



RACIAL, ETHNIC, AND PRIMARY LANGUAGE
DATA COLLECTION IN THE HEALTH CARE SYSTEM:
AN ASSESSMENT OF FEDERAL POLICIES AND PRACTICES

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Copies of Volume 1 of the complete analysis upon which this report is based are available from the Summit Health Institute for Research and Education, Inc. (SHIRE), by calling 202-371-0277. Copies of Volume 2 are available from the National Health Law Program, Inc. (NHeLP), by calling 202-289-7661 or from NHeLP's website, www.healthlaw.org.

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EXECUTIVE SUMMARY

Over the past two decades, persistent evidence of differences in medical treatment and health outcomes has focused attention on how race, ethnicity, and English proficiency can affect access to quality health care. Indeed, the issue of racial and ethnic health disparities has taken center stage in the national health care debate. This, in turn, has led to a greater recognition of the importance of collecting and reporting health data broken down by individuals' race, ethnicity, and primary language.

Data collection and reporting by race, ethnicity, and primary language across federally supported health programs are essential for identifying, monitoring, and eventually eliminating health disparities. These data are vital to develop and implement effective prevention, intervention, and treatment programs and enforceable standards to ensure nondiscrimination; facilitate the provision of culturally and linguistically appropriate health care; and identify and track similarities and differences in performance and quality of care in various geographic, cultural, and ethnic communities. The collection and reporting of these data, however, encompass a wide array of policies and practices that influence why, how, when, and with what success data are collected, reported, and used. Further, considerable confusion remains among health care providers, insurers, and administrators about the legality of collecting racial, ethnic, and primary language data.

This study was conducted to delineate the context in which health-related data collection and reporting by race, ethnicity, and primary language take place at the federal level, particularly within the U.S. Department of Health and Human Services. With a grant from The Commonwealth Fund, the Summit Health Institute for Research and Education, Inc., in partnership with the National Health Law Program, Inc., conducted a survey of the statutes, regulations, policies, and procedures of federal agencies to identify when the collection and reporting of data on race, ethnicity, and primary language are required. The study also assessed current understanding and implementation of existing laws and regulations as expressed by 60 respondents associated with the administration of health care services.

FINDINGS

Four major findings emerge from the investigation:

1. Collection and reporting of data on race, ethnicity, and primary language are legal and authorized under Title VI of the Civil Rights Act of 1964. No federal statutes prohibit this collection, although very few require it.

2. An increasing number of federal policies emphasize the need for obtaining racial and ethnic data (see Table 1). There is high-level agreement that primary language data should be collected as well.
3. General agreement prevails that racial, ethnic, and primary language data are critical to promote health and quality health care for all Americans.
4. Despite its importance as a tool for assessing the progress of stated goals, federal data collection is not uniform. Data requirements and methods for collection and reporting vary across federal agencies and do not fully reflect consensus on the value of gathering this information.

Table 1. Major Federal Policies Governing Racial, Ethnic,
and Primary Language Data Collection and Reporting

Generally Applicable Policies and Initiatives
Office of Management and Budget (OMB) Revised Standards (1997)
Health Insurance Portability and Accountability Act of 1996
Initiative to Eliminate Racial and Ethnic Disparities in Health (1998)
Consumer Bill of Rights and Responsibilities (1997)
Benefits Improvement and Protection Act (2000)
Report of U.S. Commission on Civil Rights, <i>The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality</i> (1999)
Executive Orders 13166 "Improving Access to Services for Persons with Limited English Proficiency," and 13125 "Improving the Quality of Life of Asian Americans and Pacific Islanders" (2000)
Minority and Health Disparities Research and Education Act of 2000
Department of Health and Human Services (HHS) Policies and Initiatives
HHS Title VI Regulations (1964)
HHS Inclusion Policy (1997)
Healthy People 2010 (2000)
Culturally and Linguistically Appropriate Services (2000)
HHS Data Council Activities (ongoing)
National Committee on Vital Health Statistics (ongoing)

The essential message conveyed by this study is that continued leadership by the U.S. Department of Health and Human Services, as the federal government's principal agent in the health arena, will be pivotal to realizing the longstanding national goal of eliminating racial and ethnic disparities in health and health care. The collection of racial, ethnic, and primary language data by federal agencies and recipients of federal funds is entirely permissible under federal law and critical for the identification and remedying of existing disparities in the delivery of health care. Policy declarations, data collection instruments, and mechanisms exist to accomplish this data collection. A recommitment to

this goal, along with sustained leadership and appropriate action to address the difficulties associated with racial, ethnic, and primary language data collection is recommended.

RECOMMENDATIONS

The Department of Health and Human Services (HHS) should recommit to the national goal of eliminating racial and ethnic disparities in health. It should do so with a firm resolution expressed through written policy and sustained action to ensure the collection and reporting of data necessary to support and facilitate achievement of this goal throughout HHS. Specifically, HHS leadership should do the following:

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

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

RACIAL, ETHNIC, AND PRIMARY LANGUAGE DATA COLLECTION IN THE HEALTH CARE SYSTEM: AN ASSESSMENT OF FEDERAL POLICIES AND PRACTICES

INTRODUCTION

As it enters the 21st century, the United States has become a proving ground for health care programs, policies, and practices that reflect and respond to its increasingly multicultural population. Nonetheless, racial and ethnic disparities in health and health care are pervasive. They remain so despite the heightened national visibility these inequities have received over the past 25 years.

The success of efforts to eradicate these disparities—such as the federal Healthy People 2000 and 2010 initiatives—depends on the availability of reliable data with which to assess, over time, the health status of minority Americans relative to the overall population. Some data exist and are routinely collected and reported. For example, the National Vital Statistics System regularly reports birth, death, and disease rates by race and ethnicity.¹ U.S. census data for 2000 allow an assessment of health insurance coverage and prevalence of disability among different population groups. Surveys conducted by federal agencies and independent researchers provide useful insights about minority health. Overall, however, the collection and reporting of these crucial data have not been systematically pursued, especially health care encounter data in federally supported health services programs.

Current health-related data collection and reporting activities largely reflect the efforts of the U.S. Department of Health and Human Services (HHS). Of its 13 operating divisions or agencies, seven are focused principally on health, and each of these collects racial and ethnic data. In the department's more research-oriented health agencies, where the data obtained tend to be more comprehensive and of higher quality, the collection of information on race, ethnicity, and, increasingly, primary language spoken has become accepted protocol. HHS agencies either collect these data themselves or establish policies encouraging, and sometimes requiring, the gathering of data by the health care providers, insurers, researchers, and administrators with whom they contract.

Yet despite HHS's considerable efforts, the federal laws, policies, and practices governing racial, ethnic, and primary language data collection are often unclear or inconsistent. As efforts to improve the health and care of minority populations grow across the nation, a better understanding of the laws, policies, and practices governing such data collection becomes increasingly important.

Under a grant from The Commonwealth Fund, the Summit Health Institute for Research and Education, Inc. (SHIRE), in partnership with the National Health Law Program, Inc. (NHeLP), conducted a study of health data collection by race, ethnicity, and primary language from July 2000 to August 2001. The major goals of the study were (1) to review the statutes, regulations, policies, and procedures of federal agencies in order to identify their standards for the collection and reporting of these data; and (2) to assess current understanding and implementation of these laws and regulations. To meet these goals, SHIRE and NHeLP analyzed 80 program-specific statutes, examined more than 100 data collection vehicles, and interviewed 60 individuals associated with the administration of health care services (see Appendix A for the study methodology and Appendix C for a list of the agencies and organizations contacted).

This report presents findings from these analyses and interviews and, in consultation with a distinguished panel of advisors, makes a number of recommendations for improving data collection policies and programs. It is expected that the study's findings and recommendations for change will be of interest to federal and state policymakers, government agencies, health plans and health care providers, and the range of foundations, associations, organizations, and individuals who are committed to improving health care for minority populations.

FINDINGS

Four major findings emerged from this investigation, each of which is discussed in further detail in the following sections:

1. *The collection of data on race, ethnicity, and primary language is legal and authorized under Title VI of the Civil Rights Act of 1964.* No federal statutes prohibit collection of this information, although very few require it.
2. *Recent policy emphasizes the need for obtaining racial and ethnic data.* There is high-level agreement that primary language data should be collected as well.
3. *The prevailing view is that the collection of racial, ethnic, and primary language data is critical for promoting good health and quality health care for all Americans.*
4. *Despite its importance as a tool for assessing the progress of stated goals, federal data collection is not uniform.* Data requirements and methods for collection and reporting vary across federal agencies and do not fully reflect consensus on the value of gathering this information.

LEGAL BASIS FOR COLLECTION OF RACIAL, ETHNIC, AND PRIMARY LANGUAGE DATA

Title VI of the Civil Rights Act of 1964, which prohibits intentional discrimination on the basis of race or national origin in the provision of any services that are at all supported with federal funds, is considered the broadest mandate the federal government has to require collection and/or reporting of data on race, ethnicity, and primary language. It is a valuable tool for redressing past discrimination and monitoring ongoing practices. In the absence of an explicit statutory requirement, Title VI provides a legal foundation for the collection of racial and ethnic data by and from recipients of federal financial assistance. Because spoken language has been recognized as a proxy for national origin, the statute also affects the policies and practices of government agencies with regard to the collection of primary language data.²

Protection under Title VI generally extends to all programs and activities of any entity receiving federal financial assistance, whether or not the particular program at issue has itself received or benefited from those funds.³ It also extends to state agencies and other recipients of federal funds, though not to federal agencies.⁴

In addition to Title VI, there is a variety of program-specific statutes for racial and ethnic data collection and reporting. However, these statutes and regulations constitute only a fraction of the more than 80 program-specific statutes examined that require reporting or collection of any data. None of the statutes mention primary language data.

Program-Specific Statutes and Regulations for Data Collection and Reporting
While this study evaluated all federal health programs, the investigation placed a special emphasis on HHS because of the agency's leading role in providing health care. For HHS programs that provide health care services—for example, Medicaid, the State Children's Health Insurance Program (SCHIP), and Medicare—three statutes explicitly require collection and/or reporting of racial and ethnic data, while two more require collection of "demographic" information or enrollee "characteristics," which implies race and ethnicity. The three statutes that explicitly mention race and ethnicity require that:

- grantees of the Maternal and Child Health (MCH) Services Block Grant provide an annual report including the number of deliveries, broken down by racial and ethnic group, in a state per year and the number of women who were provided prenatal, delivery, or postpartum care under MCH or Medicaid;

- the Substance Abuse and Mental Health Services Administration (SAMHSA) evaluate mental health services by conducting surveys that include data on race and ethnicity; and
- grantees of SAMHSA who provide services to children of substance abusers collect data on the ethnicity of the children served.

The two statutes that implicitly include racial and ethnic data in other data collection and/or reporting require that states report the characteristics of children and families served by SCHIP, and that grantees report demographic data of individuals served by HIV/AIDS programs authorized under the Ryan White CARE Act.

For agencies that conduct clinical research or monitor diseases, five statutes exist that address the collection and reporting of racial and ethnic data. All except one relate to health surveillance programs operated by the Centers for Disease Control and Prevention (CDC). Two of these require collection of racial and ethnic data, and two require collection of demographic data. The fifth statute requires the National Institutes of Health (NIH) to operate a national database and clearinghouse for women's health research that includes either ethnic or racial data.

In addition to statutory provisions, five sets of federal regulations require racial and ethnic data collection and/or reporting, four in health services and one in research. The health services regulations require that:

- states provide Medicaid managed care organizations and primary health plans with the race, ethnicity, and primary language of enrollees;⁵
- states produce quarterly reports of the race and ethnicity of SCHIP program enrollees;⁶
- the End-Stage Renal Disease Program includes identification and social data in patient records; and
- states provide racial and ethnic data, if available, for the population receiving prevention services funded through SAMHSA.

In the research arena, the Food and Drug Administration requires applications for approvals of new drugs to include an analysis of the drug's effect on different demographic groups.

Because many statutes delegate to federal agencies decisions on which data to collect, an analysis of statutory and regulatory authority for data collection and reporting does not present the entire picture. NHeLP identified over 100 databases, surveys, and other instruments that collect data on race, ethnicity, and/or primary language. Most of this data collection arises from internal HHS and/or agency (e.g., National Institutes of Health or Centers for Disease Control and Prevention) policies.

Currently, no statutes require collection and reporting of primary language data. Medicaid managed care regulations proposed by the Centers for Medicare and Medicaid Services (CMS) would require states to provide enrollees' primary language data to managed care organizations upon enrollment.

FEDERAL POLICY GUIDING COLLECTION OF RACIAL, ETHNIC, AND PRIMARY LANGUAGE DATA

For purposes of this study, the policies that guide racial, ethnic, and primary language data collection can be divided into those designed and implemented by HHS and those enacted by entities external to HHS. Our discussion will begin with the latter, recognizing that HHS leadership often played a pivotal role in the development and enactment of these policies as well.

Policy Developments External to HHS

This study identified eight federal policies that have or will greatly affect the collection of data on race, ethnicity, and primary language.

OMB Revised Standards (1997)

In 1997, the Office of Management and Budget (OMB) published *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity* to address the need for more refined data on ethnicity than that mandated by OMB's 1977 Directive No. 15.^{7,8} The revised race categories established by the 1997 standards are:

- American Indian/Alaskan Native;
- Asian;
- Black/African-American;

- Native Hawaiian/Other Pacific Islander; and
- White.

In addition, the 1997 standards established a minimum of two ethnic categories: (1) Hispanic or Latino; and (2) Not Hispanic or Latino. The 2000 census was designed to conform to the 1997 standards, and all new data collection instruments must use them. Federal agencies have until January 1, 2003, to integrate the new standards into current data collection efforts.

When self-identification of race/ethnicity is used (such as in a survey of health program enrollees), the revised standards specify that individuals must be able to select more than one category of race—for example, African-American *and* White. In addition, the OMB standards require two separate questions: “What is your race?” and “What is your ethnicity?” For either question, the choices must include “Hispanic” as a category co-equal with the other categories. When self-identification is not feasible or appropriate, a combined race/ethnicity question may be used: “What is your race/ethnicity?” If the combined question is used, OMB suggests allowing the designation of ethnicity and race or multiple races; however, providing only one option is also acceptable.⁹

It is important to note that OMB does not mandate the collection of racial, ethnic, and primary language data, but rather sets the standards by which data are to be collected and presented. These standards are not applicable to states and private industry.

Health Insurance Portability and Accountability Act (1996)

In stark contrast to the other federal policy initiatives, which encourage the collection of racial and ethnic data, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) erected new hurdles to the consistent and uniform collection of these data. Among Congress’s goals in passing HIPAA was to improve the efficiency and effectiveness of the health care system “by encouraging the development of a health information system through the establishment of standards and requirements for the electronic transmission of certain health information.”¹⁰

The proposed rules designating these standards have generated extensive discussion both within HHS and among external organizations to whom Congress has given considerable standard-setting authority. Key HHS groups working on data issues recommended the inclusion of racial and ethnic identifiers as “required” in HIPAA standards. However, the final HIPAA regulations regarding claims standards—despite

preamble language that expresses the intent of HHS to work toward the broader collection of racial and ethnic data—designate the reporting of racial and ethnic data as “not used.” There is no data set for primary language.

Many federal observers view this outcome as a significant reversal of an otherwise expanding HHS commitment to racial and ethnic data collection and reporting. Failure to mandate racial and ethnic data as part of the core HIPAA data standards may have far-reaching implications for collection and transmission of such data by all agencies and organizations.

Initiative to Eliminate Racial and Ethnic Disparities in Health (1998)

During his administration, President Clinton announced his intention to commit the nation to eliminate disparities in six areas of health status by 2010 while continuing progress made in improving the overall health of Americans. In response, HHS established its own initiative, focusing on infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV/AIDS, and immunization. HHS noted that reliable racial and ethnic data are necessary to track the progress and success of this initiative.

Consumer Bill of Rights and Responsibilities (1997)

President Clinton convened the Advisory Committee on Consumer Protection and Quality in Health Care to advise him on changes occurring in the health care system and to recommend measures to promote and assure health care quality and value and protect consumers. As part of its responsibilities, the committee developed a Consumer Bill of Rights and Responsibilities (CBRR), also known as the Patients’ Bill of Rights.¹¹ It prohibits discrimination based on race, ethnicity, or national origin in the delivery of health care services. In addition, the CBRR prohibits such discrimination in both the marketing and enrollment practices of health care providers.¹² Although it does not require data collection, the CBRR provides additional authority for monitoring nondiscrimination and ensuring compliance with federal civil rights laws. Subsequently, President Clinton issued an Executive Memorandum in 1998 that required all federal agencies to ensure that all health plans they oversee or administer comply with the CBRR.¹³

Benefits Improvement and Protection Act (2000)

Under the Benefits Improvement and Protection Act (BIPA), managed care organizations and private fee-for-service plans participating in the Medicare+Choice program must include, as part of their quality assurance programs, a special focus on racial and ethnic minorities. This applies to non-network medical savings account plans as well. There is no

specific requirement to collect racial, ethnic, or primary language data. Every two years, HHS must submit a report to Congress detailing how well quality assurance programs are addressing quality-of-care issues in the minority Medicare population.

Report of U.S. Commission on Civil Rights (1999)

A comprehensive study conducted by the U.S. Commission on Civil Rights, "The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality," addressed the issue of equality of access to quality health care in HHS-sponsored programs.¹⁴ Using the rationale that equal access to quality care is a civil right, the Commission provided a range of recommendations for eliminating racial, ethnic, and gender disparities in health care and improvement of the civil rights enforcement activities of HHS. The Commission's recommendations were specific and targeted:

HHS should develop a comprehensive minority health database, including information on health status, service utilization rates, and methods of financing. All operating divisions should be required to contribute to the database information on minority subgroups pertaining to their individual functions (for example, the [CMS] should provide information on Medicaid and Medicare use; the National Institutes of Health should provide disease-specific information; and the Food and Drug Administration should provide information on drug and treatment effectiveness).¹⁵

Executive Orders

In recognition of the unique problems individuals with limited English proficiency face in participating in federal programs, President Clinton issued Executive Order (EO) 13166, "Improving Access to Services for Persons with Limited English Proficiency," in 2000. EO 13166 requires each federal agency to develop a plan for improving these individuals' access to and participation in its programs and activities.¹⁶ The executive order and subsequent guidance provided by the Department of Justice and HHS do not explicitly discuss data collection.^{17,18} However, to monitor compliance effectively, agencies can require recipients of federal funds to collect primary language data under the same rationale that Title VI provides for the collection of racial and ethnic data. HHS guidance suggests, for example, that program staff enrolling clients or patients should record an individual's primary language in his or her record so that staff can identify specific needs for language assistance.

In addition to EO 13166, several orders issued by the Clinton Administration have implications for data collection and reporting by race, ethnicity, and primary language. In particular, EO 13125, "Improving the Quality of Life of Asian Americans and Pacific

Islanders,” cited as its goal an improvement in the quality of life of this group through increased participation in federal programs where they may be underrepresented. One method to achieve this goal was to foster research and data collection for Asian-American and Pacific Islander populations and subpopulations.

Minority Health and Health Disparities Research and Education Act (2000)

The Minority Health and Health Disparities Research and Education Act of 2000 is the most recent of several acts of Congress addressing the collection of racial and ethnic data within the context of health care initiatives.¹⁹ The act charges the National Academy of Sciences with conducting a comprehensive study of HHS data collection systems and practices, as well as collection or reporting systems required under HHS programs and activities, with regard to information on race and ethnicity. Following completion of the investigation, a final report that will be presented to Congress in November 2001 is expected to identify data needed to support evaluation of the health-related effects of race, ethnicity, and socioeconomic status. The report will also include estimates of the costs involved in implementing its recommendations.

Policies and Initiatives of the Department of Health and Human Services

The Department of Health and Human Services (HHS) has led the way with policies and initiatives designed to expand access to health care and eliminate disparities among different population groups. A brief overview of the most important of these is presented in Table 2. In addition, several of the agencies within HHS have played pivotal roles in assuring the collection of data. The activities of two of these—the Office of Minority Health and CMS—will be discussed in detail. In general, HHS policies encourage and support the widespread collection of racial and ethnic data, and, increasingly, primary language data, with the previously noted exception of HIPAA transactions.

HHS Title VI Regulations

As noted above, entities receiving federal financial assistance through HHS must abide by the requirements of Title VI of the Civil Rights Act of 1964. The HHS regulations issued to implement Title VI provide a basis for collecting racial, ethnic, and primary language data. Under these regulations, every application for federal financial assistance shall, as a condition of its approval, include an assurance that the program will be conducted or the facility operated in compliance with all requirements of Title VI.²⁰

Table 2. HHS Policies and Initiatives

HHS Policy for Improving Race and Ethnicity Data (Inclusion Policy) (1997)²¹

- Requires inclusion of race and ethnicity data, using OMB standards, in HHS-sponsored data collection systems. Applies to all HHS program administrative records and research and survey data.
- Three stated purposes: (1) to ensure relevance of data collected to the HHS's goals; (2) to ensure standardization of data collection and reporting; and (3) to address major health data omissions identified for racial and ethnic groups.
- Allows for case-by-case exemptions and calls for administrative-level reporting of program services data "wherever possible."

HHS Plan to Improve the Collection and Use of Racial and Ethnic Data (1999)²²

- Comments on basic problems associated with racial and ethnic data collection.
- Specific recommendations of particular relevance to the present study:
 - Effect of program interventions on minority populations should be studied by tracking exposure to interventions and measuring intermediate outcomes related to the program.
 - HHS should advocate for and, wherever possible, require the inclusion of racial and ethnic data in administrative records; existing authority should be used to require routine collection of racial and ethnic data for health care settings.
 - Agencies should research methods to improve reporting of race and ethnicity for administrative and medical records, including assessment of the most appropriate method of collecting such data (e.g., observer or self-reported).
 - HHS should develop mechanisms for matching individual records from among government data sets, within and among federal departments, for all research purposes, and should encourage and support legislative changes to allow such matching to occur with the appropriate privacy and confidentiality safeguards.²³
- A special HHS budget item or incorporation of sustained appropriate funding as part of the applicable agency's budget should be used to fund these initiatives.

Healthy People 2000 and Healthy People 2010²⁴

- Strategic management tools for achieving the nation's prevention agenda.
 - Involve federal, state, community, and private sector partners.
 - Healthy People 2010 has two overarching goals: (1) increase quality and years of healthy life, and (2) eliminate health disparities.
 - Addresses the issue of data. Noting that the "goal of eliminating health disparities will necessitate improved collection and use of standardized data to correctly identify disparities among select population groups," the report's authors describe the need to assess health status not only by life expectancy, birth, mortality, and morbidity rates, but also other measures, such as quality of life, risk factors, use of ambulatory and inpatient care, and health insurance coverage.²⁵
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In addition to the required assurances, all recipients must keep records and submit compliance reports “in such form and containing such information” as the responsible HHS official determines is necessary to ascertain whether the recipient is complying with the regulations.²⁶ According to an example included in the regulations, recipients should have racial and ethnic data showing the extent to which members of minority groups are beneficiaries of and participants in the federally assisted programs. In cases of subcontracting or subgranting, these secondary recipients must submit compliance reports to the primary recipient to allow it to carry out its obligations under the regulations. The Title VI regulations do not specifically address collection of primary language data, but collection can be justified by the need to monitor compliance with the national origin nondiscrimination requirements.

Healthy People

Originating in 1979, the Healthy People initiative is a comprehensive, nationwide health promotion and disease prevention agenda involving both the public and private sectors at the federal, state, and local levels. The plan for Healthy People 2010 was released in January 2000 by HHS Secretary Donna Shalala and Surgeon General David Satcher, M.D. With the participation of over 350 national organizations and 250 state agencies as well as the general public, Healthy People 2010 presents two overarching goals for achievement: “increase quality and years of healthy life” and “eliminate health disparities.” Within these goals are 467 objectives organized into 28 health-related focus areas.

In the introduction to *Healthy People 2010, Volume 1*, it is noted that the “goal of eliminating health disparities will necessitate improved collection and use of standardized data to correctly identify disparities among select population groups.” The report discusses the need to assess health status not only by life expectancy, birth, mortality, and morbidity rates, but also by such other measures as quality of life, risk factors, use of ambulatory and inpatient care, accessibility of health personnel and facilities, and health insurance coverage.

HHS Policy for Improving Race and Ethnicity Data (Inclusion Policy) (1997)

This policy requires the inclusion of race and ethnicity data in HHS-sponsored data collection systems and is applicable to all HHS program administrative records and research and survey data.²⁷ Three purposes were advanced for including these data: (1) to ensure relevance of data collected to HHS goals; (2) to ensure the standardization of data collection and reporting; and (3) to address major health data omissions identified for racial and ethnic groups. The policy allows for case-by-case exemptions and calls for administrative-level reporting of program services data “wherever possible.” The policy also requires HHS to use the OMB standards for race and ethnicity data collection and reporting.

OMH Culturally and Linguistically Appropriate Standards (2000)

The mission of the Office of Minority Health (OMH) is to improve the health of minority populations through the development of policies and programs aimed at eliminating disparities in health. Although OMH does not independently oversee any data collection, it recently published standards for the provision of Culturally and Linguistically Appropriate Services (CLAS) for health care.²⁸ The CLAS standards are intended to offer guidance on preparing for and responding to culturally sensitive situations. The standards are divided into three categories: mandates, guidelines, and recommendations. In OMH terminology, guidelines are activities recommended for adoption as mandates. CLAS standards include a guideline stating that health care organizations should ensure that data on patients' race, ethnicity, and spoken/written language(s) are collected in health records, integrated into the organization's management information systems, and updated periodically. The standards encourage self-identification by patients and suggest that the primary language of parents or caregivers of minor patients be noted.

Although their implementation is not required, CLAS standards have been incorporated in proposed purchasing specifications for Medicaid managed care and have been recommended for adoption by federal, state, and national accrediting agencies. The adoption of these standards, as has been suggested by HHS, would greatly increase the collection of data on primary language, racial, and ethnic data.

HHS Data Council

In 1995, Secretary Shalala created the HHS Data Council to coordinate all of the department's health and nonhealth data collection and analysis activities. The mission of the Data Council is to implement a data collection strategy and coordinate HHS activities, data standards, and related data and privacy policy activities.²⁹

The Data Council has a number of subgroups, including the Working Group on Racial and Ethnic Data. In December 1999, the working group, in conjunction with the Data Work Group for the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health, issued a report with recommendations to improve the collection and use of racial and ethnic data, focusing on four categories: data collection, data analysis and interpretation, data dissemination and use, and data research and maintenance.³⁰

In addition to drafting this report, the working group also compiled the Directory of HHS' Health and Human Services Data Resources.³¹ The directory includes data resources currently in use or those that could potentially be used by, for example, recurring surveys and disease registries either maintained or sponsored by HHS.

The work of the Data Council is crucial to ensuring that data collection is uniform and comparable across all of HHS' programs. The implementation of HHS' Inclusion Policy, discussed previously, is in turn crucial to ensuring that data are collected.

Reports of the National Committee on Vital and Health Statistics

The National Committee on Vital and Health Statistics (NCVHS) was asked by HHS in 1994 "to provide information and advice that would help maximize the utility of core person and encounter data for meeting the Department's responsibilities."³² During 1995, the Subcommittee on Health Statistics for Minority and Other Special Populations prepared recommendations that pertained to immigrant populations and reflected concern about the lack of sociocultural information in HHS data systems. Recommendations were to collect language usage and language of interview data and to translate into Spanish the National Health Interview Survey, a core HHS data collection vehicle.

In 1996, following an investigation of core data sets from the United States and other countries and interviews with parties that report and use standardized data sets, NCVHS proposed 42 core health data elements for standardization. Race and ethnicity were items three and four on the list, but neither primary language nor country of origin were included. NCVHS has continued to address important data issues, such as the availability of racial and ethnic identifiers in administrative and record systems maintained by the Social Security Administration and CMS.

Centers for Medicare and Medicaid Services: Evolution of Health Data Collection Policy

Within HHS, the primary responsibility for delivering health care services supported by federal funds rests with the Centers for Medicare and Medicaid Services (CMS), formerly known as the Health Care Financing Administration. CMS provides services to approximately 77 million Americans through its flagship programs, Medicare and Medicaid. These programs provide services to one of four Americans, including people with disabilities, people with special needs, the elderly age 65 and older, and 18 million children. More than 50 percent of Medicaid beneficiaries and approximately 15 percent of Medicare beneficiaries are members of minority groups.³³ Thus, the data collection policies mandated by CMS, as well as its policies for enforcement, in many ways exemplify the federal government's commitment to obtaining racial, ethnic, and primary language data.

Since its establishment, CMS's statutory mission has been expanded to include other programs, including oversight of Medigap insurance and clinical laboratories, and, under HIPAA, regulation of small-group market health insurance. In addition, the Balanced Budget Act of 1997 (BBA) gave CMS overall responsibility, in partnership with

the states, for SCHIP, which has the potential for reaching nearly 11 million uninsured children. According to 2000 census data, 60 percent of these children are African-American, American Indian, Asian and Pacific Islander, and/or Hispanic.³⁴

Policy guidance for CMS data collection and reporting. Numerous policies exist to address and support racial, ethnic, and primary language data collection and reporting. In addition to the broadly applicable federal policies already mentioned, CMS interviewees made note of several other policies that had special implications for CMS, including the BBA. Regulations implementing the BBA include provisions that require “cultural competency” of managed care organizations participating in the Medicare+Choice and Medicaid managed care programs.

Three additional policies that originated within HHS have had similar impact. One policy, known as the “Aetna letter,” was issued by the Office for Civil Rights and the Surgeon General. Directed principally at health plans, it reaffirmed the legality of racial and ethnic data collection. The *HHS Plan to Improve the Collection and Use of Racial and Ethnic Data*, issued in 1999, provided an important impetus for policy implementation (see Table 2). The third policy was contained in Operational Policy Letter No. 93 (OPL 99.093). This advised health plans participating in the Medicare+Choice program that race and ethnicity information may be collected on a voluntary basis from beneficiaries before, during, or after enrollment.

Equally important have been the policies initiated by CMS itself. The most significant policy development cited by respondents in this study was CMS’s issuance of regulations governing Medicaid managed care and CHIP in January 2001. These regulations were placed on hold for further review after the change in administration. In July 2001, an interim final rule was published by CMS requiring states participating in the SCHIP program to provide CMS quarterly reports on race and ethnicity using OMB standards. Of note, CMS dropped the original requirement for reporting of primary language data. In August 2001, CMS published a proposed rule for Medicaid managed care that requires states to report to health plans (although not explicitly to CMS) the race, ethnicity, and primary language of all Medicaid enrollees in managed care organizations.

In assessing the reach and impact of these and other policies, participants in this study agreed that CMS’s approach has been to permit—and increasingly to encourage—data collection and reporting by race, ethnicity, and primary language. However, CMS has not formally articulated its own policy rationale for the collection and reporting of

these data in a systematic way to assess the quality and quantity of services received or health outcomes experienced by Medicare, Medicaid, and SCHIP beneficiaries.

CMS collection and reporting initiatives. Despite the many challenges to data collection and reporting (summarized below), CMS has implemented policies not only to increase available racial, ethnic, and primary language data but also to report and use available data for quality improvement purposes. These efforts, some of which have been mandated by federal statute, include the following:

- *Medicare Current Beneficiary Survey (MCBS)*. This comparative survey collects data on health care experiences and consumer satisfaction for Medicare beneficiaries enrolled in Medicare's traditional fee-for-service program and for those in Medicare+Choice. The MCBS includes questions on race and ethnicity.
- *Medicare Health Outcomes Survey*. Conducted as part of the Health Plan Employer Data and Information Set (HEDIS), this survey assesses plan performance from beneficiaries' perspectives and collects data on race and ethnicity.
- *Peer Review Organizations*. In all 50 states, peer review organizations contract with CMS to assess and promote quality of health services. They have been charged with reducing disparities in care received by minority patients.
- *Medicare+Choice Quality Assessment Performance Improvement Project*. Under initiatives targeted for 2003, managed care plans will identify racial and ethnic disparities in clinical outcomes and assess the cultural and linguistic appropriateness of patient services.
- *Research Data Assistance Centers*. Centers at four universities, including one historically black college, provide technical assistance and other support needed to facilitate access to CMS databases.
- *State strategies for managed care quality assessment and improvement*. In addition to the recent rules governing racial, ethnic, and primary language data collection in the Medicaid program, states are also expected to develop and implement a quality assessment and improvement strategy for managed care plans under contract.

Challenges for CMS data collection and reporting. Since CMS relies on the Social Security Administration (SSA) for Medicare racial and ethnic beneficiary data,

reliability and completeness of CMS health care data files for this population are negatively affected by: (1) SSA's enumeration-of-birth program, which assigns Social Security numbers to 90 percent of all infants at the time of birth without capturing racial or ethnic data; (2) continued use of incomplete SSA data files that collect information for a limited number of race categories, thus requiring costly, ongoing "repopulation" of files; and (3) policies that assign to SSA/Medicare auxiliary beneficiaries (e.g., spouses of beneficiaries) the race of the wage earner.³⁵ Nearly 18 percent of Medicare beneficiaries fall under this category.³⁶

Although CMS's efforts to adjust for the incompleteness of SSA data have been costly, they have met with some success. From 1993 to 1997, these efforts have identified the racial or ethnic background of approximately half of individuals with "unknown/other" designations. Nonetheless, independent analysts have compared Medicare enrollment database information with data from the U.S. Census and the Medicare Current Beneficiary Survey and estimated that the SSA database is less than 60 percent accurate for all classifications other than black or white.³⁷

Other challenges facing CMS include:

- The availability of data on health care service utilization by Medicare beneficiaries enrolled in managed care plans is currently limited to inpatient hospitalizations.
- Collection and reporting by states of Medicaid and SCHIP beneficiary data are often inconsistent and incomplete.
- Deletion of prior requirements that mandated states to collect and report primary language data for SCHIP enrollees will limit CMS's capacity to monitor services to populations with limited English proficiency.
- The respective roles and responsibilities of CMS, states, and managed care organizations in data collection and reporting need to be clarified.

SUPPORT FOR THE COLLECTION OF RACIAL, ETHNIC, AND PRIMARY LANGUAGE DATA

Among those interviewed for this study, there was general agreement that administrative, service, and research data on race, ethnicity, and primary language should be collected and reported systematically at the federal and state levels. Participants also expressed considerable support for the collection of data related to health services delivered at the

provider level as well. They cited the need to promote public health, achieve more equitable access to health care, improve quality of care delivered, counter discrimination, and promote delivery of culturally competent health services as the rationale for gathering and reporting these data. Furthermore, a strong “business case” can be made: health plans that can demonstrate high satisfaction rates and the comparative effectiveness of their programs for minority patients may be able to improve their competitive advantage in the health care marketplace.

Specific Comments

An overwhelming majority of study participants agreed that data collection and reporting by race, ethnicity, and primary language constituted sound policy and were fully justified, notwithstanding the costs or technical challenges involved. The most urgent reason given for collecting these data was the elimination of disparities. As one interviewee explained: “We have to do this until we know that differences we see have nothing to do with race, ethnicity, and language.” Data collection focusing on racial and ethnic subgroups was also given high priority, to help determine often significant differences within larger populations.

The rationale for data collection can be linked to the goals of federal agencies. Study participants noted a direct link between the availability of data and the formulation of agency policy and resource allocation. An individual with the Agency for Healthcare Research and Quality (AHRQ) identified a connection between the availability of racial and ethnic data and effective study of issues of access, use, and quality of care:

The [AHRQ] was established to figure out the impact of health care services on end results. When you find out you have important confounders, you have to deal with them. We know that there are enormous variations in the care that people get. It is incredibly important to know what factors affect those variations and what can be changed.

Several respondents also saw the need for policy to address discrimination on the basis of race, ethnicity, and primary language and ensure that the requirements of Title VI are met.

More than one-third of those interviewed provided a business case for data collection and reporting. These respondents noted that use of racial, ethnic, and primary language data helps keep health care providers competitive in an increasingly multicultural environment. “You cannot compete if you don’t know what people you serve.” They

described increasingly prevalent social marketing practices in the corporate sector as evidence of the effectiveness of this strategy. As one HHS employee observed:

[One] goal of the health profession is getting people healthy enough to work. Poor health is antibusiness. If you value a diverse workforce, there is a business reason to do this.

Some respondents, including representatives from the private sector, countered that racial and ethnic data collection had strong validity on moral grounds. One respondent observed that “sounding a business case for collecting [these] data could obscure the positive reasons health plans are part of this effort.” Similarly, a study participant with training in anthropology viewed data collection by race, ethnicity, and language as fundamental: “You must take account of the changing demographics of the United States. Culture is not just one variable. It shapes everything we do.”

The positions of different agencies on the reach and impact of policies addressing multicultural data collection influence the degree to which such data is pursued. Some agencies, such as the National Center for Health Statistics (NCHS), are perceived to have a clear institutional mandate. As an NCHS official explained:

NCHS has a policy goal to collect and publish data on health differentials, and there are several legislative mandates for that policy. There is an institutional mandate, carried out through the management structure, to collect and report data by race and ethnicity. You won't find a specific NCHS document on the subject, but we don't need it.

The Bureau of Primary Health Care (BPHC) also has demonstrated success in collecting data, despite relying on external agents. BPHC's Universal Data System stores data from 700 grantees at 3,000 health care sites. With the backing of a statutory mandate, the BPHC has established specific racial, ethnic, and primary language data collection and reporting requirements applicable to its network of community health centers. Enrollment data have been collected periodically, and plans are under way to secure disaggregated data to assess and report on clinical outcomes by race, ethnicity, and primary language.

In another positive example, National Institutes of Health (NIH) respondents cited its enabling statute and the agency's policy provisions regarding the participation of women and minorities in clinical trials: “We are implementing the law. The law is important—we can't just say we don't want to.”

The more common approach among agencies, however, was summed up by one of the participants this way: “Data collection by race and ethnicity is always encouraged and required if possible.” Many agencies relying on states and other external agencies to implement data programs, such as SAMHSA, CDC, and CMS, fall into this category. Similarly, AHRQ, although it is required by statute to collect such data and places that requirement on its own personnel and contractors, does not necessarily pass that mandate on to grantees.

Incongruity Between Federal Policy and Practice

Current federal practice does not fully reflect the legal foundation and numerous federal policies supportive of collection and reporting of racial, ethnic, and primary language data, nor does it reflect the general acknowledgement of its importance in reducing disparities in health and health care. As a result, collection and reporting efforts are often fraught with difficulties. These challenges generally fall under one of the following categories:

- inconsistent or conflicting policy messages;
- fears of potential misuse or misinterpretation of data;
- lack of enforcement;
- lack of uniform standards for data collection;
- lack of a centralized authority governing data collection; or
- technical difficulties with data collection and maintenance.

Inconsistent or Conflicting Policy Messages Across Federal Agencies

Study respondents raised many issues related to the will of institutions and agencies to follow current policy recommendations about the collection of racial, ethnic, and primary language data. Institutional will is seen as a powerful influence in determining whether data are consistently collected or regulations enforced. Many interviewees believe that several HHS agencies have yet to fully exercise their discretion to require the collection of these data on a department-wide basis.

CMS respondents, for example, reported a growing recognition of the importance of racial and ethnic data, as exemplified by a variety of ongoing efforts to improve the Medicare database. Nonetheless, improved data collection practices, they said, are being

hampered by a variety of obstacles, ranging from inadequate allocation of resources to inaccuracies and omissions in available databases.

Several interviewees considered the HHS inclusion policy a major accomplishment, and sufficient justification for agency-wide racial and ethnic data collection. In the words of a respondent who had helped develop the policy, the intended message should be clear: “If you collect data using HHS funds, you must collect data by race and ethnicity.” This individual and others acknowledged, however, that there were loopholes in the policy, particularly with respect to collecting data from state and administrative systems. Consequently, the policy does not have the full reach its authors intended.

Of considerable concern was the issuance of regulations by HHS that established standards for the electronic transmission of health information required under HIPAA. In the view of these agency employees, the fact that race and ethnicity were not defined as “required” was a “lost opportunity” with potentially serious repercussions. Unless the situation is rectified, the HIPAA standards could undercut current efforts by federal and state agencies to collect racial and ethnic data.

Potential Misuse or Misinterpretation of Data

Although racial and ethnic data collection and reporting at federal and state levels have broad support, many study participants believe there is nonetheless a need for mechanisms to safeguard privacy and security and prevent the misuse or abuse of data on minority populations. Such concerns were expressed by approximately one-third of those interviewed. A stated fear was that the data could be used “to divide rather than unify.”

In particular, some participants cited the use of language data as a proxy for identifying one’s immigration status, or racial and ethnic data to limit enrollment in managed care plans, as examples of ways in which this information could be employed for discriminatory purposes. One respondent, noting that “people have different agendas when looking at data,” commented:

When...data are not put in a particular context, [they] can be interpreted in ways that may not be an accurate reflection of reality...[I]t is not always possible to correct interpretations once data are in the hands of others.

In addition, some respondents said that public program beneficiaries’ concerns, and possible resistance to, queries about race, ethnicity, and primary language would also need to be addressed.

Available facts suggest, though, that these concerns may be overstated. For example, more than 90 percent of individuals requesting Social Security cards voluntarily provide information about their racial and ethnic identity.³⁸ “The fear is misplaced,” maintained one HHS respondent. “We already give up sensitive data for jury duty or for reporting immigration status.”

Most respondents were of the opinion that the two objectives—obtaining data and protecting beneficiaries—were not inherently in conflict. To counter any fears, respondents recommended providing the public with clear justifications for gathering and using racial and ethnic data.

Lack of Enforcement

Several interviewees maintained that specific requirements should be enunciated to collect data on the race, ethnicity, and primary language of recipients of federal funds to help determine whether minority populations were being equitably served in HHS programs. At the same time, they recognized the lack of adequate HHS resources for effective enforcement of its provisions. In cases where policies are in place, gaps in data collection may exist because entities within HHS have insufficient knowledge of those policies or decline to enforce data requirements. For example, study participants frequently reported they sought to achieve state compliance with federal administrative data requirements through negotiation, persuasion, education, or the provision of technical assistance—rather than through the use of sanctions.

As noted previously, certain agencies impose requirements for racial and ethnic data collection and reporting on agency staff and contractors, but not on grantees, including those conducting research. Grantees are either not required to collect such data or are not sufficiently monitored to determine the extent of their compliance with grant requirements.

Lack of Uniform Standards for Data Collection

States and agencies frequently depend on outside entities for data. Respondents from AHRQ, NCHS, CDC, SAMHSA, and CMS commented in detail on their dependence on states to forward racial, ethnic, and other data required to ascertain program enrollment and participation. Further, because HHS has not consistently used its authority to set standards and enforce existing data policies, data from states are often missing, incomplete, or not of uniform quality. An exception to this pattern appeared to be the Division of Vital Statistics within the NCHS, which has collected racial and ethnic data on births and

deaths from the 50 states and the District of Columbia since 1920, using a combination of strategies such as encouragement, persuasion, and financial incentives.

Other federal agencies have attempted to optimize data collection and reporting through alternative programs. AHRQ, for example, has developed the Health Care Utilization Project (HCUP), which analyzes state administrative data sets with respect to hospital stays; the Medical Expenditure Panel Survey (MEPS), a system of patient self-identification involving 10,000 families in face-to-face surveys; and, more recently, Excellence Centers to Eliminate Ethnic/Racial Disparities (EXCEED), which have, with NIH support, committed \$45 million over a five-year period for a research initiative to improve knowledge of the factors underlying ethnic and racial inequities in health care.

In a last example, the CDC provides funds to states for population surveys or disease/condition-specific surveys, such as the tobacco-related youth surveillance survey. Through these surveys, the CDC is able to obtain racial and ethnic data. CDC observers note, however, that sample sizes are often too small, in part because of patient refusal to supply demographic information and lack of provider participation.

Lack of Central Authority

A widely recognized barrier to consistent and thorough collection of racial, ethnic, and primary language data is the fact that no one office exists within HHS that has institutionalized responsibility and authority for initiating, coordinating, monitoring, and documenting policies and practices governing these data's collection. Nonetheless, HHS is the federal institution principally responsible for promoting health status parity, program quality, equality of access, participation, and satisfaction, and equitable health outcomes for all beneficiaries. To meet these obligations, HHS must play a proactive role in the months and years ahead.

CMS's responsibility for data varies with the sponsored program. For example, CMS has sole responsibility for Medicare, but has joint responsibility, with the states, for administering Medicaid and SCHIP. Despite its ability to coordinate data collection, CMS has delegated responsibility for Medicaid and SCHIP data collection to the states and to health care providers, resulting in inconsistencies. As mentioned in the previous section, Medicare data are obtained through SSA files, which are incomplete with respect to racial, ethnic, and primary language data. CMS also delegates data collection for Medicare managed care enrollees to the plans themselves. Although CMS has statutory authority to require data collection, it has largely depended on the efforts of states and of contracted health plans. Until August 2001, CMS placed no racial/ethnic data requirement on the former.

Finally, although there is general recognition among federal interviewees of the technical and cost implications of collecting and reporting data, particularly by states, insurers, health plans, and other providers, many strongly believe these challenges are surmountable. Federal financial support, it was noted, is available to states on a matching basis for the development or enhancement of data systems to address these requirements.

Technical Difficulties with Methods of Data Collection

Hampering data collection and reporting is the fact that data systems at federal and state levels are not sufficiently comparable to permit the easy exchange of data, particularly with respect to assessing health care services delivered and received. A secondary issue relates to the challenges associated with creating and maintaining a database that includes race, ethnicity, and primary language in an environment concerned with privacy and security. Among the study participants, those familiar with such challenges, while acknowledging them, were confident that solutions could be found. Speaking of the implications of the OMB standards for Medicare data collection, one data expert remarked, "This is not a big deal, but there are more complications for 40 million people; you have to have the software in place."

This study also found that:

- The consensus among respondents is that self-reported data represents the "gold standard." Third parties are not the best judges of racial, ethnic, or primary language data; multiple third parties may result in inconsistencies in reporting.
- Assessments of whether data are consistent and comparable across programs must include an evaluation of how the data were collected.
- State administrative data obtained on a mandatory basis are superior to data obtained through voluntary arrangements.
- The inclusion of race and ethnicity fields in reporting forms does not guarantee that these data are actually collected.
- Reporting data for Hispanic/Latino people remains inconsistent. Not all agencies have changed this category from "race" to "ethnicity." OMB requires two fields for race and ethnicity if data is self-reported, but one if it is supplied by a third party.

- Individualized data from all program participants should be the goal; currently, much data is still obtained from small research or survey samples.

CONCLUSIONS

With a population more diverse than any other nation in the world, the United States has become a proving ground for policies, programs, and practices that both reflect and respond to its multicultural identity. Collecting and reporting data on race, ethnicity, and primary language are viewed as an indispensable tool for decision-makers at every level of government, and increasingly in the private sector. This study has served to document consensus on that point within HHS and selected other federal departments. Available evidence suggests, however, that current policies and practices have not been fully responsive to this high level of agreement.

Participants in this study have described an approach to minority data collection and reporting that is inconsistent and sometimes contradictory. There are strong foundations for a consistent approach in Title VI of the Civil Rights Act of 1964, OMB standards, and the HHS inclusion policy. Thus, implementation and enforcement of existing policies are recommended, as well as reaffirmation by HHS of a clear department-wide mandate for racial, ethnic, and primary language data collection and reporting that establishes accountability and provides for implementation by all agencies, states, and private sector partners involved in federally funded programs.

Among the immediate challenges facing HHS are the ongoing review of the comprehensive Medicaid managed care and SCHIP rules and questions about the department's revision of HIPAA standards so as to require the collection and reporting of racial, ethnic, and primary language data. Long-term challenges include addressing inconsistencies in policy, a lack of enforcement of existing statutes, the technical challenges of obtaining these data and maintaining them in a secure environment, and the social challenges of assuring those whose information is sought that these data will not be misused.

As the federal institution principally responsible for facilitating equitable access to health care and parity in health outcomes, HHS must continue to play a proactive role in the months and years ahead. The principal message conveyed by this study is that leadership by the Department of Health and Human Services will be pivotal in realizing long-standing national commitments to eliminate racial and ethnic disparities in health and health care. Just as essential will be the active involvement of the many institutions and individuals with an awareness of the value of racial, ethnic, and primary language data collection in achieving parity in health and health care for all of this nation's residents.

RECOMMENDATIONS

The Department of Health and Human Services should recommit to the national goal of eliminating racial and ethnic disparities in health. It should do so with a firm resolution expressed through written policy and sustained action to ensure the collection and reporting of data necessary to support and facilitate achievement of this goal throughout HHS. Such a commitment will require necessary budgetary resources, as well as the designation of a central authority within HHS to supervise this policy's dissemination, implementation, and compliance. Specifically, HHS leadership should do the following:

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

data collected, and implement effective educational strategies to maximize beneficiary and provider cooperation with data gathering efforts.

7. Encourage public and private agencies to participate in the development and implementation of approaches to improve data availability and promote data collection and reporting. In support of agencies, HHS should:
 - create a “tool kit” containing information on effective data-related techniques, technologies, and privacy safeguards currently in use;
 - bolster the HHS Data Council’s efforts to identify and document the benefits of collecting and reporting racial, ethnic, and primary language data, with representation from health plans and insurers, community health centers and other health care providers, federal officials, purchasers of care, representatives of state and local governments, advocacy and minority group representatives, and other knowledgeable parties; and
 - support national policies to facilitate data-sharing among all federal and state agencies.
8. Expand or create public and private educational programs to:
 - inform insurers, health plans, providers, private/public agencies, and the general public that data collection and reporting by race, ethnicity, and primary language are legal and in many instances required by federal law and regulations;
 - raise public awareness that the collection and reporting of these data are prerequisites for the achievement of Healthy People 2010 goals and essential to demonstrate compliance with the nondiscrimination requirements of Title VI; and
 - inform decision-makers that effective strategies exist for achieving compliance with data collection and reporting policies, including risk-adjustment, and make such compliance a condition for receiving government resources.
9. Provide states and health care providers with greater access to aggregated and disaggregated racial, ethnic, and primary language data acquired at the federal level,

subject to privacy and confidentiality regulations, for purposes that include program monitoring, quality improvement, policy development, and budget allocations.

10. Support research on existing best practices for racial, ethnic, and primary language data collection, as currently used by health care providers receiving federal funds, such as managed care organizations, community health centers, and hospitals. Also emphasize documentation of the relationship between best practices and improved health outcomes.

APPENDIX A. METHODOLOGY

To conduct this investigation, the Summit Health Institute for Research and Education, Inc. (SHIRE), assumed overall direction of the project and the responsibility of assessing how current law is understood, interpreted, and implemented from the point of view of federal personnel and other individuals with informed perspectives on these issues.

From October 2000 to March 2001, SHIRE interviewers consulted with 53 individuals from the Department of Health and Human Services (HHS); the Departments of Education, Labor, and Justice; and the Office of Management and Budget (OMB) at the federal level; and seven individuals from state or private-sector organizations (see Appendix C for a list of agency divisions and organizations contacted). This portion of the study also included participant views on the rationale for, limitations of, and issues related to policy implementation. As the agency responsible for providing health care services for one of four individuals in the United States, the Centers for Medicare and Medicaid Services (CMS) received special attention in this regard.

An understanding of the wide array of statutes, regulations, agency policies, practices, and data collection vehicles that influence the collection and reporting of racial, ethnic, and primary language data is essential to placing the respondents' comments into context. The National Health Law Program, Inc. (NHLP), performed a legal review and analysis of existing federal laws, policies, documented practices, and available methods for collecting data. It includes an assessment, with an emphasis on HHS, of the extent to which these policies actually mandate the collection and reporting of these data. (Volumes I and II of this analysis are available from NHLP and SHIRE.)

To identify the people eventually interviewed for this study, SHIRE established a referral or "cascade" approach. From an initial round of interviews, SHIRE staff secured the names of individuals in various agencies who were considered particularly knowledgeable and involved in data issues. Individuals identified on several lists were contacted first, and were also given the opportunity to recommend others. Through this process, SHIRE was able to establish priorities among potential respondents and to locate appropriate substitutes when individuals were not available.

At the onset of the project, SHIRE selected a distinguished panel of experts in consultation with Commonwealth Fund staff. These 11 individuals, composing the project's advisory work group, served in multiple capacities throughout the study (see Appendix B for a list of members). In addition to providing responses for the interview

portion, this group also reviewed draft reports and served as technical experts on the study strategies, findings, and recommendations.

HHS employees represent a substantial majority of the 60 people interviewed for this study. Acting upon the advice of key contacts, SHIRE determined that it would also be useful to obtain the views of representatives from other federal departments, which had established racial and/or ethnic data policies. These were the Departments of Education, Justice, and Labor. Although not the focus of this investigation, perspectives from a limited number of people representing state and private-sector organizations were secured from members of the advisory work group.

Project staff obtained information from several approaches, principally a questionnaire administered by SHIRE representatives and designed to elicit responses to inform both the legal analysis and the assessment of agency perspectives.³⁹ To ensure candid responses, the participants' comments were recorded without attribution.

The methodology for NHeLP's survey focused on researching applicable statutes and regulations using both commercial and noncommercial search engines: Westlaw, Lexis, the Cornell University Legal Information Institute's compilation of the United States Code, the Government Printing Office's compilation of the Code of Federal Regulations, and the Federal Register. Project staff obtained policies and practices by researching materials available on the World Wide Web, including agency guidance documents, policy manuals, letters, and transmittals. Additional information was obtained through conversations with agency staff and relevant nongovernmental organizations. Data collection vehicles and racial and ethnic data fields were identified through analysis of agency publications, data collection requests submitted to the OMB, and communication with designated collection officers. Interviews conducted by SHIRE also yielded information.

Shortly after the project began, with the issuance of Executive Order 13166 "Improving Access to Services for Persons with Limited English Proficiency," SHIRE and NHeLP decided to broaden their inquiry to include the identification and analysis of information on primary language data policies and practices.

After initial interviews, it also became clear that the preeminent role of CMS in financing and delivery of health care services to 25 percent of Americans warranted special attention. SHIRE's interviews with key CMS personnel were facilitated by means of a focus group comprising 10 CMS staff. In-depth interviews were also conducted with five

CMS employees. In addition, CMS policies and practices were commented on by several other individuals who were particularly knowledgeable about the agency by virtue of prior positions of responsibility. Finally, proceedings from a conference cosponsored by CMS during the summer of 1999 yielded substantive information of direct relevance to the SHIRE and NHeLP inquiry.⁴⁰

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APPENDIX C. LIST OF AGENCIES AND ORGANIZATIONS CONTACTED

AMERICAN ASSOCIATION OF HEALTH PLANS

MARYLAND HEALTH CARE COMMISSION

MOREHOUSE SCHOOL OF MEDICINE

National Center for Primary Care

MOUNT SINAI NYU HEALTH

NATIONAL ASSOCIATION OF URBAN-BASED HMOS

OFFICE OF MANAGEMENT AND BUDGET

SQUIRE, SANDERS AND DEMPSEY, LLP

U.S. DEPARTMENT OF EDUCATION

Office for Civil Rights

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Administration for Children and Families

Agency for Healthcare Research and Quality

Center for Outcomes, Effectiveness and Research

Center for Primary Care Research

Centers for Disease Control and Prevention

Division of Vital Statistics

National Center for Health Statistics

Office of Analysis and Epidemiology

Office of Minority Health

Centers for Medicare and Medicaid Services

Center for Medicaid and State Operations

Office of Clinical Standards and Quality

Office of Strategic Planning

Health Resources and Services Administration

Office of Data Evaluation Analysis and Research

Bureau of Primary Health Care

National Institutes of Health

Division of Research Programs Training and Review Policy

Office of Behavioral and Social Science Research

Office of Extramural Research

Office of Research on Women's Health

Office of the Assistant Secretary for Planning and Evaluation

Management Information and Analysis Division

Office of Minority Health

Division of Policy and Data

Office of Public Health & Science

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (continued)

Substance Abuse and Mental Health Services Administration

Center for Mental Health Services

Center for Substance Abuse Treatment

Office of Applied Studies

U.S. DEPARTMENT OF JUSTICE

Civil Rights Division

U.S. DEPARTMENT OF LABOR

Bureau of Labor Statistics

Office of Federal Contract Compliance

APPENDIX D. U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES OPERATING DIVISIONS/AGENCIES

Office of the Secretary of Health and Human Services (OS)

Advises the President on health, welfare, and income security plans, policies, and programs of the federal government. The Secretary administers these functions through the Office of the Secretary and the Department's 12 operating divisions, including a budget of \$376 billion and a workforce of 59,000 employees.

Administration for Children and Families (ACF)

Responsible for some 60 programs which provide services and assistance to needy children and families; administers the new state-federal welfare program, Temporary Assistance to Needy Families; administers the national child support enforcement system and the Head Start program; provides funds to assist low-income families in paying for child care; and supports state programs to provide for foster care and adoption assistance.

Agency for Healthcare Research and Quality (AHRQ)

Supports cross-cutting research on health care systems, health care quality and cost issues, and effectiveness of medical treatments.

Centers for Disease Control and Prevention (CDC)

Provides a system of health surveillance to monitor and prevent outbreak of diseases. With the assistance of states and other partners, CDC guards against international disease transmission, maintains national health statistics, and provides for immunization services and supports research into disease and injury prevention.

Centers for Medicare and Medicaid Services (CMS)

Administers the Medicare and Medicaid programs, which provide health care to America's aged and indigent populations, including nearly 18 million children, and nursing home coverage for low-income elderly. CMS also administers the State Children's Health Insurance Program through approved state plans that cover more than 2.2 million children.

Food and Drug Administration (FDA)

Assures the safety of foods and cosmetics, and the safety and efficacy of pharmaceuticals, biological products, and medical devices.

Health Resources and Services Administration (HRSA)

Helps provide health resources for medically underserved populations. HRSA supports a nationwide network of 643 community and migrant health centers, and 144 primary care programs for the homeless and residents of public housing, serving 8.1 million Americans each year. HRSA also works to build the health care workforce and maintains the National Health Service Corps, oversees the nation's organ transplantation system, works to decrease infant mortality and improve child health, and provides services to people with AIDS through the Ryan White CARE Act programs.

Indian Health Service (IHS)

Supports a network of 37 hospitals, 60 health centers, 3 school health centers, 46 health stations, and 34 urban Indian health centers to provide services to nearly 1.5 million American Indians and Alaska Natives of 557 federally recognized tribes.

National Institutes of Health (NIH)

Comprising 17 separate institutes; NIH is the world's premier medical research organization, supporting some 35,000 research projects nationwide in diseases like cancer, Alzheimer's, diabetes, arthritis, heart ailments, and AIDS.

Substance Abuse and Mental Health Services Administration (SAMHSA)

Works to improve the quality and availability of substance abuse prevention, addiction treatment, and mental health services.

Source: U.S. Department of Health and Human Services, September 24, 2000.

NOTES

¹ The National Vital Statistics System is operated by the National Center for Health Statistics (NCHS), which is a component of the Centers for Disease Control and Prevention. NCHS obtains information on births and deaths from the registration offices of all states, New York City, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. Race and ethnicity are provided by the mother at the time of birth, and by the funeral director at the time of death, based on information supplied. For additional information about the National Vital Statistics System, see Appendix I, *Health, United States, 2000*, pages 373–77; or visit the NCHS home page at www.cdc.gov/nchs/.

² See, e.g. *Garcia v. Gloor*, 618 F.2d 264 (5th Cir. 1980), *cert denied*, 449 U.S. 1113 (1981); *Gutierrez v. Municipal Court of S.E. Judicial District*, 838 F.2d 1031, 1039 (9th Cir. 1988), *vacated as moot*, 490 U.S. 1016 (1989).

³ 42 U.S.C. § 2000d-4a. In certain limited circumstances, all of an entity's programs or activities will not be required to comply.

⁴ See 42 U.S.C. § 2000d-4a, definition of "program or activity."

⁵ This provision is included in a proposed rule released by CMS in August 2001. This rule is subject to change pending finalization in 2002.

⁶ This provision is included in an interim final rule published in July 2001, which deleted a prior requirement to report primary language. This rule is subject to change pending CMS's consideration of submitted comments.

⁷ 62 Fed. Reg. 58782 (October 30, 1997). Many federal agencies still refer to these standards as OMB Directive No. 15, a version of the standards issued when OMB was part of the Department of Commerce. The current standards are not, however, a directive.

⁸ Office of Management and Budget (OMB) Statistical Directive 15, *Racial and Ethnic Standards for Federal Statistics and Administrative Reporting*, May 12, 1977.

⁹ 62 Fed. Reg. at 58786.

¹⁰ The brief description of HIPAA included here and elsewhere in this report is intended to explain the provisions relevant to the collection of racial and ethnic data. For more information on other aspects of HIPAA, see <http://aspe.hhs.gov/adminsimp/index.htm> or <http://www.hhs.gov/ocr/hipaa.html>.

¹¹ Appendix A: Consumer Bill of Rights and Responsibilities, Executive Summary at 1, <http://www.hipaonet.com/cbrr.htm>. See also <http://www.consumer.gov/qualityhealth/rights.htm>. Congress is considering whether to enact a statutory patients' bill of rights to protect all enrollees in health maintenance organizations.

¹² *Id.*, Chapter Five: Respect and Nondiscrimination, at 56.

¹³ *Memorandum on Federal Agency Compliance with the Patient Bill of Rights* (February 20, 1998), <http://www.gpo.gov/nara/pubpaps/srchpaps.html>. This Memorandum was based in part on a report to the Vice President, *Progress Report in Implementing the Patient's Bill of Rights*. The HHS compliance report is available at <http://aspe.hhs.gov/health/vpreport.htm>.

¹⁴ U.S. Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality: Volume 1—The Role of Governmental and Private Health Care Programs and Initiatives*, September 1999.

¹⁵ *Ibid.*

¹⁶ Executive Order No. 13166, *Improving Access to Services for Persons with Limited English Proficiency* (August 11, 2000). One noteworthy aspect of this executive order is that it requires federal agencies to develop a system by which individuals with limited English proficiency can meaningfully access their services. This is the first time that the mandates of Title VI have been extended to the federal agencies themselves. The guidance does not, however, directly require collection and reporting of primary language data.

¹⁷ U.S. Department of Justice, *Enforcement of Title VI of the Civil Rights Act of 1964: National Origin Discrimination Against Persons with Limited English Proficiency, Policy Guidance*, 65 Fed. Reg. 50123 (August 16, 2000). The Guidance emphasizes that it does not create any new obligations but only clarifies existing Title VI responsibilities.

¹⁸ U.S. Department of Health and Human Services, Office for Civil Rights, *Title VI of the Civil Rights Act of 1964: Policy Guidance on the Prohibition Against National Origin Discrimination as It Affects Persons with Limited English Proficiency*, 65 Fed. Reg. 52762 (August 30, 2000). Like the Department of Justice guidance, this guidance does not create any new obligations but only clarifies existing Title VI responsibilities of recipients of federal financial assistance through HHS.

¹⁹ Minority Health and Health Disparities Research and Education Act of 2000, Title III, Data Collection Relating to Race and Ethnicity, Section 301 (b)(3). Another relevant provision of the act calls for the establishment of a National Center on Minority Health and Health Disparities, replacing the previously established Office of Research on Minority Health.

²⁰ 42 C.F.R. § 80.4(a).

²¹ The Secretary of Health and Human Services. *Policy Statement on Inclusion of Race and Ethnicity in DHHS Data Collection Activities*. October 24, 1997. IV. C. (“Racial and Ethnic Data Collection Enhancement Options”).

²² HHS Data Council Working Group on Racial and Ethnic Data, *HHS Plan to Improve the Collection and Use of Racial and Ethnic Data*. December 1999, pp. 2–4.

²³ *Ibid.* pp. 4–7.

²⁴ U.S. Department of Health and Human Services, *Healthy People 2010, Conference Edition—Volume 1*, January 2000.

²⁵ *Ibid.* p.21.

²⁶ 42 C.F.R. § 80.6(b). While HHS must monitor compliance with Title VI, whether to collect data is left to the discretion of HHS. See *Madison-Hughes v. Shalala*, 80 F.3d 1121, 1124–5 (6th Cir. 1996).

²⁷ The Secretary of Health and Human Services. *Policy Statement on Inclusion of Race and Ethnicity in DHHS Data Collection Activities*, October 24, 1997, <http://aspe.os.dhhs.gov/datacncl/inclusn.htm>.

²⁸ Office of Minority Health, *National Standards on Culturally and Linguistically Appropriate Services in Health Care*, 65 Fed. Reg. 80865 (December 22, 2000). The complete report and other supplementary materials to these standards are available at <http://www.OMHRC.gov/clas>.

²⁹ These responsibilities include: developing an agency-wide data collection strategy, including coordination and consolidation of surveys; working with HHS's program and policymakers, the National Center on Vital and Health Statistics (NCVHS), the research community, states, the private sector, and others so that data collected by HHS will meet the needs of all users and be easily accessible; working towards consensus in data standards and privacy; serving as HHS's liaison to and contact point for the NCVHS to determine its focus, obtain issue specific reports, monitor its work, and make recommendations for membership and rechartering; responding to data standards and privacy issues presented by NCVHS and others; overseeing surveys and general statistical analysis; and implementing the Vice President's charge to lead an interagency effort in four areas of information system policy: data standards, privacy, telemedicine, and enhanced health information. See <http://aspe.hhs.gov/datacncl/index.htm>.

³⁰ *HHS Plan to Improve the Collection and Use of Racial and Ethnic Data*, HHS Data Council Working Group on Racial and Ethnic Data (December 1999); <http://aspe.hhs.gov/datacncl/racerpt/index.htm>.

³¹ The full directory is available at <http://aspe.hhs.gov/datacncl/datadir/introduc.htm>. Information is provided on each data resource, including the categories of race and/or ethnicity collected, information on the status of collection and accessing the data, and a contact person.

³² National Committee on Vital and Health Statistics, *Core Health Data Elements, Executive Summary*, August 1996, page 2. This report is also available at <http://aspe.os.dhhs.gov/ncvhs/NCVHSR1.H>.

³³ U.S. Department of Health and Human Services, *1999 CMS Statistics*, p. 7. See also Health Care Financing Administration, *Medicaid Beneficiaries and Vendor Payments by Race, 1996–1998*, Table 8. Available at <http://www.CMS.gov>. Data on the percentages of Medicaid recipients with "unknown" race information was compiled by Jacqueline Patterson, Center on Budget and Priorities, undated document.

³⁴ Based on analysis of the March 2000 Current Population Survey, U.S. Census Bureau, conducted by the Children's Defense Fund, March 2001.

³⁵ For a succinct overview of the SSA/CMS historical relationship and data connection, see Susan L. Arday, et al., "HCFA's Racial and Ethnic Data: Current Accuracy and Recent Improvements," *Health Care Financing Review* 21 (Summer 2000):107–108.

³⁶ *Ibid.* p.108.

³⁷ *Ibid.* p.107.

³⁸ Reported by a CMS respondent who works with racial and ethnic data.

³⁹ Group and individual discussions centered on consistent areas of inquiry were also used to collect data.

⁴⁰ "Conference Proceedings: Eliminating Racial, Ethnic, and SES Disparities in Health Care: A Research Agenda for the New Millennium," *Health Care Financing Review* 21 (Summer 2000).

RELATED PUBLICATIONS

In the list below, items that begin with a publication number are available from The Commonwealth Fund by calling our toll-free publications line at 1-888-777-2744 and ordering by number. These items can also be found on the Fund's website at www.cmwf.org. Other items are available from the authors and/or publishers.

Are Urban Safety Net Hospitals Losing Low-Risk Medicaid Maternity Patients? (April 2001). Darrell J. Gaskin, Jack Hadley, and Victor G. Freeman. *HSR: Health Services Research*, vol. 36, no. 1, part 1. Copies are available from *HSR: Health Services Research*, Foundation of the American College of Healthcare Executives, Publication Services, One North Franklin, Suite 1700, Chicago, IL 60606-3491, Fax: 312-424-0703.

Addressing Racial Disparities in Health Care Delivery: A Regional Response to the Problem (January 2001). Alan R. Fleischman and Emily B. Wood, New York Academy of Medicine. Copies are available from the New York Academy of Medicine, 1216 Fifth Avenue, New York, NY 10029, Tel: 212-822-7222, E-mail: ewood@nyam.org.

Reforming the Medicaid Disproportionate Share Hospital Program (Winter 2000). Teresa Coughlin, Leighton Ku, and Johnny Kim, The Urban Institute. *Health Care Financing Review*, vol. 22, no. 2. Copies are available from Teresa A. Coughlin, The Urban Institute, 2100 M Street, NW, Washington, DC, 20037, E-mail: TCoughli@ui.urban.org.

Reforming the Medicaid Disproportionate Share Hospital Program in the 1990s (January 2000). Teresa A. Coughlin, Leighton Ku, and Johnny Kim, The Urban Institute. This discussion paper, part of the Assessing the New Federalism program, compares a 1997 40-state survey of Medicaid DSH usage with one from 1993, finding that a much higher share of federal DSH funds were being paid to local hospitals in 1997. Copies are available from The Urban Institute, 2100 M Street, NW, Washington, DC 20037, Tel: 202-833-7200.

Vulnerable Populations and Medicare Services: Why Do Disparities Exist? (2000). Marian E. Gornick. Copies are available from Century Foundation Press, The Brookings Institution, 1775 Massachusetts Avenue, NW, Washington, DC 20036, Phone: 800-552-5450, Fax: 202-797-6004, www.tcf.org.

Minority Health in America (2000). Carol J. Rowland Hogue, Martha A. Hargraves, and Karen Scott Collins (eds.). This book reviews findings from The Commonwealth Fund's 1994 *National Comparative Survey of Minority Health Care*, providing the documentation needed to assess the successes and failures of the current system with regard to minority health care and to chart productive directions for the future. Copies are available from the Johns Hopkins University Press, 2715 North Charles Street, Baltimore, MD 21218-4363, Tel: 410-516-6900, Fax: 410-516-6968, E-mail: www.press.jhu.edu.

#351 *The Dependence of Safety Net Hospitals and Health Systems on the Medicare and Medicaid Disproportionate Share Hospital Payment Programs* (November 1999). Lynne Fagnani and Jennifer Tolbert, National Association of Public Hospitals and Health Systems. As the federal government begins reducing subsidies for safety net hospitals, the authors detail the reliance of safety net hospitals—which treat all patients regardless of their ability to pay—on the Medicare and Medicaid disproportionate share hospital payment programs.

Experiences of Minority Primary Care Physicians with Managed Care: A National Survey (October 1999). Elizabeth R. Mackenzie, Lynne S. Taylor, and Risa Lavizzo-Mourey. *American Journal of Managed Care*, vol. 5, no. 10. From their analysis of a national survey of primary care physicians, the authors determine that differences in rates of termination, type of practice, board certification rates, and managed care affiliation are related to physician ethnicity. Copies are available from Elizabeth Mackenzie, Division of Geriatric Medicine, University of Pennsylvania Health System, 5 Maloney, 3400 Spruce Street, Philadelphia, PA 19104-4283, E-mail: emackenz@mail.med.upenn.edu.

Population Characteristics of Markets of Safety Net and Non-Safety Net Hospitals (September 1999). Darrell J. Gaskin and Jack Hadley. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, vol. 76, no. 3. This article reports that urban safety net hospitals disproportionately serve minority and low-income communities that otherwise face financial and cultural barriers to health care. Copies are available from the New York Academy of Medicine, 1216 Fifth Avenue, New York, NY 10029-5293.

Race, Gender, and Partnership in the Patient-Physician Relationship (August 11, 1999). Lisa Cooper-Patrick, Joseph J. Gallo, Junius J. Gonzales, Hong Thi Vu, Neil R. Powe, Christine Nelson, and Daniel E. Ford. *Journal of the American Medical Association*, vol. 282, no. 6. Copies are available from Genuine Article/Institute for Scientific Information, 3501 Market Street, Philadelphia, PA 19104, Phone: 1-800-336-4474 option 5, Fax: 215-386-4343, E-mail: ids@ininet.com.

#321 *U.S. Minority Health: A Chartbook* (May 1999). Karen Scott Collins, Allyson Hall, and Charlotte Neuhaus. This chartbook, which is intended to serve as a quick reference for currently available information on minority health, shows that minorities continue to lag behind whites on many important health indicators, including infant mortality rates, life expectancy, and health insurance coverage.

#300 *Community Health Centers in a Changing U.S. Health Care System* (May 1999). Karen Davis, Karen Scott Collins, and Allyson G. Hall. In this policy brief, the authors discuss how major changes in the health care system—the growth of managed care and an increasingly for-profit health care sector—affect the delivery of health services provided by community health centers. These centers have played a critical role in serving some of the most vulnerable populations for more than 30 years.

#311 *Medicaid Managed Care and Cultural Diversity in California* (March 1999). Molly Coye and Deborah Alvarez, the Lewin Group. The authors examine the effect of cultural competence contract provisions that were enacted in 1993 by Medi-Cal, California's Medicaid program. Analysis finds early promise in improving access to and understanding of health care services for low-income, non-English-speaking minority enrollees.

#314 *Employer-Sponsored Health Insurance: Implications for Minority Workers* (February 1999). Allyson Hall, Karen Scott Collins, and Sherry Glied. This report shows that disparities in minorities' health insurance coverage can be found across industries, occupations, and part- and full-time workers, and that no matter what the company size, minority workers are less likely to receive health insurance from their employer.

#309 *Safety Net Hospitals: Essential Providers of Public Health and Specialty Services* (February 1999). Darrell J. Gaskin, Georgetown University. This study attempts to identify the public health and specialty services that are provided primarily by safety net hospitals and determine whether communities rely on these hospitals for such services.