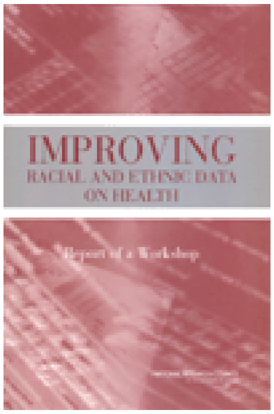

Improving Racial and Ethnic Data on Health: Report of a Workshop

Daniel Melnick and Edward Perrin, Editors, Panel on DHHS Collection of Race and Ethnicity Data, National Research Council

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IMPROVING RACIAL AND ETHNIC DATA ON HEALTH

Report of a Workshop

Panel on DHHS Collection of Race and Ethnicity Data

Daniel Melnick and Edward Perrin, *Editors*

Committee on National Statistics

Division of Behavioral and Social Sciences and Education

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PANEL ON DHHS COLLECTION OF RACE AND ETHNICITY DATA

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Acknowledgments

I would like to thank, on behalf of the Panel on DHHS Collection of Race and Ethnicity Data, all of the individuals involved in the production of this report and the Workshop on Improving Racial and Ethnic Data in Health. I first thank the authors and discussants for their active involvement during the workshop (listed in Appendix C to this report); they all deserve accolades for their participation. The panel is especially grateful to the authors of the papers written for and presented during the workshop for their work on the drafts and revisions to the papers, and the workshop attendees for their active involvement during the meeting. We also thank James Scanlon and Dale Hitchcock of the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the Department of Health and Human Services (DHHS) for their continual assistance in developing the workshop.

The panel is grateful for the excellent work of the staff of the Committee on National Statistics and the National Research Council for developing and organizing the workshop and for writing this workshop summary. Daniel Melnick, consultant to the panel, should be commended for preparing the draft of this report in a timely manner and for persistent attention to subsequent revisions. Michele Ver Ploeg, study director for the panel, helped to develop the workshop and guided the summary through the review process. She was aided in development of the workshop by Mary Grace Kovar, consultant for the panel. Jamie Casey, research assistant, helped organize the workshop and helped to check references and quotations for the document. The panel is thankful for the heroic efforts

Tanya Lee, project assistant, to make sure the workshop went off without a hitch and in the editing and development of this summary.

As chair of this panel, I thank my fellow panel members for their participation in the development of the workshop, for chairing sessions of the workshop, and for their commitment in reviewing multiple drafts of the workshop report.

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the Report Review Committee of the National Research Council. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We thank the following individuals for their review of this report: Olivia Carter-Pokras, Department of Epidemiology and Preventive Medicine, University of Maryland School of Medicine; Kevin Fiscella, Departments of Family Medicine and Community & Preventive Medicine, University of Rochester School of Medicine & Dentistry; Thomas A. Louis, Department of Biostatistics, Johns Hopkins Bloomberg School of Public Health; Jim Loyd, executive director, Texas Health Care Information Council, Austin, TX; and Vickie M. Mays, Department of Clinical Psychology, University of California, Los Angeles.

Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the final draft of the report before its release. The review of this report was overseen by Richard Kulka, Social and Statistical Sciences, Research Triangle Institute. Appointed by the National Research Council, he was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

Edward Perrin, *Chair*
Panel on DHHS Collection of Race and
Ethnicity Data

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IMPROVING
RACIAL AND ETHNIC DATA ON HEALTH

INTRODUCTION

Disparities in health outcomes and in health care access, utilization, and quality between people of different races and ethnic backgrounds are well documented in the literature (IOM, 2002a). Government and private-sector parties have sought to better understand these disparities in order to formulate strategies to ensure better health and the highest quality of care for everyone. Often, however, these efforts have been hampered by the limited availability and inconsistent quality of data on race, ethnicity, and other characteristics of individuals.

Concerns about these data weaknesses led Congress to ask that the National Academies conduct a comprehensive study of the adequacy of the Department of Health and Human Services (DHHS) data collection systems in measuring race, ethnicity, and socioeconomic status to better understand disparities (PL 106-525, 2000). The DHHS Office of the Assistant Secretary for Planning and Evaluation (ASPE), with support from several other DHHS offices, asked the Committee on National Statistics (CNSTAT) of the National Academies to convene a panel of experts to review the Department's data systems.[1] ASPE and CNSTAT developed the

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[1] Other DHHS agencies sponsoring the study include the Agency for Healthcare Research and Quality,, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the HIV/AIDS Contingency Fund, the National Institutes for Health, the Office for Civil Rights, and the Office of Minority Health.

charge for the study based upon this legislation and upon the Department's own needs for review of their data systems, giving the panel flexibility to review other related data needs as they arose. The Panel on DHHS Collection of Race and Ethnicity Data is reviewing DHHS' systems and practices for collecting racial, ethnic, socioeconomic, and language data as well as related practices in other federal agencies such as the Social Security Administration and in private providers and insurance companies. The panel is identifying:

- Data needed to evaluate the effects of race, ethnicity, and socioeconomic status on disparities in health, health care, and access to health care;
- The effectiveness of the data systems of DHHS, other federal, state, and local agencies, and the private sector in the collection and utilization of data on race, ethnicity, and socioeconomic status.
- Critical gaps in data on race, ethnicity, and socioeconomic status in existing systems, and methods for filling those gaps.

The Workshop

Up to now, public consideration of data used to measure and understand health and health care disparities has focused on federal public health data systems. However, many federally published statistics about health conditions and health care are derived from data systems maintained by states and by private health care systems.

Because these data sources are very diverse and fragmented, the information is incomplete, not standardized, and not comparable across the health care system.

The panel convened the Workshop on Improving Racial and Ethnic Data in Health to review information about current private-sector and state data collection practices in light of existing federal, state, and local regulations, laws, and requirements.[2] The workshop presentations featured the perspectives of data users, health care providers, insurance plan representatives, state and local public health officials, and regulatory officials. Participants assessed policies, practices, barriers, and opportunities for collecting racial and ethnic data in their settings, and explored ways that private and

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[2] The workshop was held December 12-13, 2002. The workshop agenda and participant list are included in Appendix C.

state systems can be improved to address data needs. In preparation for the workshop, the panel commissioned four background papers to fill gaps in knowledge of private-sector and state government policies and practices and to address the importance of racial and ethnic data collection (Bocchino and Wheeler, 2003; Fremont and Lurie, 2003; Geppert et al., 2003; and Nerenz and Currier, 2003).[3] The panel is also examining the role of socioeconomic status regarding health and health care disparities. However, the workshop intended to focus only on racial and ethnic data collection. The panel's final report will contain a full consideration of the collection of racial, ethnic, and socioeconomic status data.

The purpose of the workshop was to examine the collection of data outside the federal government, i.e., by states, localities, and nongovernment entities including health plans, groups, and providers. As such, the workshop focused on the role of private organizations and state governments in collecting and reporting about health care and health status statistics. Much of this information is collected in the context of providing health care, and therefore is generally used in the context of measuring health care utilization, quality, and treatment and treatment outcomes rather than health status. There are, however, important differences in collecting, reporting, and using *health status* and *health care* indicators for racial and ethnic groups. Health status refers to the health of an individual, the presence of a health condition, or illness (e.g., obesity or suffering from hypertension), while health care refers to the process of treating illness or injury and preventive measures.

The panel recognizes that there are also important concerns related to reporting health status indicators for racial and ethnic groups. These concerns were addressed in the workshop only to the extent that sources of data used to measure health status are collected by states or private sector sources. Data used to measure both health status and health care disparities will be further addressed in the panel's final report.

This report summarizes the workshop's discussions and the views expressed by workshop participants without commentary or response by the panel.

Discussions emphasized information collected by states and private organizations from health care records, rather than on information col-

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[3] Summaries of these papers are included in Appendix B, the full papers will be published with the final report of the panel.

lected from persons, households, and families through health surveys. The panel will consider these more fully as it prepares its final report, which will review federal, state, and private-sector data sources and will contain conclusions and recommendations for improvement of this data infrastructure.

Main Themes

The following themes emerged from the workshop presentations and discussions:

1. Racial and ethnic data help providers, plans, and state and local officials measure and address disparities among racial and ethnic groups in health status and care. These data provide important information about variations in access to care, quality outcomes, and the underlying causes of the variations. The data are used to implement improvements and to promote informed health care decisions, including policy, consumerism, and value purchasing.

2. Some health care providers, insurance plans, and local officials erroneously believe that federal law prohibits collection of racial and ethnic data on individuals. One legal analysis presented at the workshop demonstrated that collecting race, ethnicity, and primary language data is legal under federal law and permitted under most circumstances by state law.

3. Differences in the definitions and procedures used to collect racial and ethnic data are a major barrier to their appropriate use. Lack of standardization inhibits the integration of this data collection in administrative records, surveys, and other health records. Representatives of health care providers and plans expressed the view that strong federal leadership was required to advance and improve the collection of racial and ethnic data and to work toward common standards for reporting. State government officials noted that much of the confusion about the appropriate racial and ethnic categories to use reflects federal agency stovepiping—i.e., uncoordinated decisions made by individual federal agencies that can result in contradictory guidance to local and state agencies. State agencies respond to different federal requirements, making it difficult for them to integrate their data at the state level (Perot and Youdelman, 2001).

4. State and local government agencies as well as private providers and health plans face problems implementing changes in their computer systems to collect consistent racial and ethnic data. Changes in management

information systems (MIS) are expensive. Many workshop participants believe that until the standardization problems are addressed, it will not be possible to make substantial changes in their MIS systems.

5. Privacy is an important concern when collecting racial and ethnic data. A number of workshop participants agreed that the need for the data must be balanced against the need to protect individual privacy.

6. There are measurement issues as well as sampling problems in collecting racial and ethnic data. On one hand, respondents may have different definitions of their own identity depending upon the circumstances, and this variability will make it difficult to construct reliable measures. On the other hand, even when reliable measures are available, survey estimates for some groups are difficult because of their small numbers. Administrative data, which provide a complete register of all persons receiving a service, could potentially provide estimates for these groups because these data sets are larger. However, the primary purpose of transaction-based records is to record health care interventions, not to collect standardized racial and ethnic data. Consequently, reliable data about racial or ethnic groups with small populations may be difficult to report.

7. The perceived costs of collecting racial and ethnic data are a major barrier to convincing private organizations to implement collection. Some workshop participants pointed out that the largest cost of collecting racial and ethnic information is the cost of modifying data collection forms, procedures, and information systems. They noted that a decision to collect racial and ethnic data on administrative records is directly related to available information technology. For example, they reported that many state government agencies use old systems, which are difficult to modify. Changes in private-sector systems are costly as well.

8. There is considerable confusion over the meaning and applicability of the Office of Management Budget (OMB) “Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity.” These standards and their appropriate implementation need to be clearly described for both DHHS agencies and non-DHHS organizations. Furthermore, it should be made clear that these represent only minimal standards that may be incorporated in a more complete set as the need arises.

The body of this report presents the workshop participants’ views on the importance of collecting racial and ethnic data, the legal and regulatory environment for the collection of such data, procedural issues, state policies and practices, and the role of private providers, health plans, and health care quality control organizations in collecting these data.

THE IMPORTANCE OF RACIAL AND ETHNIC DATA COLLECTION

Workshop participants argued that without racial and ethnic data, health care providers, insurers, and government agencies cannot work to identify or mitigate racial and ethnic disparities in health and health care. These indicators are important for enforcing civil rights law, identifying health and health care disparities and promoting understanding of the underlying causes of disparities, monitoring access to care, measuring the quality of care and implementing improvements in health care quality, and stimulating consumerism and value purchasing.

Participants see the goal as improving health for all. In the words of Gem Daus of the Asian and Pacific Islander American Health Forum, "we can all be equally sick and the disparity will be gone." But, he said, the goal is for everyone to have the best health possible.

Historical Context and Impacts

The historical prevalence of discrimination in the United States on the basis of race and ethnicity is undisputed. Policies that have included slavery, segregation, and restrictive immigration have served to severely disadvantage African-Americans, Hispanics, and other racial and ethnic groups. These policies were used in the field of health care as well—for example, as health care facilities were segregated on the basis of race. Although civil rights laws and court decisions eliminated the legal basis for these policies by the end of the 1960s, ending overt legal segregation in health facilities (Smith, 1999), disparities in health status and care persist. As noted in the recent IOM study (2002a), subtle differences in treatment exist even when providers believe they are acting without regard to race.

The impact of historical segregation and other inequities lingers in social and economic disparities between groups. It not only influences health status, but also access to and use of care (IOM, 2002a)

Enforcing Civil Rights Laws

Title VI of the Civil Rights Act of 1964 requires government agencies to enforce equal access to care. Racial and ethnic data help regulators detect both overt and subtle differences within health care organizations (Smith, 1999).[4]

Identifying Disparities

In order to reduce or eliminate differences, the nation needs data on current conditions and trends. Yet in a time of increasing demands for accountability and transparency in health care, even a rudimentary ability to track basic processes and outcomes of care, including racial and ethnic information, is missing (Fremont and Lurie, 2003). In particular, the nation needs data to (a) identify racial and ethnic groups that are statistically more likely to experience different health outcomes; (b) determine protective factors (i.e., practices that lead to improved health outcomes) that can improve health; and (c) to understand more clearly the effect of socioeconomic status and its interaction with race and ethnicity on the health of the individual. Trends in these factors need to be monitored across racial and ethnic groups at the national, state, and local levels. For example, it is important to measure the relationship between racial data and morbidity and mortality rates for major diseases such as cancer, heart disease, diabetes, and HIV/AIDS (U.S. Department of Health and Human Services, 2000).

Understanding the underlying causes and impacts of disparities is a first step toward reducing them. Racial and ethnic data help health care providers understand the effect of disparities on the services they provide and the facilities they maintain or support. While effective interventions are likely to vary across settings, it is important to monitor settings and sites in order to develop appropriate interventions and identify risk factors for people in different racial and ethnic groups, with different levels of language acculturation and literacy, in order to measure the impact of such factors on health status and health care.

Access to Care

Equal access to health care is protected by civil rights laws, and racial and ethnic data can be used to establish whether the goals set forth in law are in fact realized in practice. Government surveys ask individuals about

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[4] Smith describes how this kind of data was used to desegregate hospitals when Medicare was enacted (1999).

access to care, including whether they have health insurance and a regular provider of health care.[5] These questions are proxies for assessing the respondents' ability to get care without delay from appropriate medical providers, including specialists. Analysts use the resulting data to track access.

Utilization of Care

Information is needed to monitor utilization of health care services as well as access. Even when patients have the same insurance coverage and are in the same settings, there may be dramatic differences in patients' uses of procedures, which may in turn indicate important differences in the quality of their health care. Key indicators include the rates of cardiovascular procedures, renal transplants, rehospitalization for congestive heart failure, and lower-extremity amputations in diabetics. Utilization of routine preventive and diagnostic services is also important.

Improvements in Health Care Quality

Workshop participants also noted the importance of ensuring quality health care. The paper prepared by Fremont and Lurie describes how racial and ethnic data can be used to improve health care (Fremont and Lurie, 2003) by serving as a basis for:

- Determining program eligibility, forecasting budgets, and conducting needs assessments,
- Evaluating the health status of the overall population or population subgroups,
- Generating hypotheses about the potential causes of observed disparities or health problems,
- Identifying the need for and helping to focus special initiatives designed to reduce disparities,
- Evaluating programs by measuring the progress achieved under those initiatives, and
- Reporting to the public and to regulatory agencies.

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[5] Some examples include, the Current Population Survey, Medical Expenditure Panel Survey, and National Health Interview Survey.

Participants also noted that identification of the primary language of clients is essential to provide equal access to care. Providers and services administrators need the data to gauge the need for translators and for creating appropriate language materials for forms and information.

Stimulating Consumerism and Value Purchasing

Value purchasing and consumerism strengthen clients' ability to demand better services by enabling them to select plans and providers who deliver the most value. Yet, the success of these mechanisms depends on providing consumers with sufficient information about the quality of care delivered. Outcome measures help consumers make more informed choices among health plans, and this enhanced consumerism improves the quality of health care and lowers its cost. Outcome measures also help employers make better choices among the coverages to offer their employees.

Comparative information about health plan performance in providing customers with access to preventive services and about customer satisfaction with care is now routinely reported by the Health Plan Employer Data and Information Set (HEDIS) for participating plans. However, because the information does not include racial and ethnic data, it is virtually impossible to monitor quality for these groups. Without such data, members of these groups are not able to assess whether their treatment by a particular health plan varies from the treatment provided for other population groups, and plans cannot assess their own performance in providing services to subgroups in their enrolled population. Absent relevant measures and information, health plans also miss the opportunity to work with providers, health departments, and elected officials to redress disparities.

Quality of Life

Disparities in health status and care contribute to an overall reduction in the quality of life for minority groups as well as the nation (IOM, 2002a and 2002b). Workshop participants noted that both have been extensively documented across a wide variety of settings and diseases that disparities in health care contribute to discrepancies in health outcomes.

LAWS, REGULATIONS, MANDATES, AND REQUIREMENTS

Federal, state, and local laws and regulations have different requirements that provide for or limit the collection of racial and ethnic data.[6] Government and regulatory requirements set the conditions under which these data are collected by providers, health plans, and physicians. During the workshop session on Legal Aspects of Race and Ethnicity Data Collection, Mara Youdelman of the National Health Law Project (NHeLP) reported on the results of a legal survey conducted by NHeLP with the support of the Commonwealth Fund (Perot and Youdelman, 2001) and offered preliminary information for a state survey conducted by NHeLP for the DHHS Office of Minority Health. Moya Gray, of the Hawaii Office of Information Practices, discussed privacy and confidentiality concerns in collecting racial and ethnic data.

On one hand, monitoring the health and health care of racial and ethnic groups can provide the evidence essential to ensure equal health care access and quality. On the other hand, concerns about use of the information for discriminatory purposes, invasion of privacy, confidentiality, cost, and client cooperation have led to restrictions in its collection.

Evidence was presented to suggest that providers collect more complete information when the reporting of hospital data is required by law. Jeffrey Geppert described the results of a Stanford University study, which found that reporting is more complete if state laws require the reporting of racial data along with hospital discharge data (Geppert et al., 2003). The study also found that the legal reporting requirement has a direct impact on data variability among hospitals: in states with mandatory reporting of racial data, discharge records are on average 97 percent complete and there is not much variation across hospitals (reporting rates range from 93 percent to almost 100 percent); but in states with voluntary compliance, average compliance is 83 percent and there is much more variability across hospitals (reporting rates range from 23 percent to almost 100 percent).

Federal and State Laws Affecting the Collection of Racial and Ethnic Data

Mara Youdelman reported that many providers, insurance plans, and local officials erroneously believe that federal law and state governments

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[6] The workshop did not review legal or regulatory requirements related to collecting information about socioeconomic variables.

prohibit collection of racial and ethnic data. But, Youdelman's legal analysis, conducted for the Commonwealth Fund and included in a report co-authored with the Summit Health Institute for Research and Education, determined that the collection of race, ethnicity, and primary language data is in fact legal under federal law and permitted under most circumstances by state law. While the federal government has many reports and data collection instruments that request racial and ethnic data from health care providers, it does not often enforce the reporting of these data.[7]

Federal Regulations

Title VI of the Civil Rights Act of 1964[8] stipulates that any entity that receives federal financial assistance may not discriminate on the basis of race, color, or national origin. Virtually all health care providers receive some federal financial assistance,[9] and so they are required to maintain records that can be used to monitor disparities (Perot and Youdelman, 2001). Data about clients' race, ethnicity, and primary language can be used to show that providers, plans, hospitals, and other organizations receiving federal funds have complied with the nondiscrimination provisions of Title VI.

Although covered entities use these data to show compliance with the legal requirements, Title VI does not in fact require any particular data collection. Rather, regulations implementing Title VI issued by the Depart-

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[7] An ongoing study by the same organization is reviewing laws, policies, and practices in all of the states and the District of Columbia. This study is examining the extent to which health insurers and managed care organizations are permitted to collect and report race, ethnicity, and primary language data. Initial results from this state survey are based on interviews in 20 states. The researchers obtained information from Medicaid agencies, some health plans, the offices of minority health, and other state and health care officials to study prevailing practices. The results reported here are based on preliminary information provided during the workshop and are not to be attributed to the study's sponsor, the DHHS Office of Minority Health. A subsequent report, expected at the end of 2003, will provide information from all states.

[8] 42 U.S.C. § 2000d, d-4a.

[9] For example, providers receive payments from Medicare, Medicaid, or the State Children's Health Insurance Program (S-CHIP). Once an entity starts to receive federal funds, it is bound by Title VI not to discriminate. This provision also extends to all programs or activities of any entity that receives federal funds.

ment of Justice[10] require data collection to document compliance (DHHS regulations on Title VI are less direct). The courts have found that enforcement of specific requirements for data collection under Title VI is left to the discretion of federal agencies that run the programs covered by the Act.[11] Thus, while data collection is a means of ensuring compliance with Title VI, specification of the data to collect and the methods to use is at the discretion of individual federal granting agencies.

As indicated above, health plans are covered by the Civil Rights Act if they receive any federal funding—for example, if they are Medicaid managed plans. When the mandates of the Medicaid managed care regulations were applied to states (effective in August 2003), they required states to notify health plans of the race, ethnicity, and primary language of beneficiaries upon enrollment in a health plan, a requirement that contrasts with the more limited federal requirements for health plans to collect racial and ethnic data. Furthermore, the Medicare Plus Choice program recently required plans to conduct a project that specifically addressed the needs of culturally and linguistically distinct groups or a project that attempts to reduce racial disparities.

In a background paper prepared for the workshop, David Nerenz reported that medical groups do not believe they are required by law to collect data on racial and ethnic identity—and most do not collect this information. However, if they accept any federal funds, medical groups are barred from discriminating based on Title VI protections. Some large medical groups collect racial and ethnic data in the context of research and community service projects, but little is known about their data collection practices (Nerenz and Currier, 2003).

State Statutes and Regulations

Several states have laws and regulations specifying how providers and plans handle the collection of racial and ethnic data; but South Carolina

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[10] 28 C.F.F. §§ 42.404, 406.

[11] In *Madison Hughes v. Shalala* plaintiffs alleged that they were discriminated against by health care providers who were recipients of DHHS funds, in violation of Title VI, which prohibits recipients of federal funding from discriminating on the basis of race, color, or national origin. The 6th District Court decided that it lacked subject matter jurisdiction. It held that there is a distinction between its discretion requiring the collection of data to enforce Title VI and a DHHS requirement under the law that the Department should use nationwide statistics to enforce Title VI [80 F.3d 1121, 1124-5 (6th Cir. 1996).]

recently repealed a requirement that health maintenance organizations collect and report racial data.[12] Texas, for example, requires all health maintenance organizations to collect primary language data from enrollees.[13] Mara Youdelman of NHeLP reported that, according to preliminary information gathered by NHeLP pursuant to a contract with the federal Office of Minority Health, only four states—California, Maryland, New Hampshire, and New Jersey—have statutes prohibiting the collection of racial or ethnic data on application forms in the individual or group insurance market, but none of them has enacted a blanket prohibition, and even in these states the law permits collection of the data after enrollment. Five states (Connecticut, Iowa, Minnesota, South Dakota, and Washington) have, as part of their prior approval processes for insurance forms, specified that forms containing any inquiry about the race or ethnicity of an applicant or covered individual will either be disapproved or carefully scrutinized, even though those states do not prohibit the collection of such data. Three of those states—Connecticut, Minnesota, and South Dakota—disapprove requests from plans or insurers to collect racial, ethnic, and socioeconomic data. Two of the states—Iowa and Washington—use their prior approval process to scrutinize any request to collect racial, ethnic, and socioeconomic data in order to prevent harmful uses. In the above examples, these states' laws, regulations, and practices were designed to prevent discriminatory redlining (NHeLP draft).

Youdelman also reported that in Hawaii, Indiana, Iowa, Kansas, Oklahoma, Oregon, and Vermont the level of protection against discrimination on the basis of race or national origin for health care consumers and managed care enrollees is uncertain. These states have no separate provisions in the insurance statutes or HMO laws that prohibit racial or ethnic discrimination, and health insurers either do not appear to fall within the ambit of the separate public accommodations statute or have been found by a state court to be covered. Alabama, Georgia, and Mississippi provide no protection for racial and ethnic health care consumers in their insurance laws, managed care laws, or general civil rights laws. Several participants discussed the proposed California Racial Privacy Initiative to be considered by

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[12] S.C. Code Regs. 61-10(11)(c).

[13] They also require that HMOs provide foreign language written materials for each limited-English-proficient population that constitutes at least 10 percent of the enrolled members.

the voters in 2003.[14] If passed, this initiative would bar the collection of racial or ethnic data by the government except for medical research and certain law enforcement procedures.

Implementation and Impacts of Federal Regulations

As mentioned above, the Department of Justice coordinates federal enforcement of Title VI, and its regulations require record keeping sufficient to demonstrate compliance (Perot and Youdelman, 2001). DHHS's Title VI regulations do not specifically require data collection, but they cite it as an example of how an entity receiving federal funds can demonstrate compliance.

However, the Department's regulations for the State Children's Health Insurance Program (S-CHIP) do require states to establish uniform racial and ethnic data collection and reporting from health care providers. Federal regulations governing Medicaid, S-CHIP, the End Stage Renal Disease Program, and the Substance Abuse and Mental Health Services Administration (SAMHSA) applications for prevention activities all require the collection and reporting of racial and ethnic data.

No federal statutes require the collection or reporting of primary language data; however, the Medicaid managed care regulations require states to provide managed care organizations with racial, ethnic, and primary language data about enrollees. The federal government's Office of Minority Health has promulgated culturally and linguistically appropriate services standards for health care, recommending that racial, ethnic, and primary language data should be included in patient records (including the primary language of both the enrollee and parent or guardian).

The implementation of these regulations is reflected in data collected as part of the administration of DHHS programs, many of which ask for racial or ethnic data; actual collection, however, depends on DHHS enforcement. For example, the financial reporting form that states submit to DHHS to claim payment for Medicaid expenditures includes fields for racial and ethnic data. However, several participants argued that the Center for Medicare and Medicaid Services (CMS) has not emphasized or en-

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[14] The official title of this initiative is "Classification by race, ethnicity, color, or national origin. Initiative for a constitutional amendment." It is Proposition 54 and is slated to be considered by the voters on October 7, 2003. For more information about this proposition see http://www.racialprivacy.org/.

forced the reporting of this information and instead concentrates on obtaining financial information.

Health Insurance Portability and Accountability Act (HIPAA)

Several participants cited implementation of the Health Insurance Portability and Accountability Act (HIPAA; PL 104-191, 1996) as an illustration of how regulatory decisions can affect the collection of racial and ethnic data. The Act is likely to have a dramatic effect on all providers and health plans: it establishes national standards for electronic transactions and requires all health plans, health care clearinghouses, and providers that conduct business electronically to comply with the new standards. The law thus requires DHHS to adopt standards for code sets and covered transactions, including claims and enrollment transactions.

Under HIPAA, data standards maintenance organizations (DSMOs) are responsible for maintaining the content and standards for covered transactions. They do so through implementation guides, which define the content and code sets of standardized data for constructing a HIPAA-compliant transaction (45 CFR Part 162, 2003), as well as the elements that providers and insurance plans report in electronic health care claims and benefits enrollment transactions. Every time health care providers electronically transmit a claim to an insurer and in turn to the Centers for Medicare and Medicaid Services (CMS), HIPAA requires them to use a standard transaction.

HIPAA implementation guidelines also designate each element in the transaction standard as *required, situational,* or *not used*. *Required* elements must be included; *situational* elements are used in certain circumstances but not others; *not used* elements are not currently reported by covered entities. In the transaction standards for health care claims, benefits, and enrollment, the racial and ethnic fields are currently designated as not used, but they designate these fields as situational for enrollment maintenance transactions. Providers are concerned that if claims-related fields were designated as *situational* or *required,* doctors would have to ask patients for racial and ethnic data each time they provided service. Workshop participants contended that because of this concern racial, ethnic, and primary language information cannot become part of the HIPAA standard transactions. But even if required, these data would still not cover the uninsured or those who pay for themselves, although HIPAA does cover the vast majority of people in the health care system.

Many providers and state officials see the implementation of the HIPAA code sets as a lost opportunity to address comparability and completeness issues by recommending the collection of racial and ethnic information by plans and providers. But this opportunity was not pursued, citing problems with guidelines for collecting racial and ethnic data in several settings. They contend that different federal agencies use different racial and ethnic categories and specify them for collection on different forms. Advocates for collecting racial and ethnic data as part of the HIPAA process argued that HIPAA does provide an opportunity to include racial and ethnic data in covered transactions if the industry would support the inclusion. A number of workshop participants agreed that inclusion of racial and ethnic data in a covered transaction will require a coordinated industry effort; greater attention by health plans, for example, could lead to the inclusion of these fields. DHHS officials pointed out that the HIPAA code sets adopted by the Department were recommended by the industry.

HIPAA also required substantial effort to revise databases at great cost in time and money. Participants affiliated with health plans argued that it would have been easier to add racial and ethnic indicators during the revisions originally required by HIPAA rather than initiating a subsequent, separate revision, which would delay and complicate HIPAA compliance activities. According to Moya Gray, an administrator of the Hawaii Uniform Information Practices Act (HUIPA), "the cost of [implementing] HIPAA is going to overwhelm health care in the first few years. To add racial, ethnic, and socioeconomic collection to that may undermine the actual point of collecting data and you will create more resistance to that than anything else."

Many states collect racial and ethnic data through hospital discharge data. In 1998, at least 27 states collected racial and ethnic data from providers (National Association of Health Data Organizations (NAHDO) and Medstat, 1999). Additionally, racial and ethnic data were identified as important fields for policy and public health purposes in a 1998 poll of members of NAHDO. At least 18 states indicated they would continue to collect racial and ethnic data even if these fields were excluded in HIPAA transaction standards. In this poll, some states also indicated that it is important to collect data on country of origin, marital status, patient living arrangements, education, and occupation, and several reported that they obtained this information by linking records across data sets.

Privacy and Confidentiality Issues

Participants reported that health care providers and plans and state officials are concerned about preserving the confidentiality and privacy of individual racial and ethnic data, believing that in order to gain the cooperation of people who use health care services, it is important to protect their privacy. If people fear that secondary use of their information could be harmful to them, many may be reluctant to fully and correctly respond to requests for information, and so the resulting information would not be accurate. There was general agreement that, while collecting racial and ethnic data is important to reduce disparities, it is equally important that such data not be used to the disadvantage of clients.

The workshop participants therefore considered how best to understand the balance between clients' needs for privacy and researchers' needs for access to data.

One view is that when a person gives information about him or herself, a social contract is made with the person who collects it. That social contract implies that the information will be used for the stated purpose and for no other purpose. In this view, data in files maintained by employers, insurers, and providers can be used only in ways that support the interests of individual clients. According to Moya Gray, "Compilations of new information about people and the secondary uses or disclosures of that new compilation raise very significant questions regarding the patient's loss of control of their intimate information."

But some workshop participants argued that data analyses used to monitor disparities are in the interest of clients. Leonard Rubenstein, executive director of Physicians for Human Rights, argued that one concern is that racial or ethnic data can be used for redlining. He noted, however, that "the history of civil rights enforcement in the United States involved using data, including racial data, to achieve civil rights objectives. When schools were desegregated, racial data were used for desegregation. When employment places were desegregated, racial, ethnic, and socioeconomic data were used. More recently, racial data have been critical in ending racial profiling on the highways." He concluded that "a balance is required between the crucial need for privacy and the possible misuse of data, and the recognition that data of this kind is required for civil rights and human rights goals."

Moya Gray reported that while Hawaii state law does not prohibit the collection of any data, the state enforces a constitutional right to privacy, including the right to control information collected by either the public or private sector. According to the Hawaii standard, in order to collect information, there must be a "compelling state interest." The Hawaii Uniform Information Practices Act (HUIPA)[15] prohibits using data for any purpose other than the one for which the data were collected, a restriction that has been interpreted to bar the use of racial, ethnic, and socioeconomic data on health care records. Gray went on to argue that racial and ethnic data do not serve a health care purpose and therefore should not be collected. In her view, such data do not appropriately identify people because these designations are political. She explained that the purpose of a birth certificate, for example, is to record information about the place of birth, parentage, and other characteristics of children, but that race is not an appropriate identifier to include among those characteristics.

Some participants wondered whether racial, ethnic, and socioeconomic identifiers collected in administrative health records should be available for research or if researchers should have to obtain the permission of clients to analyze them. It was pointed out that it is very costly for researchers to go back to clients for consent to access their administrative records. Participants then discussed several mechanisms that could be used to protect client privacy while allowing researchers access to client records. For example, HIPAA mandates the appointment in each covered entity of an officer who is accountable for privacy protection. Some participants raised concerns, however, about whether these officers have sufficient resources to deal with the large amount of data generated by the health care industry and the many privacy issues that this data collection raises.

COLLECTING THE DATA

Workshop participants examined practical considerations in the collection, categorization, and reporting of data. For example, those affiliated with health care providers and plans expressed concern that collecting racial and ethnic data will increase the cost of record keeping. Participants therefore urged that requirements to collect racial and ethnic data be adopted after consideration of their costs as well as their benefits, and that practical and broadly accepted standards for measurement be developed.

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[15] Chapter 92F of the Hawaii Revised Statutes; see http://www.state.hi.us/oip/uipa.html.

Options for Obtaining Data

Participants identified three ways to report racial and ethnic data:

- Use existing data,
- Collect new data, or
- Infer data when racial and ethnic information is missing.

Using Existing Data Sources

Workshop participants identified a large array of existing data about health status and care. These data are collected by federal, state, and local governments as well as private health plans and some large provider organizations. Issues related to these data were considered during the workshop presentation and discussions.

Participants reported that the primary source of existing administrative health care data with racial and ethnic information is Medicare, though Medicaid and hospital discharge data also are potentially useful. But Allen Fremont, of RAND, pointed out that "all these sources are severely limited by inaccurate and incomplete data and often are noncomparable across sources in terms of how they code racial and ethnic data." For example, while Medicare recently improved the accuracy and completeness of its data, experts believe that their records still have only 60 percent accuracy in some racial and ethnic data, such as for Hispanic and Asian subgroups.

CMS gets Medicare racial and ethnic indicators from the Social Security Administration's (SSA) enrollment files; but the SSA files frequently contain information using broad categories of racial classification which were used in the past: "white," "black," and "other" according to workshop participant Marion Gornick. SSA also collects information on language, but according to Nicole Lurie, RAND, "it is virtually impossible to link this data to Medicare beneficiaries." Participants urged the panel to examine alternatives to SSA data or to recommend improvements in SSA procedures.

Collecting New Data

Collecting new racial and ethnic data presents important challenges. It involves added costs either for survey administration or to modify computer systems for new administrative records. New data collections also face issues related to the methods used to categorize respondents, obtain cooperation, and apply appropriate analysis. For example, there may be differences between racial and ethnic data obtained from a patient or enrollee and those completed by a clerk who attempts to identify the race or ethnicity based on observation.

Some data collection methods were considered. Surveys, for example, have the advantage that they can be designed to use standardized procedures administered by trained staff, and they frequently use respondents' own identification of their racial and ethnic affiliation rather than caregivers' estimates. On the other hand, surveys rely on samples that are usually too small to capture information about smaller ethnic groups or for individual providers or insurance plans.

Lurie described the approach used by Aetna, which examined demographic changes in the country and determined that in the future much of its new market share would come from minority populations. The company decided that it was important to provide high-quality care for these groups, and therefore began collecting racial and ethnic data from all enrollees in order to discern any discrepancies in health care services.[16] The information was collected on enrollment forms after an individual was accepted for coverage or when an individual changed coverage.

Inferring Missing Data

Workshop participants discussed the possibility of inferring missing racial and ethnic information on health data sets by appending census-based socioeconomic characteristics of residential areas to individual records. While this method can reveal patterns of association, especially where residency patterns are still substantially segregated, and may thus provide an indication of a person's racial or ethnic affiliation, there is considerable uncertainty about its accuracy. Participants described two inference methods that have been attempted:

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[16] In March 2003 the Aetna Corporation announced that it was collecting racial and ethnic data for its enrollees in an attempt to analyze service utilization and find out if there are disparities in the care it pays for. They based this decision on the 2002 IOM study that called attention to subtle differences in care and health status. The company started collecting this information from newly enrolled members in the District of Columbia and 13 states and is also planning to collect it from physicians who provide services to enrollees.

- ***Geocoding*** estimates racial data from the characteristics of people living in a subject's neighborhood as reported in the census.

This involves using results reported for a census block group (typically an area with about a thousand people who tend to be fairly homogeneous) to impute the likely racial or ethnic data about a health care client. Little empirical attention has been given to the validity of this approach, but workshop participants pointed out that the procedure is less accurate in heterogeneous areas. A study by Geronimus and Bound in 1998 used samples from nationally representative data sets linked to census data in order to estimate health outcomes of different racial groups. Their analysis investigated "whether statistical power is sensitive to the timing of census data collection or to the level of aggregation of the census data; whether different census items are conceptually distinct; and whether the use of multiple aggregate measures in health outcome equations improves prediction compared with a single aggregate measure" (Geronimus and Bound, 1998, p. 475). The authors found little difference in estimates when using 1970 data compared with 1980 data from the U.S. Bureau of the Census, or zip code data compared with tract-level variables. However, aggregate variables are highly multicollinear; associations of health outcomes with aggregate measures are substantially weaker than with microlevel measures. The authors concluded that aggregate measures cannot be interpreted as if they were microlevel variables, nor should a specific aggregate measure be interpreted to represent the effects of what it is labeled.

- ***Surname analysis*** uses an individual's family name to determine likely racial and ethnic data.

This method is typically used to collect data on Asians and Hispanics. However, Gem Daus of the Asian and Pacific Islander American Health Forum pointed out that surname analysis often misclassifies some Asians, especially those with Hispanic names from areas such as the Philippines.

Standard Set of Racial and Ethnic Categories

Agreement on a standard set of categories was identified by many participants as one of the most important prerequisites for collecting better racial and ethnic data. Many argued that standards should make it possible for states to aggregate data based on local conditions and to enable comparisons with other states. Standards should also facilitate integrated analyses across socioeconomic indicators, using them as a set of measures to avoid the kinds of false inferences one might obtain from any particular data element in isolation.

But progress toward such standardization has been slow and inconsistent. According to Andrew Webber of the National Committee for Quality Assurance (NCQA), in order to mandate plans to report HEDIS performance measures by racial and ethnic categories, "we would need to see much greater movement towards uniformity and standardization of racial and ethnic data capture by plans." While the Office of Management and Budget (OMB) has issued a standard set of racial and ethnic categories, workshop participants reported that these are not consistently applied. And although OMB has issued guidelines for bridging the gaps between the multiple race responses allowed under the new federal standards for racial and ethnic data and the more limited information collected under the old standards (OMB, 2000), many participants professed confusion. Some called for the federal government to help users make decisions as to which census denominator should be used to calculate rates.

Matthew Snipp, of Stanford University, reported that surveys conducted to test the effect of using multiethnic categories showed that adding a multiracial question or adding instructions that would allow multiracial responses would not actually affect the aggregate results because the number of respondents was relatively small, something on the order of between 1 and 2 percent. Nonetheless, for small groups such as Native American tribes or several Asian and Pacific Island American groups, the impact could be significant.

Evaluating Accuracy

Accuracy and data quality are key attributes, and it is especially important to evaluate the accuracy of health-related racial and ethnic indicators. Jay Buechner, of the Rhode Island State Department of Health, argued that "the best practice would be to evaluate the data by going back to the source and comparing information in the database to the perceptions of the persons represented in it. This is too costly to be feasible on a regular basis. However, it is useful even if it can only be done periodically." He suggested that another way of evaluating the reported data is "to estimate expected race and ethnicity based on other characteristics of the individual and compare the information with what was actually collected. While this probably is not definitive at the individual level, it might be used to identify patterns suggesting systematic reporting errors."

Buechner reported on a study in Rhode Island that compared data from a surveillance study of traumatic brain injury with hospital discharge records. Investigators collected information on all traumatic brain-injured patients who were treated in hospitals in Rhode Island; about 2,800 cases were identified over a 4-year period. Data from the study were compared with routine hospital discharge data linking medical records to the hospital discharge abstract. The study used trained abstracters who went into all the hospitals in the state and examined the medical records to collect information on the patient. Both the medical records and the hospital discharge data rely on reports compiled by hospital staff, and so the comparison relied on the same underlying data. Neither the medical records nor the discharge data involved collecting information from the patients.

The comparison showed that hospital record keepers do a good job of identifying white clients. Almost 99 percent of the white patients identified in the traumatic brain injury study were correctly identified as white in the hospital discharge data. But for all of the minority populations, those rates were lower. In particular, only one of the nineteen Native Americans in the study was identified as Native American in the hospital discharge data.

STATE AND LOCAL DATA COLLECTION AND REPORTING

States collect health care data from many sources, and workshop participants noted that racial and ethnic data play an important role in all of them. These include the following:

- vital records, used to compile birth and death statistics;
- registries of people suffering from particular diseases—for example, cancer registries or screening registries for risks such as exposure to lead;
- surveillance databases that compile information on conditions reportable to the Centers for Disease Control and Prevention (CDC) as well as other conditions defined by states as reportable;
- encounter and administrative data, including hospital discharge records, data for public payers, Medicaid, administrative data, and enrollment data;
- health workforce data—for example records of practitioners' licenses;

- population health surveys, which many states implement to gather health status information on groups of state residents.

Several participants believe there are important interactions among these sources, and that the data can be made more useful and informative by linking records from various databases. For example, Geppert suggested that linking death certificate data with encounter records, or hospital discharge data with birth data, will produce better measures of health outcomes. Participants observed, however, that such linkages can be hampered by variations in racial and ethnic categories both among states and between states and the federal government. Sources of such variation include:

- ***Variation among states*** in data formats, content standards, code sets, tabulation, and reporting.
- ***Variation within states*** in policy, procedures, and training.

For example, Daniel Friedman reported that only about half of roughly 75 individual record data sets at the Massachusetts Department of Public Health have racial and ethnic data, and most of those three dozen data sets derive, directly or indirectly, from federal programs such as those of the CDC. He observed that, "Even though we are 5 years past the issuance of the 1997 revised federal racial and ethnic standards, there is variation from program to program in how racial and ethnic identifiers are operationalized—due largely to differences in federal agency requirements." This creates a particular problem for states because their data collection is more centralized. Consequently, states find that they have to accommodate their systems to multiple federal standards.

- ***Challenge of small numbers.*** States also face the problem that federal standards specify reporting for particular groups, which might not be numerous within a particular state. This can and does cause imbalances in state reporting—groups that are more numerous may not be reported, while the reporting of smaller groups is required.
- ***Reporting detailed groups.*** In the past, states have followed the practice of reporting two groups, "whites" and "nonwhites." The problem with this approach is that it obscures important differences within these groups.
- ***Different perspectives of federal and state governments.*** Federal

and state governments have different reasons for reporting and using racial and ethnic data.

In the words of Friedman, "State governments and local governments are not just mini federal governments, and state health departments and county health departments are not mini-Centers for Disease Control [and Prevention] [CDC]."

- ***Requirements for public health initiatives.*** States need racial and ethnic data to design effective public health interventions.

Friedman argued that "Broad race categories are totally and completely insufficient for this purpose. Detailed ethnicity categories—including detailed ethnicity categories for Blacks, Latinos, Asians—are needed in order to launch appropriate interventions." He reported that in Massachusetts the difference in low birth weight rates and adequacy of prenatal care between Cambodians and American-born Chinese is almost 50 percent; between Cuban Americans and Puerto Ricans born in the continental United States, roughly 25 percent; between mothers who identify themselves as African-American and those who identify themselves as Barbadian or Jamaican, roughly 25 percent. Thus, the variation within a racial group is just as great as the variation between racial groups. Consequently, a public health intervention designed for "Asians" or "Latinos" or "Blacks" cannot be effective.

Buechner pointed out that those who actually must collect the data are not consistently trained. Many of them do not work for state agencies but for health care facilities, providers, or funeral homes, and they report to the state under different programs. Turnover in these jobs can be high and continual retraining is often required. Quality control procedures are required. These include feedback to the data collectors, the checking of basic data entry for consistency, accuracy, and relevance, and follow-up quality control studies.

A study conducted by Jeffrey Geppert, of the Stanford Center for Health Policy, identified 77 specific state initiatives that were based in whole or in part on health status, health care, or public health data disaggregated for different racial and ethnic groups (Geppert et al., 2003). For example, the Florida Chronic Disease Community Intervention Program aims to reduce cardiovascular disease, diabetes, and associated complications. The study targeted migrant agricultural workers in Florida's rural Pascal County for intervention based on national data that report higher prevalence of these conditions. The health department initiated door-to-door health assessments (blood pressure, cholesterol, and blood glucose screenings), referrals to community clinics, and sponsorship of community centers that conducted classes that encouraged physical activity.

It used bilingual health practitioners to teach better nutritional practices through cooking classes and other kinds of health promotion activities. The program measured the reduction of disease prevalence 5 years later.

Limited Information Technology

Lorin Ranbom, with the Ohio Department of Health, reported that the limited information technology resources available to state government offices determine how data are compiled and analyzed. Statisticians and epidemiologists originally created systems on their desktop computers with only limited support from computer professionals and using relatively simple off-the-shelf software. Years later, the states have found themselves relying on these systems to generate information for state policy and regulatory decisions and to implement score cards. But these discrete legacy systems do not use the same data element definitions for unique patient identifiers, for geography, or for demographics, including racial and ethnic data, and the discrepancies greatly increase the effort required to achieve comparable data sets.

Ranbom described how over the past 5 years state Medicaid programs transformed themselves from the payer of last resort to population-based health plans that are consumer focused and performance based. Therefore, he said, “Understanding and reducing health disparities is, or should be, a big part of our work in Medicaid programs.” He reported that in the past, about 80 percent of eligibility determinations were based on personal interviews of clients, whereas now roughly 70 percent of eligibility determinations are initiated through a mail-in system. Thus Medicaid programs have moved toward self-determination of racial and ethnic information.

But he cautioned that “African-Americans have a much lower response rate to consumer surveys than other minorities and whites.” While the survey attempts to compensate by oversampling and by weighting responses, in his view “the NCQA and the National CAHPS Benchmarking Database requirements for health plans lack the methodological sophistication to deal with these issues" and as a result health disparities are often misrepresented.

Counties

Counties are on the front line of data collection efforts targeted to help eliminate racial disparities. David Solet, an epidemiologist with King County (Seattle, Washington) Health Department, summarized a project he conducted. The study included a special risk factors survey designed to obtain data for five different Asian groups, Latinos, African-Americans, and whites. The resulting data were used to implement initiatives to meet the needs of these groups.

The survey found that a large number of African-Americans believed they suffered discrimination when they used health care providers and, as a result, were less likely to visit health care providers when they had health problems. The county invited selected respondents to provide more detailed information in longer interviews and focus groups. They found that respondents believed they suffered from differential treatment and offensive comments. The county now uses this information to influence health care providers to address these concerns.

PRIVATE-SECTOR DATA COLLECTION

Several workshop participants presented papers on how health plans, hospitals, and medical groups approach disparities in the context of quality improvement (Nerenz and Currier, 2003; Bocchino and Wheeler, 2003). The presenters contended that such disparities erode the quality of care, but that health plans, hospitals, and medical groups have mechanisms—including the collection of racial, ethnic, and other consumer-related data—for measuring and improving quality, and these mechanisms can be used to address the disparities. Furthermore, each of the entities has a clear and formal line of accountability that runs from purchasers to health plans to hospitals and medical groups and ultimately to individual patients. This accountability is embodied in formal contractual relationships that include expectations about the absence of inconsistencies or disparities.

Workshop participants from the private sector suggested that both public and private purchasers can and should play an important role in reducing health care disparities through the use of improved data collection. For example, Nerenz observed, "in the city of Detroit if the three auto companies get together they can substantially influence the structure of health care. If the purchasers rally around a particular point and say it matters to them, the world changes."

Health Plans

Eileen Peterson, from the Center for Health Care Policy and Research at United Health Group, discussed the collection of racial and ethnic data by health plans. According to Peterson, health plans collect racial and ethnic data from their members or enrollees for a variety of reasons: for evaluating differences in access to care and compliance with therapies, for designing culturally appropriate educational and member communications, and for designing clinical in-service quality improvement activities. In her view, "health plans recognize cultural diversity as an important issue, which offers challenges and opportunities. Health plans have collected some data mainly through indirect methods, through census tracking, through surveys, and voluntarily on enrollment forms. Even though there is no consistent or sufficiently recognized approach, health plans are using this data to improve access to appropriate and culturally sensitive care." She affirmed that "health plans are interested in participating in a coordinated and directed effort to accelerate the collection of accurate race and ethnicity data. Health plans would really like a consistent approach across the industry." But, she cautioned that "there is no intentional, routine, complete, and validated collection of racial and ethnic information going on in the private sector." In her view, "if we don't really understand the scope of the problem, we can't address it, I think, in a concrete way."

David Nerenz reported on a demonstration project that involved 13 health plans in an examination of the collection and use of racial and ethnic data (see Nerenz and Currier, 2003). This study found that plans can get racial and ethnic data for their members and that the information can be linked to quality measurements found in HEDIS. When this was done, analysis revealed evidence of racial and ethnic disparities at the individual plan level.

The project showed that plans not previously engaged in gathering racial and ethnic data could do so when they had a special opportunity and some support for it. The study also produced some unexpected findings: in some plans the disparities *favored* one or more minority groups (Perot and Youdelman, 2001).

Carmella Bocchino of the American Association of Health Plans presented the results from a review of information from 30 health plans (Bocchino and Wheeler, 2003). Sixteen of the plans were preselected because they had collected racial and ethnic data in the past (whether they had been successful or had experienced numerous barriers in trying to collect the data); fourteen plans were randomly selected from a subset of plans participating in an annual industry survey. In the surveyed plans, enrollment ranged in size from 100,000 to 6 million members, thus representing a wide variety of health plans. The plans offered a mix of HMO, PPO, and point-of-service products.

The health plans reviewed use a variety of sources and methods to collect racial and ethnic data, both directly and indirectly. For example, they reported using census tract results (based on the addresses of enrollees), satisfaction surveys (such as the CAHPS) data, or plan-initiated surveys. Seven of the 24 plans received racial and ethnic data directly from Medicare or Medicaid enrollment files. Six asked for race, ethnicity, and primary language information on enrollment forms. Others asked for primary language as clients entered a specialized disease management program.

While health plans have accurately collected racial and ethnic data on commercial (non-Medicaid or non-Medicare) members, their strategies are limited to specific subpopulations (e.g., HMO members or members who elect to participate in specific disease management programs). Health plans have no systematic way to accurately collect data on their overall membership.

Bocchino stated that "a coordinated, directed effort to accelerate the collection of accurate data would be supported by health plans and would remove many of the barriers that we found when we did these interviews . . . this involves and must include the federal and state governments. The core of this effort must be to instill or renew the public's trust that this information will be used for the benefit of health plan members . . . we really do need a very strong public education campaign to help members understand how important this data can be for their cultures." She also called for "a coordinated public and private effort to educate not only consumers, but the entire health plan and health care industry regarding legal issues and breaking down . . . misperceptions."

Hospital Data Collection

According to Romana Hasnain-Wynia of the Health Research and Educational Trust (which is affiliated with the American Hospital Association), “We do not currently have, at least within the hospitals within the United States, a systematic way of collecting data on race, ethnicity, or primary language. If you speak to four hospitals within the same region and ask them [how they collect racial and ethnic data], you are going to get [different] responses from” each of them. She added that there can be considerable variability in how racial and ethnic data are recorded even within a facility. For example, in a hospital the main inpatient admitting office may use a procedure that is different from that used in the emergency department, an outpatient clinic, or a dedicated maternal and child health clinic.

Hasnain-Wynia said that hospitals need racial and ethnic data and other characteristics of their patients to assess disparities, design targeted interventions to improve the quality of care, and evaluate outcomes. Recently, she reported, the American Hospital Association (AHA) started a project with a consortium of six hospitals and health systems to develop a uniform framework for collecting racial, ethnic, and primary language data.[17] The project is conducting site visits and working with consortium members at the six participating sites to learn about current practices.

AHA will also administer a survey to all hospitals in the United States to learn how these data are currently collected and what impedes or facilitates data collection. The project will develop procedures to collect data uniformly across the six participating sites, pilot test the procedures at the six sites, and then move from there toward actually developing and implementing interventions that will improve the quality of care for different population groups. AHA hopes to use this as a means to educate hospitals around the country about the importance of collecting racial, ethnic, and primary language data.

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[17] These include Massachusetts General Hospital, Henry Ford Health System in Detroit, University of Pittsburgh Medical Center Health System, Northwestern Memorial Hospital in Chicago, Kaiser Permanente in Northern California, and Parkland Memorial Hospital in Dallas.

The National Committee for Quality Assurance

Participants reported that routine collection of services utilization data for racial and ethnic groups is currently limited to the Medicare program.[18] Researchers also collect the data as a part of special health care projects. Many delivery systems, including those in managed care plans, do not routinely collect or maintain racial and ethnic data on health care utilization of services. In the cases where analysts do have data, such as from Medicare or hospital discharge records, the information is often inaccurate and incomplete.

Andy Webber of the National Committee for Quality Assurance, a national nonprofit organization that accredits health care groups, talked about the work of his organization, which evaluates HMOs and "will soon be evaluating providers. This reflects a move towards placing accountability for clinical quality at the provider level. The NCQA advocates the need to coordinate public- and private-sector activity in this arena to ensure consistency and to reduce provider burden." One problem Webber highlighted is that "consumers currently do not understand the role of an accountable health plan, in improving, organizing, coordinating health care quality." The NCQA is considering adding a data element that requires health plans to monitor disparities of health care in their enrolled populations. Once this monitoring has been established, "we could then potentially move to requiring—as CMS did of Medicare and Choice plans—that specific plan-level quality improvement activities address disparities in health care."

Litigation Exposure

Several participants noted that private providers and insurance companies are afraid that racial and ethnic data could serve as the basis for private action in court—i.e., they could be sued. In the words of Nicole Lurie:

> It is sort of 'you are damned if you do and you are damned if you don't.' If you collect data on race and ethnicity to look at quality of care, particularly for your enrollees by race and ethnicity, are you then potentially more open to being sued in a civil rights case because you have got this data, because you have done a responsible thing and looked internally to see if you had disparities? There is clearly a school of thought that says, yes, this makes me more vulnerable. On the other hand, there is a school of thought that says if you do

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[18] This information is also collected by the Indian Health Service.

> the responsible thing and go ahead and look at this, in some sense, it kind of immunizes you against those kinds of lawsuits. I think the jury is out. I did have an opportunity recently to speak with one health plan executive, who told me a really sad tale about being sued by a potential enrollee who had applied for insurance under the individual market and had been underwritten out presumably because of preexisting conditions and then brought a civil rights lawsuit against the health plan.

Bocchino and Wheeler (2003) reported that 15 of 24 health plans cited legal concerns among their members or the plan's legal counsel. Health plan members were concerned about how the data would be used; some worried the information would be used to discriminate against them. However, if they entered a disease management program or a particular program where targeted material was developed to help them access the health care system or better comply with their therapies, then they began to understand how important the data could be. This view was not generally shared across the population of enrollees.

Health plans surveyed by Bocchino and Wheeler (2003) suggested it would be helpful to have a public education campaign, involving members and employers, with site programs to enhance understanding of why this information has to be collected and how useful it can be to enrollees in their health care needs. Eighteen of 24 plans felt that having members understand the positive aspects of data collection would be a first step in moving forward.

CONCLUSION

Workshop participants considered the use of racial and ethnic data in health statistics and agreed that there is great value in collecting this information to help health plan efforts to reduce disparities and improve both the health and health care of minority groups. They reviewed the extent of collection of these data and variety of data collection methods in the private, state, local, and federal government sectors, and called for the standardization of federal program collection as a prerequisite for more universal private, state, and local government collection methods and reporting. In a discussion of the legal environment for the collection and reporting of such data it was noted that the collection of this information is mandated under federal law and permitted under most state and local laws.

However, certain factors need to be considered in the effort to enhance the collection of racial and ethnic data. There can be significant monetary and institutional costs incurred in increased record keeping and in upgraded computing capabilities. In addition, the public needs to be educated about the purposes of such data collection and convinced of its benefits and appropriateness. In this area participants also called for careful consideration of the implications of such data collection for the privacy of respondents.

In summary, the workshop participants expressed support for racial and ethnic data collection efforts but called for stronger federal leadership. The panel will consider these and the other perspectives and issues presented at the workshop as it completes its work.

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Appendix A

Abbreviations

AHA	American Hospital Association
CAHPS	Consumer Assessment of Health Plans
CMS	Center for Medicare and Medicaid Services, DHHS
DHHS	United States Department of Health and Human Services
DOJ	United States Department of Justice
DSMO	data standards maintenance organization
HEDIS	Health Plan Employer Data and Information Set
HIPAA	Health Insurance Portability and Accountability Act
HUIPA	Hawaii Uniform Information Practices Act
Medicaid	U.S. government-sponsored medical insurance program
NAHDO	National Association of Health Data Organizations
NCQA	National Committee for Quality Assurance
NHeLP	National Health Law Program
SAMHSA	Substance Abuse and Mental Health Services Administration in the U.S. Public Health Service
S-CHIP	State Children's Health Insurance Program

Appendix B

Abstracts of Papers Commissioned for the Workshop

Title: *Race and Ethnicity Data Collection by Health Plans*
Authors: Carmella Bocchino, Vice President, Medical Affairs, American Association of Health Plans, Deborah Wheeler, Medical Affairs, American Association of Health Plans

Health plans have recognized the importance of responding to patients' varied perspectives, beliefs, and behaviors about health and well-being, as well as the considerable health consequences that will result in a failure to value and manage cultural and communal differences in the populations they serve. Through the emerging field of culturally competent care, health plans are developing strategies to reduce disparities in access to and quality of health care services. The collection of racial and ethnic data is a first step in designing and advancing such strategies. Health plans generally are supportive of the collection of racial and ethnic data on their members. They see these data as having great utility in a number of areas, which are delineated in this paper. Barriers, however, do exist—collection is not consistent across the industry and is often fragmented—which make it difficult to evaluate the quality of such data and subsequently determine solutions to advance culturally competent care. Even so, some strong examples of data collection and related innovative strategies for use are emerging.

Based on the paper's findings, several recommendations were made. The paper first recommended the development of a coordinated, uniform approach across the health care industry to accelerate the collection of accurate racial and ethnic data, which would include input and active participation from health plans, employers, and federal and state governments. The paper also recommended identifying models that work to balance the extensive research concentrating on gaps in health care quality linked to race and ethnicity. Finally the paper recommended funding new research directed at specific methods to reduce or eliminate inconsistencies in medical care experienced by some racial and ethnic minorities. This would include identification of specific factors that prevent culturally diverse populations from obtaining quality health care and how these factors interact with the health care system.

Title: *The Role of Race and Ethnicity Data Collection in Eliminating Disparities in Health Care*
Authors: Allen Fremont, MD, PhD, and Nicole Lurie, MD, MSPH, RAND

This paper provides a framework for describing the role of racial and ethnic data in supporting essential functions of the health care system. The authors first illustrate the value of racial and ethnic data collection by describing ways it can be used to reduce disparities, particularly with respect to the quality of care. They describe how data on primary language and socioeconomic status can complement racial and ethnic information. They then assess current sources of racial and ethnic information and the challenges inherent in collecting it. The paper concludes with a series of recommendations for enhancing the availability and use of racial and ethnic data in the public and private sectors.

The paper recommended that standards be developed to ensure uniform collection of data at the federal, state, and local levels. Guidance is needed to clarify how these data should be collected in different settings (e.g., when, how, by whom), and training is necessary for frontline personnel. The paper also recommended creating a centralized body that could provide guidance and oversight regarding standards for and collection of data. This body should propose a set of incentives for the collection of such data, as well as penalties for failing to collect it in ways that meet a minimum standard. Another recommendation suggested sampling of major racial and ethnic groups for all major epidemiologic and health status data collection efforts funded by the federal government, including those that provide important subnational data. Finally, the paper asserted that data collection within the health care system itself provides the basis for assessing disparities in care and for benchmarking progress.

Title: *State Race and Ethnicity Data Collection*
Authors: Jeffrey J. Geppert, Sara J. Singer, Jay Buechner, Lorin Ranbom, Walter Suarez, and Wu Xu, Center for Health Policy, Stanford University

This paper analyzed variations in the current collection of racial and ethnic data both among states and between states and the federal government, assessed the costs and benefits of enhancing or standardizing such data collection, and described selected recommended practices regarding race and ethnicity data collection and use. The authors examined how selected states approach race and ethnicity data collection through interviews with health agency staff and review of published sources. The background section describes states' most commonly used data sources that include racial and ethnic data. The methods section describes the authors' data collection procedure for interviews and data analysis. The results section describes some of the variation among states in the collection of race, ethnicity, and other socioeconomic characteristics data, and the benefits and costs of such data collection from the perspective of state administrators. The conclusion section provides some considerations for further research.

The paper suggests that a standardized set of socioeconomic and cultural factors of importance to identifying meaningful subgroups be implemented across data sources. In addition to race and ethnicity, other individual characteristics might include income, education, and insurance status, based on existing evidence from health services and clinical research. The paper also recognizes that there are advantages and disadvantages to using both administrative and nonadministrative data and suggests that each approach should be pursued simultaneously and the bridge between them narrowed through standardization and automation.

Title: *Collection of Data on Race and Ethnicity by Private-Sector Organizations: Hospitals, Health Plans, and Medical Groups*

Authors: David R. Nerenz, PhD, and Connie Currier, PhD, Institute for Health Care Studies, Michigan State University

Disparities among racial and ethnic groups on measures of health, access to health care, and quality of care have been well documented. Many underlying reasons for disparities have been identified, but systematic efforts to reduce or eliminate disparities are relatively new, so not much is known about their effectiveness. Initiatives to reduce disparities that involve private-sector health insurers or delivery organizations generally must often rely on those organizations' collection of data on race and ethnicity to support either key features of program design (e.g., identifying members of target populations for intervention) or program evaluation. Hospitals have been required to document nondiscriminatory treatment of patients since the mid-60s, but procedures for the collection of racial and ethnic data on patients in support of that documentation requirement vary from hospital to hospital and enforcement of policies on data collection can be weak to nonexistent. Health plans and medical groups are not legally required to collect racial and ethnic data. A few states have prohibitions on the collection of these data. Data collected for special purposes (e.g., CAHPS survey data for health plans; disease registries for medical groups), can be used effectively for initiatives aimed at reducing disparities.

Appendix C

Workshop Agenda and Participant List

WORKSHOP ON IMPROVING RACIAL AND ETHNIC DATA IN HEALTH
December 12-13, 2002

Thursday, December 12, 2002

10:00 **Welcome and Introductions**

Edward Perrin, University of Washington (Panel Chair)
Andrew White, Committee on National Statistics
James Scanlon, Office of Science and Data Policy, Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services

10:15 **The Importance of Collecting Data on Race, Ethnicity, and Socioeconomic Status**

Session Chair: **David Williams**, University of Michigan (Panel Member)

Authors: **Nicole Lurie** and **Allen Fremont**, RAND

10:45 Discussants:
Olivia Carter-Pokras, University of Maryland
Gem Daus, Asian and Pacific Islander American Health Forum

11:15 Open Discussion

11:30 **Legal Aspects of Race and Ethnicity Data Collection (Including Privacy Issues)**

Session Chair: **William Kalsbeek**, University of North Carolina, Chapel Hill (Panel Member)

11:30 Legal Framework: **Mara Youdelman**, National Health Law Program

12:00 Privacy Issues: **Moya Gray**, Director, Hawaii Office of Information Practices

12:30 Open Discussion

1:45 **Race and Ethnicity Data Collection by Private Organizations**

Session Chair: **L. Carl Volpe**, WellPoint Health Networks Inc. (Panel Member)

General Overview—Collection of Data on Race/Ethnicity of Patients by Hospitals, Medical Groups, and Health Plans

Author: **David Nerenz**, Michigan State University

2:15 **The Collection of Race and Ethnicity Data by Health Plans**

Author: **Carmella Bocchino**, American Association of Health Plans

3:00 Discussants:
- **Eileen Peterson**, United Health Group
- **Romana Hasnain-Wynia**, Health Research and Education Trust
- **Andrew Webber**, National Committee for Quality Assurance

4:00 Open Discussion

Moderator: **Edward Perrin**, University of Washington (Panel Chair)

Friday, December 13

8:30 **Race and Ethnicity Data Collection by States**

Session Chair: **Denise Love**, National Association of Health Data Organizations (Panel Member)

Authors: **Sara Singer** and **Jeff Geppert**, Stanford University; **Jay Buechner**, Rhode Island; **Wu Xu**, Utah; **Walter Suarez**, Minnesota; and **Lorin Ranbom**, Ohio

9:00 Discussants:
Dan Friedman, Massachusetts Department of Public Health
Carla Edwards, Florida Agency for Health Care Administration
David Solet, Public Health, Seattle and King County

9:30 Open Discussion

10:00 **Attendee Comments on Race and Ethnicity Data Collection**

Session Chair: **Anthony D'Angelo**, Computercraft (Panel Member)

Workshop attendees were invited to sign up to give brief comments on the collection of racial and ethnic data

11:15 **Perspectives of Data Users**

Session Chair: **Jonathan Skinner**, Dartmouth College (Panel Member)

Panelists:
Matthew Snipp, Stanford University
Rhonda BeLue, Metro Nashville Public Health Department
Marian Gornick, Consultant, Health Services Research

WORKSHOP PARTICIPANTS LIST

Presenters

Edward Perrin (*Panel Chair*), University of Washington
Rhonda BeLue, Metro Nashville Public Health Department
Jay Buechner, Rhode Island Department of Health
Carmella Bocchino, American Association of Health Plans
Olivia Carter-Pokras, University of Maryland, Baltimore Campus
Anthony D'Angelo, Computercraft
Gem Daus, Asian and Pacific Islander American Health Forum
Carla Denise Edwards, Florida Agency for Health Care Administration
Allen Fremont, RAND
Dan Friedman, Massachusetts Department of Public Health
Jeffrey Geppert, Stanford University
Marian Gornick, Health Services Research
Moya Gray, Hawaii Office of Information Practices
Romana Hasnain-Wynia, Health Research and Education Trust
William Kalsbeek, University of North Carolina, Chapel Hill
Denise Love, National Association of Health Data Organizations
Nicole Lurie, RAND
David Nerenz, Michigan State University
Eileen Peterson, United Health Group
Lorin Ranbom, Ohio Department of Health
James Scanlon, Office of Science and Data Policy, Department of Health and Human Services
Jonathan Skinner, Department of Economics, Dartmouth College
Matthew Snipp, Stanford University
David Solet, Public Health, Seattle and King County
Walter Suarez, Minnesota Department of Health
L. Carl Volpe, Strategic Health Partnerships, WellPoint Health Networks Inc.
Andrew Webber, National Committee for Quality Assurance
Andrew White, Committee on National Statistics, National Academies
David Williams, Department of Sociology, University of Michigan
Mara Youdelman, National Health Law Program

Invited Guests

Steven Auerbach, Health Resources and Services Administration
Roman Baez, Dental School Multicultural Programs
John Burton, Council on African American Affairs, Inc.
Audrey Burwell, Department of Health and Human Services
Shari Campbell, Bureau of Primary Health Care
Marcia Changkit, National Cancer Institute
Kenneth Chu, Center for Reduce Cancer Health Disparities
Beverly Coleman-Miller, M.D., Washington, DC
Pam Curry, DHHS Office of Counter Terrorism and Pediatric Drug Development
Charles Daly, Bureau of Primary Health Care
Shelia Davis, Summit Health Institute for Research and Education
Shirley Delaleu, Council on African American Affairs, Inc.
Elaine Elinksy, Elinsky Consulting
Roland Garcia, National Cancer Institute
Kenneth Gerlach, Cancer Surveillance Branch
Linda Greenberg, Centers for Medicare and Medicaid Services
Robert Hahn, Centers for Disease Control and Prevention
Jan Heffernan, National Institutes of Health
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Diane Hopkins, U.S. Department of Health and Human Services
Jin In, U.S. Department of Health and Human Services
Debbie Jackson, National Center for Health Statistics, CDC
K.A. Jagannathan, DHHS Administration for Children and Families
Cheedy Jaja, Indiana University Center for Bioethics
Yvonne Johns, DHHS Office of Minority Health
Steve Jones II, United States Congress
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Onelio Lopez, U.S. Department of Health and Human Services
Jennifer Madans, Centers for Disease Control
Diane Makuc, National Center for Health Statistics
Jennifer Malat, University of Cincinnati
Mildred Martinez, Kaiser Permanente
Donielle Newell, Council on African American Affairs, Inc.
Ly Nguyen, Morgan State University
Edna Paisano, DHHS Office of Public Health
JoAnn Pappalardo, DHHS Office of Public Health

Sharyn Parks, National Center for Injury Prevention and Control
William Rodriguez, DHHS Office of Counter Terrorism and Pediatric Drug Development
Beatrice Rouse, Substance Abuse Mental Health Services Administration
Leonard Rubenstein, Physicians for Human Rights
Theodore Small Jr., Council on African American Affairs, Inc.
Bryon Sogie-Thomas, National Medical Association
Edward Sondik, Centers for Disease Control
Irene Tsai, Kaiser Permanente
Luz Vega, District of Columbia Department of Health
Irene Zimmerman, Washington Association of Professional Anthropologists

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