion in the details of collection.⁵⁵ As with health care, public subsidies for housing reach deeply into the private sector.

The Home Mortgage Disclosure Act (HMDA), passed in 1975, provides citizens and public officials with loan data that can be used to determine whether financial institutions are serving the housing needs of the communities in which they are located, and to assist in identifying possible discriminatory lending patterns and enforcing anti-

utilization. CMS uses these databases and surveys to regularly update its racial data. As a result, the system employed to track racial and ethnic data of Medicare beneficiaries gives Medicare data an added precision not common to other federal health care programs. See generally, Marshall McBean, Medicare Race and Ethnicity Data, National Academy of Social Insurance (2004), available at:

http://www.nasi.org/usr_doc/McBean.pdf.

⁵³ 42 U.S.C. § 3604.

⁵⁴ *Id.* at §§ 3608(a), (e)(6).

⁵⁵ 24 C.F.R. § 121.2 (participants in the program “shall furnish to the Department such data concerning race, color, religion, sex, national origin, age, handicap, and family characteristics of persons and households who are applicants for, participants in, or beneficiaries or potential beneficiaries of, those programs as the Secretary may determine to be necessary or appropriate to enable him to carry out his or her responsibilities under the authorities referred to in §121.1”). The discretionary language is similar to that in the HHS regulations. See 45 C.F.R. § 80.6(b).

discrimination statutes.⁵⁶ The Act reaches into the banking industry, one of the most private of private endeavors. The Act was originally passed to identify banks that were taking deposits from lower-income neighborhoods without reinvesting that money in the form of loans to the same neighborhoods.⁵⁷ From the mid-1970s to the late 1980s, institutions were required to report aggregate statistics about the dollar amounts and specific locations of their residential loans but did not have to disclose their lending on a loan-by-loan basis.⁵⁸ In the late 1980s, the focus changed from “disinvestments” to discrimination, and an amendment in 1989 expanded HMDA reporting to include an applicant’s race and ethnicity.⁵⁹

This Act applies to depository institutions and other mortgage lenders.⁶⁰ Lenders are required to compile specific data in a Loan Application Register (LAR) about applications for, originations of and purchases of home-purchase loans, home-improvement loans and refinancing of home-purchase loans.⁶¹ The regulations require lenders to ask each applicant about their race and ethnicity, although the applicant is not required to provide the information.⁶² Data must be disclosed to the agency by March 1, following the calendar year for which the loan data are compiled.⁶³ The Federal Financial Institutions Examination Council (FFIEC) then prepares a public disclosure statement based on the data submitted by each institution.⁶⁴

HMDA data are most often used by government agencies as an indication of which lender’s practices may warrant investigation for compliance with fair lending laws, including the Equal Credit Opportunity Act (ECOA), which prohibits creditors from discriminating based on race, color and other categories consistent with the FHA.⁶⁵ The FFIEC has continuously emphasized that although HMDA data are used as “indicators,” they are not conclusive evidence of discrimination because they do not include important factors that are considered in determining loan pricing or approval.⁶⁶

⁵⁶ 12 C.F.R. § 203.1(b).

⁵⁷ Joseph Kolar and Jonathan Jerison, *The Home Mortgage Disclosure Act: Its History, Evolution, and Limitations*, 59 CONSUMER FIN. L. Q. REP. 189, 189-90 (2005).

⁵⁸ *Id.* at 190.

⁵⁹ 12 C.F.R. § 203.4(a)(10).

⁶⁰ *See Id.* at § 203.1(c). This is in contrast to the FHA, which is broader in scope and applies to discrimination in housing by landlords and real estate companies as well as banks, other lending institutions, and homeowners’ insurance companies. *See* <http://www.usdoj.gov/crt/housing/faq.htm>.

⁶¹ 12 C.F.R. 203.4(a). *See* <http://www.ffiec.gov/hmda/pdf/hmdalar2004.pdf>.

⁶² 12 C.F.R. Part 203 Appendix B. The regulations advise lenders that the applicant can be informed that the federal government requests this information in order to monitor compliance with federal statutes that prohibit lenders from discriminating against applicants on these bases. *Id.*

⁶³ *Id.* at § 203.5(a)(1).

⁶⁴ *Id.* at (b)(1).

⁶⁵ *See* Kolar, *supra* note 56, at 200; *see also* *United States v. Northern Trust Company*, Complaint, <http://www.usdoj.gov/crt/housing/documents/northerncomp.htm> (HMDA data indicated substantially higher denial rates of home mortgage applications for African-Americans and Hispanics as compared to whites and were used as evidence of disparate treatment prohibited by the FHA and ECOA).

⁶⁶ *See* <http://www.ffiec.gov/hmcrpr/hm091305.htm>. In a September 2005 press release, the FFIEC cautioned that “[t]he HMDA data are not, by themselves, a basis for definitive conclusions regarding whether a lender unlawfully discriminates against particular borrowers or takes unfair advantage of them.” *Id.*

The FFIEC collects and assembles HMDA data to show trends over time in the number of loans by race and ethnicity.⁶⁷ The data show a consistent improvement in lending practices, even though significant problems remain.⁶⁸ The critical importance of the data is that at all levels of government, policy makers have a national sense of both a baseline and progress on key measures of accountability for a system as a whole.

Employment

Title VII of the Civil Rights Act of 1964 prohibits “unlawful employment practices,” such as refusing to hire any individual; discriminating with respect to his compensation, terms, conditions, or privileges of employment; classifying employees or applicants for employment in any way which would deprive any individual of employment opportunities; or adversely affecting the status of an employee because of race, color, religion, sex, or national origin.⁶⁹ Equal Employment Opportunity Commission (EEOC) regulations require every employer to make and keep records relevant to the determinations of whether unlawful employment practices have or are being committed, and subsequently to make reports for the enforcement of the Act or its regulations.⁷⁰ The regulations apply to private employers, joint labor-management committees with apprenticeship programs, labor unions, state and local governments, public schools and institutions of higher education.⁷¹ As such, they span the system of employment, not merely employers that receive federal financial assistance. This systemic collection of race and ethnicity data related to employment has survived legal challenge.⁷²

In sum, both the credit and lending industries and the entire employment sectors of the economy are expected by law to supply race and ethnicity data as part of an overall system of federal regulation and accountability. As the effort to achieve health system interoperability through health information unfolds, race and ethnicity of patients similarly could be thought of as a core operational element of such a system, with commensurate transparency in disclosure at a reporting unit level of race and ethnicity data.

⁶⁷ See <http://www.ffiec.gov/hmcrpr/hmda03.pdf#table7>.

⁶⁸ See <http://www.ffiec.gov/hmcrpr/hmda03.pdf#table7>.

⁶⁹ 42 U.S.C. § 2000e-2.

⁷⁰ See *Id.* at § 2000e-8(c), 29 C.F.R. § 1602.1.

⁷¹ See 29 C.F.R. §§ 1602.7, 1602.15, 1602.22, 1602.32, 1602.41, and 1602.50.

⁷² In *United States v. New Hampshire*, 539 F.2d 277 (1st Cir. 1976), the state of New Hampshire challenged the power of the federal government to collect data under Title VII and argued that furthermore, the Act was unconstitutional. The court disposed of all of the state’s arguments, holding that the federal government had the legal power to interpret Title VII to require such data, noting the importance of statistics, especially in the area of racial discrimination. The court rejected state claims regarding the potential for misuse of data, declaring that the “possible and purely hypothetical misuse of data” does not mandate the banning of reasonable approaches to gather such information. The court also found that record-keeping and reporting in the case of state governments was authorized by the Fourteenth Amendment to the United States Constitution and furthermore represented a valid exercise of congressional power under the commerce clause.

ADDRESSING CONCERNS OVER STATE LIABILITY

Previous research into the state of state civil rights law has found no evidence of prohibitions against race and ethnicity data collection and reporting. In addition, no state appears to classify health care providers as a public accommodation for purposes of prohibiting discrimination on the basis of race or ethnicity. While health care providers are bound by federal and state employment laws, they are not subject to reporting and regulatory standards applicable to private enterprises open to the public. In a civil rights context, this special classification is reserved for persons with disabilities under the ADA.

Nonetheless, providers may be concerned that extensive information on patient care and outcome by race and ethnicity could be relevant to other forms of liability, most notably liability for medical negligence. In other words, the concern is that evidence of past performance toward one particular racial or ethnic group might be relevant to a determination of liability for poor outcome in the context of a single case.

It is never possible to predict whether admissible evidence may be used in a fashion that incriminates or exculpates. There is a fair argument to be made that, in a medical negligence action, evidence of overall attention to health care quality for patients, both generally as well as with respect to distinct patient sub-populations, might serve as evidence of adherence to a patient-centered standard of care. In effect, evidence of the extent to which a provider is willing to go to assure health care of equal quality would tend to dispel the notion that negligent inattention to personal patient characteristics played a role in a poor health outcome.

At the same time, it is never possible to give complete assurances. One option might be to develop model legislation that classifies as evidence of adherence to a professional standard of care the existence of an overall quality improvement program that is consistent with the elements outlined above, including purpose, collection methods, uniformity and utilization and disclosure of results. In effect, liability law could be used to incentivize the adoption of quality improvement systems that include data on race and ethnicity, by classifying the use of such systems as evidence of a high quality of care.

USING THE PATIENT SAFETY AND QUALITY IMPROVEMENT ACT TO INCENTIVIZE PATIENT RACE AND ETHNICITY DATA COLLECTION AND REPORTING

An alternative approach might be linkage of health care quality improvement systems incorporating race and ethnicity data to the federal privilege established under the Patient Safety and Quality Improvement Act of 2005 (PSQIA). The PSQIA was enacted in order to “reduce the incidence of events that adversely affect patient safety” through the creation of incentives to adopt patient safety reporting systems.⁷³ The law

⁷³ See P.L. 109-41 (2005).

establishes entities known as patient safety organizations (PSOs),⁷⁴ which contract with health care providers to receive and review patient safety information, known as “patient safety work product.” Patient safety work product is defined as “any data, reports, records, memoranda, analyses . . . assembled or developed by a provider for reporting to a PSO and are . . . reported to a PSO or developed by a PSO for the conduct of patient safety activities.”⁷⁵ These patient safety activities include efforts to improve patient safety and quality of health care, collection and analyses of patient safety work product, the development and dissemination of information to improve patient safety, such as recommendations or protocols, the utilization of patient safety work product to encourage a culture of safety and of providing feedback and assistance to minimize patient risk, and maintenance of procedures to preserve confidentiality of patient safety work product.⁷⁶

In exchange for providing patient safety work, reporting entities receive a federal privilege covering the work product. The privilege would act as a shield against the introduction of such evidence in a liability action: the law provides that patient safety work product is not subject to “federal, state or local civil, criminal, or administrative proceeding, not subject to the Federal Freedom of Information Act, not admissible as evidence in any federal, state, or local, governmental, civil, criminal, or administrative proceeding, and not admissible in any professional disciplinary proceeding of any state professional disciplinary body.”⁷⁷

The privilege attaches only if and when the information is reported to the PSO. Merely assembling or developing data to help reduce medical errors or improve quality is not sufficient to qualify for the privilege. Additionally, there are limited exceptions to the privilege. But unlike other privileges such as those that attach to state medical error reporting and the HIPAA privacy regulations, even if the patient safety work product is disclosed, it continues to be privileged.⁷⁸

Thus, the PSQIA may create an additional option for ensuring that patient race and ethnicity data are not subsequently used in a liability action. This result might be achieved by classifying patient race and ethnicity data as an essential part of patient safety information to be reported to PSOs. Of course because privilege acts as a shield, one limitation of this approach is whether it might undermine the broader goal of transparency in health information. The tension between transparency and the shield may not be insurmountable, however. The PSQIA contemplates extension of the shield even when data become public. It thus would appear that quality reporting by PSOs and reporting health care entities, both overall and by race and ethnicity, could be squared with the *uses* of such data in private enforcement actions predicated on one or more theories of legal liability.

⁷⁴ *Id.* at Section 2, adopting new Public Health Service Act § 921(4).

⁷⁵ *Id.* at § 921(7)(A).

⁷⁶ *Id.* at § 921(5).

⁷⁷ *Id.* at § 922(a).

⁷⁸ *Id.* at § 922(d).