Report to Congress

Improving the Identification of Health Care Disparities in

Medicaid and CHIP

Sylvia Mathews Burwell
Secretary of the Department of Health and Human Services
November 2014
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXECUTIVE SUMMARY</td>
<td>2</td>
</tr>
<tr>
<td>I. INTRODUCTION</td>
<td>3</td>
</tr>
<tr>
<td>II. THE NEW HHS DATA COLLECTION STANDARDS AND THE DEVELOPMENT PROCESS</td>
<td>4</td>
</tr>
<tr>
<td>III. PROGRESS IN IMPLEMENTING APPROACHES FOR IDENTIFYING, COLLECTING, AND EVALUATING DATA</td>
<td>5</td>
</tr>
<tr>
<td>ON HEALTH CARE DISPARITIES IN MEDICAID AND CHIP</td>
<td></td>
</tr>
<tr>
<td>A. Efforts to Improve Data Collection</td>
<td>6</td>
</tr>
<tr>
<td>B. Efforts to Improve Data Analysis and Reporting</td>
<td>7</td>
</tr>
<tr>
<td>IV. RECOMMENDATIONS FOR IMPROVING THE IDENTIFICATION OF HEALTH CARE DISPARITIES IN MEDICAID</td>
<td>9</td>
</tr>
<tr>
<td>AND CHIP</td>
<td></td>
</tr>
<tr>
<td>V. CONCLUSION</td>
<td>11</td>
</tr>
</tbody>
</table>
EXECUTIVE SUMMARY

The Department of Health & Human Services (HHS) is committed to both understanding and reducing health and health care disparities. The Patient Protection and Affordable Care Act, as amended by the Health Care and Education Reconciliation Act of 2010 (collectively referred to as the Affordable Care Act), strengthened this commitment by including provisions that pertain to the expansion of health insurance coverage, workforce development, quality of care, and prevention and health promotion. A key provision relates to improving data collection and analysis in order to better understand the needs and gaps behind measured disparities and opportunities to eliminate health disparities.

Section 4302(a) of the Affordable Care Act amended the Public Health Service Act (PHS Act) to add new section 3101, and requires the Secretary of HHS to develop data-collection standards for five demographic categories: race, ethnicity, sex, primary language, and disability status. Federally conducted or supported health care or public health programs, activities, and surveys are required, under section 3101 of the PHS Act, to collect and report data on these categories, to the extent practicable. The final standards apply to the collection of data in national population health surveys that rely on self-reporting.\(^1\)

Section 4302(b) of the Affordable Care Act requires the collection of data on these five demographic characteristics in Medicaid and the Children’s Health Insurance Program (CHIP). Collection and reporting of these data are to adhere to the standards developed under section 3101 of the PHS Act. Additionally, section 4302(b)(2) added section 1946 of the Social Security Act (the Act), which, at subsection (a), requires an evaluation of approaches for the collection of data in Medicaid and CHIP that allow for the ongoing, accurate, and timely collection and evaluation of data on disparities in health care services and performance on the basis of these five demographic categories. Under section 1946(b)(1) of the Act, the Secretary of HHS was required to report to Congress on the findings of the evaluation by September 23, 2011, and, under section 1946(c) of the Act, implement the approaches by March 23, 2012.\(^2\)

This report meets the requirements of section 1946(b)(2) of the Act, as amended by section 4302(b)(2) of the Affordable Care Act, by reporting on the progress in implementing approaches for identifying, collecting, and evaluating data on health care disparities in Medicaid and CHIP, including recommendations for improvement. HHS has made progress in addressing health care disparities in Medicaid and CHIP by updating data-collection systems and tools; stratifying performance measures by demographic characteristics; developing new measures specific to populations of interest; and promoting data sharing, collaboration, and analyses, but there is more work to be done. To improve upon these efforts, HHS recommends improving the:

1. Quality of health care disparities data across delivery systems; and
2. Completeness of health care disparities data collection in managed care.

Taken together, these activities can support a more focused national strategy to eliminate health and health care disparities among Medicaid and CHIP enrollees.

---


I. INTRODUCTION

Medicaid and the Children’s Health Insurance Program (CHIP) play important roles in providing health coverage for low-income Americans. Together, the Medicaid and CHIP programs currently facilitate access to health care for over 80 million individuals each year, including 44 million children, 20 million adults, 11 million blind and disabled individuals, and 6 million elderly adults. Medicaid and CHIP are also critically important for population subgroups who disproportionately have lower-incomes, including racial and ethnic minority groups, the elderly and people with disabilities, individuals with limited English proficiency (LEP), individuals with complex health care needs, or individuals who have historically suffered disparate health care access and health outcomes (e.g. rural population groups).

The Patient Protection and Affordable Care Act, as amended by the Health Care and Education Reconciliation Act of 2010 (collectively referred to as the Affordable Care Act), established new health coverage options for Americans, including the expansion of Medicaid eligibility to low-income individuals previously ineligible for the program, such as adults without dependent children. Coverage expansions, combined with the ever-changing demographics of our country, create an even more urgent need for improved data collection and analysis for the Department of Health & Human Services (HHS) to better understand and address the health care needs, experiences, and outcomes of the Medicaid and CHIP beneficiaries.

The existence of disparities in health care access and quality on the basis of race, ethnicity, sex, primary language, and disability status are well documented. However, further data collection and monitoring is a critical first step in eliminating these disparities, as these data can support HHS’ efforts regarding targeted interventions and support innovation that aims to reduce health and health care disparities. Health and health care disparities not only affect access to and quality of care, but also pose significant economic costs: one report estimates that racial and ethnic health disparities result in excess costs of $17 billion in Medicare and Medicaid.

HHS’ commitment to reducing health and health care disparities is evidenced by initiatives such as the HHS Action Plan to Reduce Racial and Ethnic Disparities, Healthy People 2020, the National Partnership for Action to End Health Disparities, and the National Stakeholder Strategy for Achieving Health Equity. This commitment was strengthened by the Affordable Care Act, which includes multiple strategies to address health and health care disparities as well as a focus on improving the quality of care and lowering health care costs. Section 4302 of the Affordable Care Act revises the Public Health Service Act and the Medicaid and CHIP statutes to call for specific attention to collecting, reporting, and analysis of data to better understand and help address health care disparities.

Section 4302(a) of the Affordable Care Act amended the Public Health Service Act (PHS Act) to add new section 3101, and requires the Secretary of HHS to develop data-collection standards for five demographic categories: race, ethnicity, sex, primary language, and disability status. Federally conducted or supported health care or public health programs, activities, or surveys are required

---


4 See, for example, the Agency for Healthcare Research and Quality’s 2013 National Healthcare Quality and Disparities Reports, available at: [http://www.ahrq.gov/research/findings/nhqrdr/index.html](http://www.ahrq.gov/research/findings/nhqrdr/index.html).

under section 3101 of the PHS Act to collect and report data on these categories, to the extent practicable. The final data collection standards published on October 31, 2011 apply to the collection of data in national population health surveys in which person-level data are collected via either self-report or from a respondent who serves as a knowledgeable household representative. The final data collection standards published on October 31, 2011 apply to the collection of data in national population health surveys in which person-level data are collected via either self-report or from a respondent who serves as a knowledgeable household representative.

HHS has begun implementing these data standards in all new surveys and is phasing them in at the time of major revisions to existing surveys.

Section 4302(b) of the Affordable Care Act requires the collection and reporting of data on these five demographic characteristics in Medicaid and CHIP. Collection and reporting of these data in Medicaid and CHIP must adhere to the standards developed under section 3101 of the PHS Act. Additionally, Affordable Care Act section 4302(b)(2) added section 1946 of the Social Security Act (the Act), which, at subsection (a) requires an evaluation of approaches for the collection of data on health care disparities in Medicaid and CHIP that allow for the ongoing, accurate, and timely collection and evaluation of data on disparities in health care services and performance on the basis of these five demographic categories. Under section 1946(b)(1) of the Act, the Secretary of HHS is required to report to Congress on the findings of the evaluation by September 23, 2011, and, under section 1946(c) of the Act, implement the approaches by March 23, 2012. Implementation of these approaches is to be followed by two reports to Congress that include recommendations for improving the identification of health care disparities in Medicaid and CHIP based on analyses of data collected through implementation.

Since the evaluation was published in September 2011, the Centers for Medicare & Medicaid Services (CMS), the HHS agency responsible for providing health coverage for Medicare, Medicaid, and CHIP beneficiaries, has undertaken a number of efforts to improve the identification of health and health care disparities in Medicaid and CHIP. The objective of this report, as required by section 1946(b)(2) of the Act, is to detail the progress HHS has made in implementing the approaches to improve how data on health care disparities are identified, collected, and evaluated in Medicaid and CHIP as well as to offer recommendations for improvement.

II. THE NEW HHS DATA COLLECTION STANDARDS AND THE DEVELOPMENT PROCESS

Section 4302(a) of the Affordable Care Act amended the PHS Act to add new section 3101, and requires the Secretary of HHS to develop data-collection standards for five demographic categories: race, ethnicity, sex, primary language, and disability status. Federally conducted or supported health care or public health programs, activities, or surveys are required to collect and report data on these categories, to the extent practicable.

To support the implementation of the new data collection standards, a special workgroup of the HHS Data Council, which included representatives from HHS, the Office of Management and Budget (OMB), and the Census Bureau, was formed to recommend data standards on race, ethnicity, sex, primary language and disability. Based on the workgroup’s recommendations, HHS

---

8 References to “the Secretary” are to the Secretary of HHS.
published the final standards for data collection on race, ethnicity, sex, primary language, and disability status in October 2011. These standards include granular categories for race and ethnicity, a question about English language proficiency, two optional questions about spoken language, and a suite of six questions about disability status. While the language included in section 3101 of the PHS Act is more expansive, the implementation guidance set forth by HHS provides that the standards apply only to population health surveys sponsored by HHS, where respondents either self-report information or a knowledgeable person responds for all members of a household. HHS has begun implementing these standards in all new surveys and at the time of major revisions to current surveys.

As the September 2011 Report to Congress, Approaches for Identifying, Collecting, and Evaluating Data on Health Care Disparities in Medicaid and CHIP, was legislatively due before the data collection standards had been finalized and the guidance issued, many of the approaches detailed, and thus implemented, speak to areas beyond surveys, including administrative data collection efforts and quality performance measures.

III. PROGRESS IN IMPLEMENTING APPROACHES FOR IDENTIFYING, COLLECTING, AND EVALUATING DATA ON HEALTH CARE DISPARITIES IN MEDICAID AND CHIP

The September 2011 Report to Congress, Approaches for Identifying, Collecting, and Evaluating Data on Health Care Disparities in Medicaid and CHIP, detailed the approaches HHS considered to better identify, collect, and evaluate data on health care disparities in Medicaid and CHIP. Approaches included updates to data-collection systems and tools; stratifying performance measures by demographic characteristics; developing new measures specific to populations of interest; and promoting data sharing, collaboration, and analyses.

In implementing the approaches identified, minimizing potential burden to states was of chief concern to HHS. As Medicaid and CHIP are state-federal partnerships administered by states, and given the link between the Medicaid/CHIP state and federal data systems, most changes to data collection and reporting at the federal level require commensurate changes for states. Therefore, some previously detailed approaches were reassessed and restructured to be less burdensome; in some cases, new approaches were explored. HHS also made an effort to align the implementation of the new data collection standards with other HHS activities, which will help to improve health care disparities data collection and reporting across the Department.

This section of the report details the progress HHS has made on these approaches, and is divided into two parts: A) efforts to improve data collection; and B) efforts to improve data analysis and reporting.

---


A. Efforts to Improve Data Collection

- Updating the Medicaid Statistical Information System (MSIS) and Supporting States in the Collection and Reporting of Data

The Medicaid Statistical Information System (MSIS) is an electronic system through which states submit key eligibility, enrollment, program, utilization, and expenditure data for Medicaid and CHIP to CMS. MSIS is the primary claims-based data system for collecting data about Medicaid and CHIP enrollees at CMS. These data provide a database of all individuals who are eligible and receiving services in all states, the District of Columbia, and the territories. CMS has been working with pilot states and other stakeholders to refine the MSIS dataset and to modernize the ongoing submission and quality review process for the dataset.

CMS has undertaken an effort to move toward a modernized Medicaid and CHIP data infrastructure known as the Medicaid and CHIP Business Information Solutions (MACBIS) initiative. One of the two primary components of this model is the Transformed-MSIS or T-MSIS, which is an expanded MSIS that streamlines several Medicaid and CHIP data-collection systems into one. T-MSIS enhances the way states will submit operational data about beneficiaries, providers, claims, and encounters and will be the foundation of a robust state and national analytic data infrastructure.

Even though the new HHS data collection standards apply only to national population health surveys, CMS integrated many of the data collection standards into the T-MSIS data dictionary for data-alignment purposes. T-MSIS is being implemented in states on a rolling basis. More information about T-MSIS can be found in the August 2013 State Medicaid Director letter.12

- Incorporating Data Standards into CAHPS, MCBS, and other Patient Experience Surveys

Medicaid Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey:

In 2014, CMS plans to conduct a Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey of adult Medicaid beneficiaries across all 50 states and the District of Columbia to attain national- and state-level estimates of their access, experience, and satisfaction with care across financing and delivery models (e.g., managed care and fee-for-service) and population groups (e.g., disabled individuals and dually eligible individuals). This nationwide survey, which includes most of the new data collection standards,13 will produce measures of Medicaid beneficiaries’ experience, including getting needed care, getting care quickly, and how well doctors communicate. Self-reported demographic information is also collected in the survey, which will allow analysis of results by demographic categories.

Medicare Current Beneficiary Survey (MCBS):

The Medicare Current Beneficiary Survey (MCBS), a nationally-representative survey that serves as a comprehensive source of information on the health status, health care use, and expenditures of

---


13 Given the CAHPS protocol to include demographic questions at the end of the survey, and constraints in how many new questions to add to the survey, the survey team did not include the full complement of data collection standards.
Medicare beneficiaries, is being updated to collect the race, ethnicity, sex, primary language, and disability status variables in accordance with the new data collection standards. The MCBS has important implications for Medicaid policy, as 14 percent of Medicaid enrollees (9.6 million) are low-income elderly adults or people with disabilities under age 65 who are enrolled in both the Medicare and Medicaid programs. Over the next few years, all CMS Medicare surveys will be adding these new variables.

- Incorporating Data Elements into the Single, Streamlined Application

An environmental scan of Medicaid applications conducted by CMS as part of the September 2011 Report to Congress revealed that of the 50 States, District of Columbia, and 4 territories with available applications, 93 percent collected information about race, 89 percent collected information about ethnicity, 91 percent collected information about sex or gender, 56 percent collected information about primary language, and 73 percent collected information about disability status. This exercise confirmed that the application can serve as a rich source of demographic information about Medicaid and CHIP enrollees.

Sections 1413 and 2201 of the Affordable Care Act directs the Secretary of HHS to develop and provide to each state a single, streamlined form that applicants may use to apply for coverage in Qualified Health Plans (QHPs), insurance affordability programs, advance payments of the premium tax credit (APTCs), cost-sharing reductions (CSRs), Medicaid, and CHIP. States can use the HHS-developed application or states may develop an “alternative” application that is approved by CMS. Individuals must be able to submit the application online, by mail, over the telephone, or in person. The application may be submitted to a Marketplace, state Medicaid agency, or to a CHIP agency.

While the new HHS data collection standards apply only to national population health surveys, and thus did not prescribe the variables or questions to be included on the single, streamlined application, CMS integrated many of the 4302 elements and questions into the application, including the granular racial and ethnic categories, to help HHS better understand and improve health care for all Americans. The Health Insurance Marketplace and state Medicaid and CHIP agencies began using the single, streamlined application on October 1, 2013.

B. Efforts to Improve Data Analysis and Reporting

- Stratifying Medicaid and CHIP Performance Measures by Demographic Characteristics

Over the past few years, CMS has worked with stakeholders to identify two core sets of health care quality measures that can be used to assess the quality of health care provided to children and adults enrolled in Medicaid and CHIP. The Core Sets include a range of quality measures encompassing...

---

15 Environmental scan conducted by CMS between July 15 and September 20, 2011.
prevention and health promotion, management of acute and chronic conditions, experiences of care, and access, and reflect the diverse populations served by Medicaid and CHIP. The goals of this effort are to: 1) encourage reporting by all states on a uniform set of measures; and 2) support states in using these measures to drive quality improvement. CMS is also beginning to promote the use of the Core Sets to help identify and evaluate health care disparities in Medicaid and CHIP.

In December 2012, CMS launched the Adult Medicaid Quality Grant Program to support state Medicaid agencies in developing staff capacity to collect, report, and analyze data on the Medicaid Adult Core Set. CMS selected twenty-six states to participate in this grant program. As part of the program, CMS has begun to test states’ ability to stratify a subset of the Medicaid Adult Core measures by demographic data categories in order to analyze gaps in health care. Participating states are to report at least 3 of 4 select measures by at least two of the following demographic categories: race, ethnicity, sex, primary spoken language, disability status, and geography. The measures selected for stratification align with other CMS and federal quality improvement initiatives, including the National Quality Strategy, Strong Start Initiative, Partnership for Patients, and Million Hearts Initiative. States began reporting on the Medicaid Adult Core Set for the first time at the end of 2013, and analysis of the stratified data is now underway. Efforts continue to ensure robust, complete, and accurate information. CMS also plans to encourage states to voluntarily report stratified data on the Child Core Set as well.

- Developing New Measures Specific to Populations of Interest

As discussed in the previous report, the Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA) required the development of a Pediatric Quality Measures Program (PQMP) to test and refine CMS’ initial core set of children’s health care quality measures, aiming to 1) make the measures more broadly applicable to Medicaid and CHIP enrollees, and 2) develop additional quality measures that address dimensions of care where standardized measures do not currently exist. CHIPRA also required that the measures developed under the PQMP be able to, in part, identify (and thereby help to eliminate) disparities by race, ethnicity, socioeconomic status, and special healthcare need. The PQMP, funded by CMS and managed by the Agency for Healthcare Research and Quality (AHRQ), leverages seven CHIPRA Centers of Excellence (CoEs) and two CHIPRA quality demonstration project grantees (Illinois and Massachusetts) in the development of measures that could be considered as improvements to the initial core set measures. The measures being developed under the PQMP by CoEs encompass topics related to duration of enrollment, availability of services, family experiences of care, identification of children with special health care needs, continuity of care, transitions and care coordination, hospital readmissions, person-reported outcomes, quality of care for children in child welfare system, quality to cost, prevention and health promotion, and management of acute and chronic conditions. In 2014, AHRQ began to post completed measures for public review and use, and new research from the CoEs has been


published in the *Journal of the American Medical Association, Pediatrics*, and other publications.22, 23, 24

- Promoting Data Sharing, Collaboration, and Analyses

The September 2011 *Report to Congress* highlighted the creation of partnerships as one mechanism to support the identification and evaluation of health care disparities data. Since the last report, CMS has continued to explore partnerships that will help identify and evaluate health care disparities in Medicaid and CHIP.

The CMS-AHRQ partnership is particularly significant. Each year since 2003, AHRQ has reported on the progress and opportunities for improving health care quality and access and reducing health care disparities in the *National Healthcare Quality and Disparities Reports*. In 2008, AHRQ produced, in partnership with CMS, “Health Care Coverage Analyses of the 2006 *National Healthcare Quality and Disparities Reports*,” which examined disparities by insurance status (private, Medicaid, and uninsured) and race/ethnicity for the non-elderly population.25 AHRQ recently finalized an update to this report, “Health Care Coverage Analyses of the National Healthcare Quality and Disparities Reports: 2000-2008 Trends,” which includes measures from the 2012 *National Healthcare Quality and Disparities Reports* and demonstrates how quality and access have changed for these groups over time. CMS and AHRQ are also exploring the feasibility of adding measures from CMS’ Medicaid and CHIP Child and Adult Core Sets to the *National Health Care Quality and Disparities Reports* to ensure more consistent monitoring of health care disparities across domains that are of particular interest to Medicaid and CHIP programs. The next report will provide an update on these efforts.

IV. RECOMMENDATIONS FOR IMPROVING THE IDENTIFICATION OF HEALTH CARE DISPARITIES IN MEDICAID AND CHIP

This section of the report includes recommendations for improving the identification of health care disparities in Medicaid and CHIP that both build upon approaches detailed in the previous report and present new strategies for consideration.

- Improve the Quality of Health Care Disparities Data Across Delivery Systems

Ensuring data quality on health and health care disparities is an ongoing challenge. Focused attention to the quality of data collected, including the accuracy and completeness of data, is an important strategy to help improve the identification of health care disparities in Medicaid and CHIP across delivery systems.

---

24 Available at: [http://www.ahrq.gov/policymakers/chipra/index.html#Core2](http://www.ahrq.gov/policymakers/chipra/index.html#Core2).
One effort currently being explored to address this challenge is the CMS Office of Minority Health’s Census Data Project. Through analyses of linked data from the Decennial Census, the American Community Survey (ACS), MSIS, and Medicare Enrollment Data Base (EDB) files, the Census Data Project will show enrollment in Medicare and Medicaid by OMB race/ethnicity categories and Census detailed race/ethnicity groups. The Census Data Project will also explore the accuracy of various imputation models that account for missing data.

These analyses will be able to provide information such as the proportion of Medicaid participants who, when linked to Census data, show the same race and Hispanic origin responses; whether any differences in race or Hispanic origin are associated with demographic, socioeconomic or contextual characteristics; and whether there are interstate differences in these results.

Along with other efforts, projects like this can help to improve the validity and completeness of racial and ethnic data at CMS where gaps exist, a critical step in better monitoring the progress in eliminating health care disparities across delivery systems.

• Improve the Completeness of Health Care Disparities Data Collection in Managed Care

As of June 2011, nearly 75 percent of Medicaid enrollees received benefits through some form of managed care. The most common arrangement is capitated managed care in which plans are accountable for providing a full range of services to enrollees and are generally required to submit encounter data to states on the services, payment, providers, and diagnosis codes provided under managed care arrangements. However, encounter data that are reported to states and CMS from Medicaid managed care organizations (MCOs) are sometimes limited. Efforts to improve the data are underway, which generally can improve the quality of managed care data and information on health care disparities.

Due in part to their purchasing power, states have an opportunity to encourage or require their MCOs to identify and address health and health care disparities among their members. The previous report highlighted ways states can use their leverage with MCOs to collect, report, and evaluate data on health and health care disparities. Approaches discussed included using encounter data to assess service use by demographic categories, using HEDIS and other performance measures that most Medicaid managed care plans are required to collect to identify health disparities, conducting performance improvement projects to address disparities, and requiring attention to disparities through managed care contract language. However, how widespread these practices are across states is unclear.

States that use a managed care delivery system must also comply with certain federal requirements, including requirements with a health equity focus. For example, MCOs are required to participate in a state’s efforts to promote the delivery of services in a culturally competent manner to all enrollees, including those with limited English proficiency and diverse cultural and ethnic backgrounds; MCOs must also adhere to regulations around language access and the availability of

---


oral interpretation services. CMS plans to issue guidance to states to support efforts in implementing managed care regulations to better measure, track, and reduce health care disparities.

V. CONCLUSION

By standardizing data collected on demographic characteristics associated with health care disparities, and by requiring collection and evaluation of this data, section 3101 of the PHS Act has better positioned Medicaid and CHIP to track progress in addressing disparities in health care. In addition, initiatives to improve the identification, collection, and evaluation data on health care disparities in Medicaid and CHIP have provided HHS with a solid foundation from which to grow.

HHS has made progress in better addressing health care disparities in Medicaid and CHIP through the implementation of these select approaches. To improve the identification of health care disparities in Medicaid and CHIP, while continuing to build off of the approaches already implemented, HHS recommends improving the:

1. Quality of health care disparities data across delivery systems; and
2. Completeness of health care disparities data collection in managed care.

Taken together, these activities can provide the information needed to drive health and health care disparities down among Medicaid and CHIP enrollees.

---

28 C.F.R. 438.206(c)(2) and; C.F.R. 438.10(c)