

EXECUTIVE SUMMARY

Assessment of State Laws, Regulations and Practices Affecting the Collection and Reporting of Racial and Ethnic Data by Health Insurers and Managed Care Plans

Preliminary Findings: Phase I

DISCLAIMER: The views, statistical analysis, findings, and opinions expressed herein are not necessarily those of the Office of Minority Health, the Office of Public Health and Science nor the Department of Health and Human Services. The National Health Law Program, Inc. (NHeLP), under contract #282-00-0026, reviewed and analyzed existing state policies related to collecting racial and ethnic data by managed care organizations and health insurers. The information in this draft report contains the findings of NHeLP and not that of the Office of Minority Health, the OPHS, nor the U.S. Department of Health and Human Services. **The study was conducted between October 2000 and May 2001. The policies and/or data per state may have changed since that time.** The findings that have been updated in this draft report are the U.S. Census data (updated so that all data is from the 2000 Census) and the Center for Medicare & Medicaid Services (CMS)/HHS Medicaid data (updated from the June 30, 2000 to the December 31, 2002 reports).

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I. INTRODUCTION

Numerous studies have documented the existence of racial and ethnic disparities in health care and health status among this country's populations. Even accounting for differences in income, education and health insurance coverage, members of racial and ethnic minority groups encounter disparate treatment in most aspects of the health care delivery system.

In light of stark health care differences like these, HHS made a commitment to work towards eliminating longstanding racial and ethnic disparities. In conformity with that goal, and as part of an effort to develop strategies for improving health plan performance measures that minimize or eliminate racial and ethnic disparities, the Office of Public Health and Science, in conjunction with the Agency for Healthcare Research and Quality (AHRQ) and The Commonwealth Fund, convened a meeting with representatives of health insurers and managed care organizations (MCOs) on June 7, 1999 to discuss the issue of racial and ethnic data collection. MCOs were the focus of the meeting because of their dominance in the delivery of health care services.

Managed care representatives expressed various concerns regarding the collection of racial and ethnic data. These included: (1) anti-discrimination obligations; (2) perceived legal barriers to collecting such data; and (3) confidentiality concerns. Despite these reservations, health plan representatives in attendance at the meeting cited many potential beneficial uses for any collected racial and ethnic data, such as designing targeted quality improvement activities, informing program development efforts, and generating interest inside the health plan to understand the scope of the problem of health disparities affecting their clients, to name a few.

In January 2000, HHS launched Healthy People 2010 (HP2010), the nation's health promotion and disease prevention objectives for the next decade. One of the two overarching goals of HP2010 is the elimination of health disparities, including those associated with race and ethnicity.

II Purpose

To clarify the state of the law regarding the collection and reporting of racial, ethnic and primary language data, the Office of Minority Health contracted with the National Health Law Program, Inc. (NHeLP) to review state laws, regulations, rules and other written policies to

determine the extent to which health insurers and managed care organizations are permitted to collect and report racial, ethnic and primary language information. In addition, the study examines the distinct domains of and overlap among civil rights laws, confidentiality laws, and health insurance/managed care laws.

The first phase of the study examined existing information from all fifty states and the District of Columbia to ascertain whether any states have laws, regulations, rules or written policies which require or prohibit the collection and/or reporting of racial, ethnic and primary language information of applicants or enrollees of health insurers or managed care plans. Phase II of this project involves selecting states for a more in-depth examination of actual data collection and reporting practices, problems and potential solutions.

III. Methodology

Legal research data bases, law library materials, and state websites were searched to locate state policies addressing racial, ethnic and primary language data collection, discrimination on the basis of race or national origin, and confidentiality of health data. A Project Advisory Group (PAG)¹ whose members reflect knowledge of federal or state laws, as well as expertise in health care delivery systems, was assembled for this project.

Data from the U.S. Census Bureau, The Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation reports on HMO penetration rates, and CMS data on Medicaid and Medicaid managed care enrollment were also reviewed to obtain demographic and health care status “snap-shots” of the 50 states and the District of Columbia.

IV FINDINGS

The review of the fifty states’ and the District of Columbia’s policies produced a number of key findings related to racial and ethnic data collection, anti-discrimination provisions, confidentiality and Medicaid (SCHIP and managed care) practices. These findings are set forth in Table 1 and include:

1. Requirement to Collect or Report Racial, Ethnic or Primary Language Data

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- South Carolina has a regulation requiring HMOs to collect and report racial data.
- Texas is the only state that requires all HMOs to collect primary language information from its enrollees.
- Four states—CA, MD, NH, NJ—statutorily prohibit health insurers and managed care plans from requesting racial and ethnic data from the enrollee in at least some contexts.
- Five states—CT, IA, MN, SD and WA—would withhold prior approval or require written justification for a submitted insurance form requesting an individual’s race or ethnicity.

2. Anti-Discrimination

- Three states—AL, GA, MS—do not have a written policy that provides protection for racial and ethnic minority health care consumers in their insurance laws, managed care laws, or general civil rights laws.
- Seven states’ policy—HI, IN, IA, KS, OK, OR, VT—lack clarity regarding the protection provided for health care consumers.

4. Confidentiality Provisions

While every state provides some level of protection for MCO or HMO enrollees with regard to confidentiality of their medical information or data, 21 of those states do not provide similar protections for those who receive their health care through some other mechanism.

5. Medicaid/SCHIP Program and Medicaid Managed Care Practices

CMS has left primary responsibility for determining what data are collected and/or reported to the states.

Table 1: State Policy on Collecting Racial and Ethnic Data (Phase I)

STATE POLICY	STATE
States that Require the Collection of Racial, Ethnic or Primary Language Data (Only by HMOs)	SC (race) TX (primary language)
States that Prohibit by Statute or Regulation the Collection of Racial and Ethnic Data in Certain Contexts	CA, MD, NH, NJ
States Whose Prior Approval Processes Would Require Justification For or Prohibit the Collection of Racial and Ethnic Data on Forms	CT, IA, MN, SD, WA
States Lacking a Policy that Protects Against Discrimination by Health Insurers or Managed Care Plans on the Basis of Race, Color or National Origin	AL, GA, MS
States Whose Anti-discrimination Protections Provided for Health Care Consumers Are Uncertain	HI, IN, IA, KS, OK, OR, VT
States Lacking Provision on Confidentiality of Medical Information or Data for Non-MCO or -HMO Enrollees	AL, CO, DE, DC, FL, GA, ID, IN, IA, KS, KY, LA, NE, NM, OK, PA, SC, SD, UT, WV, WI
Medicaid/SCHIP Program and Medicaid Managed Care Practices	State Option

VI. CONCLUSION

The vast majority of states do not prohibit or require the collection or reporting of racial, ethnic or primary language data by health insurers, health care plans, or health providers. Most states do offer explicit protection against discrimination based on race or ethnicity, and the vast majority endeavor to protect the confidentiality of personal information that is collected within the health care context.

South Carolina requires its HMOs to collect racial data from their enrollees, and concomitantly provides protection against discrimination on the basis of race, color, national origin or ancestry to any enrollee or applicant for enrollment. Texas requires HMOs to collect primary language data from all their enrollees.

Only four states have an explicit prohibition against the collection of racial and ethnic data by health insurers and MCOs. In Maryland, New Hampshire, California, and New Jersey, this prohibition applies only to the application form. Although not statutorily prohibited,

Connecticut, Minnesota and South Dakota have indicated that they would deny prior approval—whereas Iowa and Washington indicated that they would closely examine—forms seeking racial and ethnic information by health insurers. The remaining forty-four jurisdictions do not prohibit health insurers and MCOs from collecting racial and ethnic data from their insureds and enrollees before, during or after enrollment.

This study plans to implement Phase II, where 20 states will be visited for a more in-depth, comprehensive review of data collection and reporting policy and practices. This phase will include interviews with government officials, health industry policy makers and representatives of health care plans and health insurers. The selection criteria for these states will include, but not necessarily be limited to, evidence from Phase I results of policies and practices related to the collection of racial and ethnic data, demographic and geographic diversity, as well as market penetration by health insurers and MCOs.