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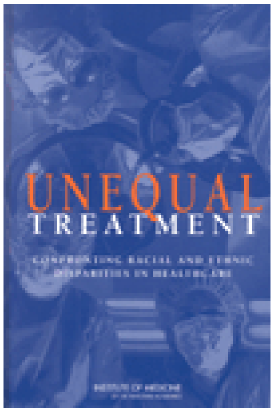

Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (with CD)

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7

Data Collection and Monitoring

The preceding chapters illustrate the complexity and variety of factors—including healthcare financing arrangements, institutional and organizational characteristics of healthcare settings, aspects of the clinical encounter, and the attitudes, perceptions, and beliefs of healthcare providers and their patients—that influence healthcare disparities. The complexity of these factors, coupled with the fact that disparities in care are not always apparent to patients or providers in clinical encounters, increases the need for data to better understand the extent of disparities and the circumstances under which disparities are likely to occur. Unfortunately, standardized data on racial and ethnic differences in care are generally unavailable. Federal, private, and state-supported data collection efforts are scattered and unsystematic, and many health plans, with a few notable exceptions, do not collect data on enrollees' race, ethnicity, or primary language, pointing to significant obstacles to the collection and analysis of such data (Perot and Youdelman, 2001).

Standardized data collection, however, is critically important in the effort to understand and eliminate racial and ethnic disparities in healthcare. Having data on patient and provider race and ethnicity would allow researchers to better disentangle factors that are associated with healthcare disparities. In addition, collecting appropriate data related to racial or ethnic differences in the process, structure and outcomes of care can help to identify discriminatory practices, whether they are the result of intentional behaviors and attitudes, or unintended—but no less harmful—biases or policies that result in racial or ethnic differences in care that cannot be justified by patient preferences or clinical need. Data collection and monitoring therefore provides critically needed information for civil rights enforcement. Further, collecting and analyzing patterns of care by patient race, ethnicity, and other demographic data can help health plans to monitor plan performance. Such monitoring can help to ensure accountability to enrolled members and payors, improve patient choice, and allow for evaluation of intervention programs. Such evaluations are likely to improve service delivery for racial and ethnic minority populations, and therefore may result in cost savings that would offset the costs of data collection.

The collection of racial and ethnic data in health systems poses special challenges, however. Traditionally, the practice of healthcare has been dominated by individual practitioners who delivered care in settings relatively unaffected by regulation, oversight, or government intervention. Hospitals enjoyed little external monitoring, and their professionally dominated and autonomous organizational structure was rarely challenged prior to the emergence of the federal government as the largest healthcare payor. Today's cost-conscious healthcare systems present an opportunity for greater healthcare practice accountability, but medicine's traditional autonomy and self-government presents little history of oversight, particularly with regard to civil rights, that can be expanded upon (Smith, 1998).

Specific recommendations regarding the types of healthcare data that should be collected, and how this information should be analyzed and reported has been the subject of intensive study and debate by governmental (U.S. DHHS, 1999) and private groups (National Quality Forum, 2001; Perot and Youdelman, 2001), and is beyond the scope of this report. Selecting indicators of healthcare disparities that can be readily measured, analyzed and reported, and developing methods to ensure reliable data collection will require careful consideration of costs, benefits, and other potential problems inherent in collecting and reporting patient care data (see discussion of obstacles to racial/ethnic data collection, below). These issues will be weighed by a forthcoming National Academies study committee that has been asked by Congress to assess the adequacy of racial and ethnic data within U.S. Department of Health and Human Services (DHHS) systems. Ideally, however, all patient encounters should be assessed for the quality of care and patient outcomes. This would enable the data to be aggregated to many different levels of the healthcare delivery system, including health plans, medical groups, and hospitals. Most of the information collected should be recorded as part of the patient's medical record, a task that in the future will be assisted greatly by the development of electronic patient records. These data should be stratified by race, ethnicity, as well as socioeconomic status and, where possible, primary language.

OBSTACLES TO RACIAL/ETHNIC DATA COLLECTION

The need for data on patients' race and ethnicity and quality of care must be balanced against other significant considerations. Foremost, patient privacy must be protected. The confidentiality and security of patient information and data transactions must, at minimum, conform with standards set forth in the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Secondly, the costs of data collection must be weighed relative to its benefits. When and how such data are collected will have broad cost implications; collection of patient race and ethnicity data at the point of plan enrollment, for example, will likely be less expensive than data collection among members already enrolled in plans whose race or ethnicity is unknown. Similarly, administrative and paperwork burdens are likely to increase as the numbers of patient data elements are increased. Formal Congressional checks on such administrative burdens (e.g., the Paperwork Reduction Act) require that administrators of publicly-funded programs assess such costs and demonstrate the utility of additional data collection relative to costs.

Other legal constraints must be assessed, as well. While the vast majority of states do not prohibit collection of patients' race and ethnicity data, some may impose restraints on when and how such data may be collected (Perez and Satcher, 2001). The extent of these restraints must be assessed and this information provided to managed care organizations (MCOs) and payors to avoid confusion over what kinds of data collection are allowed, and under what circumstances.

Political concerns must be also addressed to ensure cooperation from all parties in data collection efforts. Resistance to data collection efforts may come from healthcare providers, institutions, plans, and patients, unless the purposes and benefits of data collection are clearly explicated. Providers, as noted earlier, may resent perceived intrusions on autonomy. Patients, particularly minority patients, may worry that racial or ethnic data collection will result in "redlining" of services, selection of enrollees, or rationing of services on the basis of race or ethnicity.

Efforts to enforce data collection from the federal level may also meet resistance from state authorities, who retain primary responsibility for determining data requirements of health plans with whom states contract for Medicaid MCO services. Federal efforts to require the collection of patients' racial and ethnic data would raise challenges from those who find federal reporting requirements already burdensome and the federal role in dictating the terms of managed care contracts too extensive. Finally, it should be noted that some individuals are broadly opposed to government involvement in monitoring race and ethnic trends among the U.S. population, and are mounting challenges to the notion that the government should collect any information about race or ethnicity. Ward Connerly, for example, the California businessman who led efforts to repeal affirmative action in that state, is spearheading a ballot initiative to prevent the state from collecting any information about race or ethnicity, except for a few limited circumstances (Jordan, 2001). This initiative would likely undercut efforts to assess racial and ethnic inequities in healthcare, as well as in other potentially discriminatory practices.

In addition, health plans have raised significant concerns regarding the collection of patient race and ethnicity information. Many plans, led by American Association of Health Plans (AAHP), increasingly see the collection of information on patient race and ethnicity as an important means to evaluate their own efforts to reduce disparities in care and develop better strategies to serve growing minority patient populations (Ignani and Bocchino, communication with Alan Nelson, M.D., March 19, 2001). However, some plans have operated under the erroneous assumption that federal and/or state law prohibits the collection of patient race and ethnicity information. Efforts by the U.S. Department of Health and Human Services Office for Civil Rights (OCR) and Office of Minority Health (OMH) to clarify federal law (Perez, 2000; Perez and Satcher, 2001) have helped to dismiss this assumption.

Many health plans, however, remain concerned that their ability to serve minority patients could be hampered should data collection efforts be seen by these populations as an effort to ration care. In addition, plans that serve disproportionately minority and lower-income populations could be hurt by the release of “report card” information that reveals their enrolled members to be less healthy or to require more services than the majority population. In such instances, information about the health status of plans’ enrolled populations and case-mix may largely reflect conditions of poverty and the generally higher incidence of morbidity and mortality among lower-income and minority populations, and may not necessarily reflect poor service on the part of health plans. This kind of information might unfairly hurt health plans’ efforts to expand their market share among minority populations, and should be taken into account (Fiscella et al., 2000).

Other challenges include the accuracy of racial and ethnic data. As noted earlier, “race” and “ethnicity” are fluid, socially defined concepts that are not consistently understood or applied in data collection efforts. Racial or ethnic identity is determined by multiple factors and may vary depending on the contexts in which these constructs are defined and the manner in which data are collected. Observers recording race and ethnicity data are notoriously inaccurate, particularly with regard to Hispanic or American-Indian populations (e.g., death certificates commonly misreport the race of American Indians). Further, a small but increasing proportion of individuals define themselves using two or more racial and ethnic categories, making simple classification difficult. Finally, efforts to address disparities in care must acknowledge the significant heterogeneity within each of the federally defined racial and ethnic groups (whites, African Americans, Native Americans, Asian Americans, Pacific Islanders, and Hispanics). Wide variations within each of these groups can be found in health status, health practices and behaviors, and healthcare resources. It is therefore important that data be collected on subgroups within these categories (e.g., Cuban American, Puerto Rican, Mexican American, Central American among the "Hispanic" ethnic group). Where possible and appropriate, data collected over several years can be combined to achieve sufficient analytic sample sizes (U.S. DHHS National Committee on Vital and Health Statistics, 1999).

These challenges underscore the need for consensus among health plans, providers, and consumers regarding data collection policies, and best practices regarding how data will be analyzed and to whom it will be presented. To this end, the committee believes that efforts by public and private groups, such as the National Quality Forum (NQF), the National Committee on Vital and Health Statistics (NCVHS), and the Agency for Healthcare Research and Quality (AHRQ), to convene experts and provide specific recommendations regarding the collection and analysis of data on patients' race and ethnicity will prove fruitful to help achieve broad consensus on best policies and practices. Development of a full, national database of healthcare quality that can be analyzed by race and ethnicity will take time, however, and it is clear that a sequence of steps must be undertaken to reach this goal. An important first step would involve an assessment of existing data sets within public and private plans that allows for an analysis of patient care by race and ethnicity.

THE FEDERAL ROLE IN RACIAL, ETHNIC, AND PRIMARY LANGUAGE HEALTH DATA

Several agencies of the DHHS, recognizing the importance of racial, ethnic, and primary language healthcare data, have attempted to promote data collection and monitoring efforts, particularly to address the challenges noted above. Despite these efforts, federal data collection remains unsystematic and lacks an overall guiding structure to ensure accountability and cooperation by HHS agencies, states, and private sector partners involved with federal health programs (Perot and Youdelman, 2001).

The Summit Health Institute for Research and Education, Inc. (SHIRE) and the National Health Law Program (NHeLP), with support from The Commonwealth Fund, analyzed an array of statutes, regulations, federal agency policies, practices, and data collection vehicles related to race, ethnicity, and primary language in healthcare settings. This analysis included an assessment of the extent to which federal policies mandate or encourage collection and reporting of race, ethnicity, and primary language data and an assessment of how current law is understood, interpreted, and implemented by federal officials. SHIRE and NHeLP analyzed 80 program-specific statutes and over 100 data collection vehicles, and developed 25 findings and 10 recommendations regarding federal data policies (Perot and Youdelman, 2001). These recommendations are listed in Box 7-1.

BOX 7-1
Recommendations, Racial, Ethnic, and Primary Language Data Collection in the Healthcare System: An Assessment of Federal Policies and Practices (Perot and Youdelman, 2001)

1. Ensure that Medicare data, as well as other data regarding individuals who are served by HHS programs or who participate in HHS research activities, are readily available and accurate by race, ethnicity, and primary language. Independent analysts have estimated that the Medicare beneficiary eligibility file compiled by the Social Security Administration is less than 60 percent accurate for all racial/ethnic classifications other than black or white.
2. Enforce state collection and reporting of data by race, ethnicity, and primary language for enrollees in Medicaid and the State Children's Health Insurance Program (SCHIP). Currently, data collection and reporting by states are often inconsistent and incomplete.
3. Revise the standards for implementation of the Health Insurance Portability and Accountability Act (HIPAA) to designate the code set for race and ethnicity data as mandatory for both claims and enrollment standards. Racial and ethnic categories used under HIPAA must be compliant with OMB standards.
4. Recommend that quality measurement and reporting tools such as the Health Plan Employer Data and Information Set (HEDIS) should collect and report health data by race, ethnicity, and primary language.
5. Ensure access to quality healthcare for people with limited English proficiency by effective monitoring of adherence to guidelines and collection of requisite data.
6. Include statutory conditions in new program initiatives, including block grants, stating that data must be collected and reported by race, ethnicity, and primary language, and that programs should allocate adequate resources to promote compliance, address technological dif-

SHIRE and NHeLP draw four principle conclusions regarding the federal role in racial, ethnic, and primary language data collection. First, the collection of such data is legal and authorized under Title VI of the Civil Rights Act of 1964. Second, a growing number of federal policies emphasizes the need for the collection of race, ethnicity, and primary language data. Third, such data is an indispensable tool for the assessment of progress toward federal goals of eliminating health disparities (U.S. Department of Health and Human Services, 1999). SHIRE and NHeLP found broad consensus within U.S. DHHS on this point, but a fourth conclusion of the investigators is that DHHS policies and practices fail to reflect this

ficulties, ensure privacy and confidentiality of data collected, and implement effective educational strategies to maximize beneficiary and provider cooperation with data gathering efforts.

7. Encourage public and private agencies to participate in the development and implementation of approaches to improve data availability and promote data collection and reporting. In support of agencies, HHS should:
   - create a "tool kit" containing information on effective data-related techniques, technologies, and privacy safeguards currently in use;
   - bolster the HHS Data Council's efforts to identify and document the benefits of collecting and reporting; and
   - support national policies to facility data-sharing among all federal and state agencies.
8. Expand or create public and private educational efforts to:
   - inform insurers, health plans, providers, private/public agencies, and the general public that data collection and reporting by race, ethnicity, and primary language are legal and in many instances required by federal law and regulations;
   - raise public awareness that the collection and reporting of these data are prerequisites for the achievement of Healthy People 2010 goals and essential to demonstrate compliance with the nondiscrimination requirements of Title VI; and
   - inform decision-makers that effective strategies exist for achieving compliance with data collection and reporting policies, including risk-adjustment, and make such compliance a condition for receiving government resources.
9. Provide states and healthcare providers with greater access to aggregated and disaggregated racial, ethnic, and primary language data acquired at the federal level, subject to privacy and confidentiality regulations.
10. Support research on existing best practices for data collection.

consensus, as data requirements and methods for collection and reporting vary across federal agencies, and no single HHS blueprint exists to provide a framework and rationale for the department's activities. Further, no department-wide mandate exists for racial, ethnic and primary language data collection and reporting, leaving only a patchwork of efforts across agencies to promote data collection and reporting (Perot and Youdelman, 2001).

The SHIRE-NHeLP report notes that two significant developments in early 2001 illustrate the "disconnect" between federal consensus and practice. In one instance, HHS finalized regulations regarding standard data elements for the electronic transmission of health information authorized under HIPAA, yet these rules failed to identify race or ethnicity as a required code, an omission that many HHS officials saw as a "lost opportunity." In another instance, HHS published regulations for Medicaid Managed Care and the State Child Health Insurance Program (SCHIP) that would require states to report the race, ethnicity, and primary language of enrollees on a quarterly basis, yet these regulations were suspended for further review following the change of presidential administrations in 2001 (Perot and Youdelman, 2001). Notably, the National Committee on Vital and Health Statistics (NCVHS), which serves to advise the federal government on health information and data policy, warned in a 1999 report that the limited data-collection practices of MCOs who serve Medicaid beneficiaries threatened to inhibit HHS's ability to monitor the quality of care provided by Medicaid MCOs. NCVHS urged that HHS develop more specific guidance about the manner and format in which Medicaid MCO data should be collected and reported by states (Mays, 2001).

Despite the lack of a framework or mandate for systematic data collection at the federal level, data on enrollee race and ethnicity is available to a limited degree for the two largest federal healthcare programs, Medicaid and Medicare. The Centers for Medicare and Medicaid Services (CMS—formerly the Healthcare Financing Administration [HCFA]) has generally required states to report patient encounter data for Medicaid enrollees, but has not required that states report data by race and ethnicity. Most states have voluntarily supplied CMS with data on Medicaid beneficiaries' race and ethnicity, and cumulative totals of beneficiaries' race and ethnicity are available from all states. As noted above, however, the proposed rule requiring all states to report the race and ethnicity of Medicaid and SCHIP recipients has yet to be implemented. Further, states would be expected, via CMS's proposed rule issued in August, 2001, to provide Medicaid MCOs with information regarding enrollees' race or ethnicity, but these data are often incomplete or inconsistent, and the rule did not require that this data be reported back to the agency (Perot and Youdelman, 2001). Medicare enrollees' race or ethnicity has been typically extracted from the Medicare Enrollee Database, which is based on Social Security Administration (SSA) information. Enrollment data is available for all Medicare beneficiaries, but SSA data are limited, particularly for data obtained prior to 1994, as SSA only identified beneficiaries' race or ethnicity as "white," "black," "other," and "unknown." Efforts by HCFA to reconstruct this data by surveying the 2.1 million beneficiaries whose race was listed as "other" or "unknown" reduced the number of unidentified race codes significantly, but accuracy of these data for beneficiaries identified as other than "black" or "white" is estimated to be less than 60% (Perot and Youdelman, 2001).

OTHER DATA SOURCES TO ASSESS HEALTHCARE DISPARITIES

Several other federal, state, and private data sources currently exist or are planned that can be tapped to assess racial and ethnic disparities in care. As will be noted later in this chapter, data from these sources can be used to help identify sources of disparities in care and/or monitor changes in racial and ethnic disparities in care over time. The following summary of data collection systems is not intended as an exhaustive listing of federal, state, or privately funded data sets that may be used to assess racial and ethnic healthcare disparities. For a more exhaustive listing of federal data collection systems, see the HHS *Directory of Health and Human Services Data Resources* (U.S. DHHS, 2001).

Several relevant national-level data sources that can be used to assess aspects of racial and ethnic healthcare disparities include:

Consumer Assessment of Health Plans Survey (CAHPS)

The Consumer Assessment of Health Plans Survey (CAHPS), supported by the AHRQ, provides information to healthcare consumers, purchasers, health plans, and others regarding the quality of healthcare plans and services. CAHPS surveys ask consumers about their experiences with health plans, such as the quality of communication with providers, the provision of translation services for patients with limited English proficiency, and the timeliness and quality of care provided for a variety of medical conditions and procedures. CAHPS survey data can be analyzed by respondents' race or ethnicity to assess group differences in patient experiences.

Medical Expenditure Panel Survey (MEPS)

The Medical Expenditure Panel Survey (MEPS), the most recent of a series of federal surveys of medical care costs, was initiated by the AHRQ in 1996 for the purpose of assessing the types, frequency of use, and costs of healthcare services used in the United States. MEPS data yield information on health services expenditures and how they are paid for, as well as the extent of health insurance coverage among the U.S. population. MEPS consists of four components: the Household Component, which samples families and individuals to assess health status, insurance coverage, healthcare use and expenditures, and sources of payment for health services; the Nursing Home Component, which samples nursing homes and residents to assess characteristics of facilities and services offered, costs, and sources of payment of these services; the Medical Provider Component, which supplements information from the Household Component by surveying hospitals, physicians, and home healthcare providers; and the Insurance Component, which assesses the amount, types, and costs of health insurance available to employees. The Household Component collects data on respondents' race/ethnicity, and while the Nursing Home Component has racial and ethnic data available, only the African-American and white samples are large enough to permit analysis (U.S. DHHS, 2001). These data can be assessed by race and ethnicity, as well as other socio-demographic indicators, such as level of education, income and assets, and employment. Several of the studies summarized in Chapter 1 utilize MEPS data to assess patterns of disparities in care.

Medicare Beneficiary Enrollment Database

Medicare's Enrollment Database (EDB), supported by the CMS, is the principal database for Medicare beneficiary services, including access to and use of services covered under Medicare. The primary source for EDB beneficiary information, however, is the Social Security Administration's Master Beneficiary Record database. As noted above, these data are unreliable with respect to racial and ethnic populations other than black and white beneficiaries.

Medicare Current Beneficiary Survey

The Medicare Current Beneficiary Survey (MCBS), supported by CMS, is a continuing sample of Medicare beneficiaries to assess healthcare use, costs, and who pays for it. A variety of demographic data are collected from respondents during an initial interview, including race/ethnicity, health and insurance status, and education level. Data can be used to assess racial and ethnic differences in costs and utilization of care, and costs paid by Medicare as well as other public and private insurance sources.

Public and privately funded healthcare plans can take advantage of survey instruments developed as part of broader quality improvement initiatives, such as the Health Plan Employer Data and Information Set (HEDIS).

Health Plan Employer Data and Information Set (HEDIS)

The Health Plan Employer Data and Information Set (HEDIS), developed by the National Committee for Quality Assurance (NCQA) in conjunction with public and private purchasers, health plans, researchers, and consumer advocates, is a set of standardized performance measures that assesses the quality of healthcare and services provided by managed care plans. HEDIS was developed to ensure that purchasers and consumers have access to information to compare the performance of managed healthcare plans. HEDIS measures the effectiveness and availability of care in areas such as childhood immunization, breast cancer screening, cholesterol management, and treatment of heart attack. In addition, HEDIS offers information on structural attributes of health plans, such as practitioner turnover and rates of board certification and residency completion. HEDIS also includes a standardized survey of consumers' experiences that evaluates plan performance in areas such as customer service, access to care and claims processing.

At the state level, new data sets being developed, such as the California Health Interview Survey (CHIS), may allow researchers to explore regional and subpopulation variation in healthcare access and use.

California Health Interview Survey (CHIS)

The California Health Interview Survey (CHIS) is a collaboration of the UCLA Center for Health Policy Research, the California Department of Health Services, and the Public Health Institute to assess the health status, health behavior and risks, and healthcare access and utilization of the state's diverse population. Data from its survey of 55,000 California households will be available in early 2002 and will be made available through published reports, public-use files, and an Internet-based system that will allow requestors to gather information tailored to particular health topics, population groups, and geographic areas. In particular, CHIS asks respondents to provide information about their usual source of care, access to and use of specific services, experiences of discrimination in healthcare settings, and recall of provider advice, among other items. Results will be analyzed by respondents' race and ethnicity, with particular attention to racial and ethnic subgroups. Funding for CHIS has been provided by the California Department of Health Services, The California Endowment, the National Cancer Institute (NCI), California Children and Families Commission, the U.S. Centers for Disease Control and Prevention (CDC), and the Indian Health Service (IHS).

MODELS OF MEASURING DISPARITIES IN HEALTHCARE

Many models of healthcare "report cards" have been developed over the past few years, as healthcare consumers and purchasers of plans have expressed great interest in timely and accurate information about the quality of care delivered by plans, hospitals, and individual providers. Few such "report cards," however, have focused exclusively or in part on racial and ethnic disparities in care. This paucity of information on disparities in care is likely to change in the near future, as federal and private initiatives are increasing visibility and attention to the problem. In one instance, the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services (U.S. DHHS) has recently commissioned a review of measures of discrimination in healthcare settings. In another federal initiative, AHRQ has initiated plans to develop a national report on racial and ethnic disparities in healthcare, and plans to incorporate measures of racial and ethnic disparities in care in a national report of quality of care. Within the private sector, the National Quality Forum (NQF), with support from The Commonwealth Fund, has produced a report on measuring and reporting the quality of care for minority populations. These activities are likely to spur efforts to increase information available to consumers and purchasers of plans and promote greater choice when selecting plans, to promote accountability to consumers and purchasers, and to spark action on the part of plans, providers, and legal and regulatory bodies to reduce disparities in care.

Two models of "report cards" that specifically address racial and ethnic disparities in healthcare are reviewed below.

"Health Accountability 36"

Smith (1998) proposes a report card to assess racial and ethnic disparities consisting of 36 consensus indicators that have been developed and utilized in other settings by a range of public and private entities. The indicators were selected based on the availability of data, sensitivity of the indicators to key health conditions for vulnerable populations, and their amenability to public health and healthcare intervention. The first 12 indicators include measures adapted from the U.S. DHHS initiative *Healthy People 2000*, and are routinely collected and reported by the National Vital Statistics report system to evaluate the health of geographically defined populations. The second 12 indicators include measures of managed care plans to provide consumers and purchasers with information about plan performance. Of these, the first six were developed by the National Committee for Quality Assurance for HEDIS, while the subsequent six indicators were selected by the former Agency for Healthcare Policy and Research (now AHRQ). The third set of 12 indicators was developed by the Joint Committee on Accreditation of Health Care Organizations (JCAHO) as part of its accreditation process to measure hospital performance, and reflect measures of obstetrical, oncologic, and cardiovascular outcomes. Smith (1998) notes that data for these indicators are currently available and can be analyzed using the standard categories for race and ethnicity adapted by the Office of Management and Budget (see Chapter 1, Table 1). A goal for public health agencies and health systems, Smith suggests, would be to bring racial and ethnic disparities to within 80%. These measures are listed in Table 7-1.

Several of the measures proposed by Smith can be criticized on the grounds that as indicators of population health, they are influenced to a far greater extent by social and economic forces such as income inequality, residential segregation (and subsequent substandard living conditions, especially for lower-income minority groups), environmental risks, and other social problems. As such, they are less amenable to health system intervention. Further, health systems that disproportionately enroll lower-income and minority patients will have a greater challenge in improving the health of a generally sicker population with higher rates of co-morbidities, and thus, may not demonstrate improvement on many of the measures. Smith (1998) notes, however, that the impact of plans' casemix can be adjusted statistically. In addition, he notes, some health plans, such as not-for-profit integrated delivery systems, recognize the impact of social and economic forces on the health of their enrolled populations and attempt to address these forces by improving screening and primary and preventive healthcare services, and by addressing housing and other social service needs of their patients.

Integrated Approaches

LaVeist and Gibbons (2001), in their report to U.S. DHHS[1] on poten-

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[1] U.S. DHHS commissioned LaVeist to "summarize the literature on racial/ethnic discrimination within healthcare settings, with the primary goal of describing how discrimination has been measured" (LaVeist and Gibbons, 2001, p. 1). In this review, the authors note that the existence of racial and ethnic disparities in healthcare does not necessarily reflect discrimination, but focus their analysis on indicators that may detect patterns of discrimination apart from disparities that are not inherently discriminatory.

TABLE 7-1 "Health Accountability 36" Report Card Indicators

Unit of Analysis	Source	Indicators
Geographically Defined Population	Healthy People 2000	1. Total age-adjusted death rate
		2. Automobile death rate
		3. Suicide death rate
		4. Lung cancer death rate
		5. Breast cancer death rate
		6. Cardiovascular death rate
		7. Homicide death rate
		8. Teen births
		9. Inadequate prenatal care
		10. % Low birthweight births
		11. Infant death rate
		12. Children in poverty
Health Plan Covered Lives	HEDIS AHCPR	1. % Women for whom prenatal care began in the first trimester
		2. % Children receiving all childhood immunizations by 24 months
		3. Cholesterol screening age 40-64 once in 5-year period
		4. % Women 51-64 continuously enrolled for 2 years who received mammogram breast cancer screening
		5. % Women 21-64 continuously enrolled for 3 years who received a Pap test
		6. % Members 2-19 with one or more asthma admissions
		7. % Diabetics 31-64 who had retinal exam during the preceding calendar year
		8. % Members 23-39 who visited a health practitioner in the past year
		9. % Rating how well the doctor listened as excellent
		10. % For whom last visit to doctor fully met their needs
		11. % Choice of doctors not a problem
		12. % Satisfied with overall plan
Hospital Patient Clinical Population	JCAHO	Obstetrical Indicators:
		1. % Low birthweight infants
		2. % Term infants admitted to NICU within one day of delivery
		3. % Neonates with an Apgar of 3 or less at 5 minutes and a birthweight > 1,500 grams
		4. % Neonates with a discharge diagnosis of significant birth trauma
		Oncology Indicators:
		5. Survival of patient with primary cancer of the lung, colon/rectum, by state and histologic type
		6. Use of test critical to diagnosis, prognosis, and treatment
		7. Use of treatment approaches that have an impact on quality of life
		8. Interdisciplinary treatment and follow-up
		Cardiovascular Indicators:
		9. Intrahospital mortality as a means of assessing multiple aspects of CABG care
		10. Extended postoperative stay as a means of assessing multiple aspects of CABG care
		11. Intrahospital mortality as a means of assessing multiple aspects of PTCA care
		12. Intrahospital mortality as a means of assessing multiple aspects of acute MI care

SOURCE: Smith (1998).

tial measures of discrimination in healthcare settings, note that such measures must not only address structural differences in receipt of care (e.g., the proportion of women receiving prenatal care in the first trimester, as suggested by Smith [1998]), but should also assess the quality of interpersonal interactions in healthcare settings. Structural differences shape the parameters of care provided to different populations, they note, but individual, subjective factors affect the quality of care in clinical interactions. They argue for an integrated approach that includes multiple measures, and meets the following criteria:

1. *Applicable to multiple racial/ethnic groups*—the indicators must be applicable to all racial and ethnic groups that make up the U.S. population.
2. *Produce unique scores for individual healthcare facilities*—the report card must be producible for individual healthcare facilities and not merely produce scores for the nation or a particular region.
3. *Data sources must be accessible*—the report card must be easily understandable to a broad audience of healthcare consumers and the indicators must have high "face validity."
4. *No confounding*—indicators must not be confounded with other variables such as health insurance, patient preferences or larger societal factors. If there is confounding, there must be a way to adjust for it.
5. *Longitudinality*—the indicators must have the ability to be replicated over time (LaVeist and Gibbons, 2001, p. 7).

LaVeist and Gibbons weigh the merits of four potential approaches to measuring discrimination in care, including Smith's (1998) "Health Accountability 36," patient assessments, administrative claims audits, and assessments of substandard care. The "Health Accountability 36" measures draw largely upon existing data, and can be applied to geographically defined populations, individuals in health plans, and hospital and clinic patients. LaVeist and Gibbons note, however, that many of the measures, particularly those assessing racial differences in health status, are confounded with larger social and economic factors.

Several measures of patient satisfaction have been extensively evaluated, according to LaVeist and Gibbons, and several studies have assessed racial and ethnic differences in patients' perceptions of the quality of care they receive (reviewed earlier). Few of these measures, however, have explicitly assessed patients' perceptions of racial discrimination in care settings (the Seattle-King County survey of patient perceptions of discrimination in care, reviewed earlier, is a notable exception). Such measures have the potential of providing unique scores for individual healthcare facilities and can be used to assess changes over time. Patient perceptions of care, however, can be influenced by a wide range of factors, and may not reflect whether patients are receiving care appropriate to their needs. Nonetheless, such perceptions form an important component of a multi-pronged assessment profile, particularly if measures can assess the degree of patient participation in treatment decisions and understanding of their diagnosis and course of treatment.

Administrative claims data have been used extensively in prior research to audit care and demonstrate racial disparities in access to diagnostic and therapeutic procedures (much of this research is reviewed in Chapter 1). Well-controlled studies using claims data have adjusted for many potentially confounding factors, such as co-morbid conditions and insurance status, to isolate the influence of patient race on receipt of care. LaVeist and Gibbons (2001) suggest that administrative audits can produce unique scores for individual hospitals and healthcare facilities. Such data often fail, however, to illuminate process-of-care variables, such as referral patterns or participation in treatment decisions (e.g., whether providers present all treatment options and whether patients accept or refuse them). Prospective studies are therefore needed to supplement typically retrospective analyses of administrative claims data (see Chapter on "Research Needs").

Measures of adverse events due to practitioner or healthcare setting error are also an important component of assessing disparities in care, according to LaVeist and Gibbons (2001). Increasingly, healthcare providers and consumers have focused on the problem of medical errors and patient safety, and at least two methodologies have been developed to evaluate adverse events. Both involve an initial screening of potentially problematic cases, typically by two trained healthcare professionals, but screening methods differ in that one approach utilizes actual medical records, while the other uses administrative claims data. Such analysis could indicate whether minority patients are differentially more or less likely to face substandard care. This method has the advantage of yielding objective data on the quality of care provided, relative to standard criteria. Data are free of confounding, and the accuracy and validity of these methods has been demonstrated, the authors note.

LaVeist and Gibbons (2001) conclude that a two-tiered, multi-assessment approach may be useful to assess discrimination in healthcare settings. In the first tier, routine monitoring of healthcare facilities can be accomplished by audits of administrative data and analyses of data on substandard care. This initial "screen" could identify facilities that should be investigated more closely. In the second assessment tier, facilities are informed of the disparities and are given a period of time to address them. If progress has not been made, LaVeist and Gibbons suggest, a method used more commonly to assess housing and employment discrimination—paired testing—may be used to further assess the possibility of racial or ethnic discrimination. In this strategy, individuals are trained to present the same needs and background information to targeted healthcare facilities, but vary only in race or ethnicity (see Chapter on "Racial Attitudes and Discrimination"). The purpose of such testing, according to the authors, is to enhance awareness and to facilitate voluntary efforts to address racial disparities in care. Should these efforts fail, judicial remedies could be explored if clear violations of civil rights laws are found (LaViest and Gibbons, 2001). Unlike paired testing in housing and employment, however, the use of such strategies in healthcare settings poses unique legal and ethical challenges that should be addressed before such strategies are adopted.

Reporting of Racial and Ethnic Disparities Using Existing Data Sets

As noted earlier, the HEDIS data sets developed by NCQA offer a ready set of measures of plan performance that are widely used and accepted by health plans, purchasers, and consumers. Health plans voluntarily report this information to NCQA, which then disseminates data as part of its Quality Compass database in regular publications such as the NCQA *State of Managed Care Quality* report. Quality Compass 2000 contains measures of plan performance in several clinical areas, such as cancer screening, childhood and adult immunization, timely outpatient care, and evidence-based treatments for hypertension, cardiovascular disease, asthma, diabetes, and depression. Approximately half of the nation's HMOs participate in Quality Compass, with another 90% participating in NCQA's Accreditation and HEDIS programs.

Some researchers and plan administrators have raised concerns that health plan performance on these or other quality measures is affected by the sociodemographic mix of plan enrollees. According to this view, plans that enroll a high percentage of low-income or racial and ethnic minorities (who tend to be sicker, face a greater number of barriers to accessing care, and are less likely to utilize preventive and primary care services) may tend to face poorer health plan performance scores as a result of factors exogenous to the health system (Zaslavsky et al., 2000). Zaslavsky et al. (2000) tested this hypothesis by studying the relationship between plan performance on HEDIS measures and sociodemographic mix, including enrollee age, gender, and area of residence as an indicator of race/ethnicity and household income. The authors found that plan performance was negatively associated with the percentage of individuals receiving public assistance and the percentage of African Americans and Hispanics in enrollees' area of residence, and positively associated with the percentage of college-educated and Asian-American residents. Adjusting for these demographic variables, however, had a limited effect on plan performance, as most plans changed by less than 5% in performance measures.

Romano (2000) argues that even if case-mix differences could be adequately adjusted statistically, such adjustment does not necessarily improve analysis of the quality of care that plans deliver. To the contrary, he argues that statistical adjustment may hamper accurate assessment of plan performance by failing to identify the direction of the relationship between case-mix and plan performance—in other words, does the plan's case-mix result in poor performance, or does poor performance lead to the observed case-mix? In addition, statistical adjustment may "excuse" health plans for failing to address socioeconomic and racial/ethnic health disparities. Adjustment for case-mix may inadvertently remove plans' incentive to reduce disparities, according to Romano, by masking differences in the level of care provided to racial and ethnic minorities and low-income enrollees. He argues for reporting of data stratified by race, ethnicity, and socioeconomic status, which would offer the advantage of highlighting, rather than masking, sociodemographic disparities, and would allow consumers to make better informed choices about plans based on their own sociodemographic profile. In addition, by presenting performance data stratified by race, ethnicity, and socioeconomic status, plans could be rewarded for efforts to reduce disparities (Romano, 2000; Fiscella et al., 2000).

DATA NEEDS AND RECOMMENDATIONS

The preceding discussion illustrates that despite the many challenges inherent in efforts to collect data on patients' race and ethnicity and monitor the quality of their care, data collection and monitoring are a feasible, critically important step in understanding and eliminating disparities in care. As Tom Perez (this volume) notes, "Effective data collection is the linchpin of any comprehensive strategy to eliminate racial and ethnic disparities in health."

Currently, data collection efforts are unsystematic and inadequate to monitor the quality of care provided to racial and ethnic minorities. These efforts must be improved to ensure accountability of plans and providers to healthcare payors and consumers, to track disparities and assess the impact of quality improvement efforts, and to identify best practices that may be replicated by other plans and health systems. Federal leadership is needed to spearhead data collection efforts; for this reason, the committee advocates that the Secretary of the U.S. Department of Health and Human Services produce periodic studies to assess progress in eliminating racial and ethnic disparities in healthcare. The private sector, however, also shares a role in encouraging data collection and reporting of patient care data by race, ethnicity, and where possible, primary language. Accreditation bodies, such as JACHO and NCQA, should require the inclusion of data on patient race, ethnicity, and highest level of education attained (in case of children, highest level of education attained by mother) in performance reports of public and private providers as part of healthcare performance measurement. Such an emphasis would help to ensure that addressing healthcare disparities is seen by plans, providers, and purchasers as central to broader healthcare quality improvement efforts.

Data collection should be accomplished using a standard racial/ethnic classification scheme. Current OMB standards can be used, but data categories must go beyond the existing minimum standards to reflect the diversity within racial and ethnic populations, particularly at the local level (e.g., subgroups of Hispanics, African Americans, Asian Americans, etc.). In addition, information is needed on patients' socioeconomic status and primary language. These data should be stratified, where possible, to better understand the relative contributions of race/ethnicity, socioeconomic status, and other demographic variables to variations in care.

In the future, a standardized, central database is needed, with safeguards for privacy and confidentiality, which can be merged with other data systems. This database should be consistent with efforts to develop electronic patient medical records, and should be compatible to merge with other data systems. Such a long-term goal will require federal leadership and financial support.

Recommendation 7-1: Collect and report data on healthcare access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language.
Standardized data should be collected on the race, ethnicity, and highest level of education (in case of children, highest level of education attained by mother) of all patients enrolled in publicly funded health programs and reported to Congress. Collection of data on patients' primary language should be encouraged, where feasible, as part of this effort. Data on healthcare access, use, and outcomes should be reported by race, ethnicity (including subgroups, and primary language where possible), and adjusted for highest level of education.

Recommendation 7-2: Include measures of racial and ethnic disparities in performance measurement.
JCAHO and NCQA should require the inclusion of data on patient race, ethnicity, and highest level of education attained (in case of children, highest level of education attained by mother) in performance reports of public and private providers as part of health care perfor-

mance measurement, such as NCQA's HEDIS indicators. The collection of data on patients' primary language should be encouraged. These performance reports should make elimination of healthcare disparities a focus of quality improvement efforts.

Recommendation 7-3: Monitor progress toward the elimination of healthcare disparities.
The secretary of HHS should conduct periodic studies to monitor the nation's progress toward eliminating racial and ethnic healthcare disparities, to provide insight into the root causes of these disparities, and to assess opportunities for intervention and improvement.

Recommendation 7-4: Report racial and ethnic data by OMB categories, but use subpopulation groups where possible.
Current OMB categories for race and ethnicity should be used in all reporting and monitoring efforts, but data categories must go beyond the existing minimum standards to reflect the diversity within racial and ethnic populations (e.g., subpopulations), particularly at the local level.