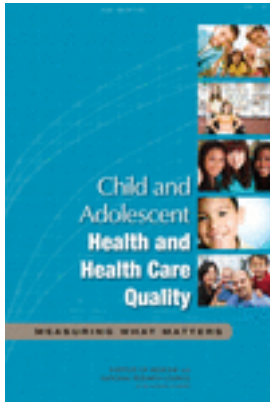


Free Summary



Child and Adolescent Health and Health Care Quality: Measuring What Matters

Committee on Pediatric Health and Health Care Quality Measures; Institute of Medicine and National Research Council

ISBN: 978-0-309-18623-0, 320 pages, 6 x 9, paperback (2011)

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Summary

Monitoring the status of the health of the nation's children and adolescents is important because health matters both in and of itself—as a measure of a society's values and capabilities—and as a direct determinant of adult health, productivity, and longevity. The health of children and adolescents in the United States is influenced by multiple factors, including biology, behavior, and social and physical environments. It also is influenced by the availability, use, and quality of health care services, especially for those with life-threatening conditions or special health care needs that require frequent interactions with health care providers. Therefore, understanding the health status of children and adolescents is closely intertwined with understanding the quality of the health care they receive.

Conceptually sound and reliable health and health care measures for children and adolescents can be used to assess the effects of disease or injury on health; identify vulnerable children in clinical settings and vulnerable population subgroups in health plans or geographic regions; measure the effects of medical care, policy, and social programs; set targets for improving health care; and improve health outcomes. Despite the presence of multiple data sets and measures, however, the United States currently has no robust national information system that can provide timely, comprehensive, and valid and reliable indicators of health and health care quality for children and adolescents.

Progress has been made in selected areas to improve measures of health and health care quality for younger populations, and interest is growing in developing standardized measures that could yield the information needed in these areas. What is needed now is a comprehensive strategy that can make better use of existing data, offer a basis for integrating or linking different data sources, develop new data sources and data collection methods for difficult-to-measure indicators and difficult-to-reach populations, and put a system in place for continuously improving the measures and the measurement system.

STUDY CHARGE

This study responds to a mandate in the Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009 for a study by the National Academies "on the extent and quality of efforts to measure child health status and the quality of health care for children across the age span and in relation to preventive care, treatments for acute conditions, and treatments aimed at ameliorating or correcting physical, mental, and developmental conditions in children." To this end, the Institute of Medicine (IOM) and the National Research Council (NRC) of the National Academies were engaged under contract with the U.S. Department of Health and Human Services (HHS) to conduct an 18-month study "to identify key advances in the development of pediatric health and health care quality measures, examine the capacity of existing federal data sets to support these measures, and consider related research activities focused on the development of new measures to address current gaps." The IOM and NRC subsequently formed the Committee on Pediatric Health and Health Care Quality Measures to conduct this study.

In interpreting its charge, the committee sought to (1) consider all of the major national population-based child health/health care reporting systems sponsored by the federal government; (2) examine strengths and deficiencies of current federal data collection efforts and reporting systems; and (3) make recommendations for improving and strengthening the timeliness, quality, public transparency, and accessibility of information on child health and health care quality.

CONCLUSIONS

The committee reviewed multiple federal sources of data on the health and health care quality of children and adolescents, 24 core measures of health care quality recommended by the Secretary of HHS in 2010 for voluntary reporting by Medicaid and CHIP programs, and a number of private-sector efforts aimed at developing valid and reliable measures of health and health care quality for children and adolescents, as well as the salient research literature. As a result of this review, the committee formulated conclusions in three key areas.

The Nature, Scope and Quality of Existing Data Sources

- Multiple and independent federal and state data sources exist that include measures of the health and health care quality of children and adolescents.
- The fragmentation of existing data sources impedes access to and timely use of the information they collectively provide.
- Existing data sources have their individual strengths and limitations, but no single data set derived from these sources provides robust information about the health status or health care quality of the general population of children and adolescents.
- Lack of standardization in the measurement of disparities in health and health care quality limits the ability to identify, monitor, and address persistent health disparities among children and adolescents.
- The absence of common definitions and consistent data collection methods impedes the standardization of common data elements (such as insurance coverage) across multiple settings, such as health care, education, and human services, in federal and state data sets.

Gaps in Measurement Areas

The conclusions in this area focus on the social and behavioral determinants of health and health care quality. Multiple longitudinal studies document the impact of physical and social environments (e.g., toxic exposures, safe neighborhoods, or crowded housing), behaviors (e.g., diet or the use of alcohol or drugs), and relationships (e.g. parent—child attachment) on the health status of children and adolescents and their use of health care services. Earlier IOM/NRC reports have documented the extent to which such information is lacking in existing federal health and health care data sets, and stressed that these contextual factors are key influences on the short- and long-term health outcomes of children and adolescents.

- Existing goal-setting efforts in the public and private sectors offer a foundation from which to develop national goals for children and adolescents in priority areas of health and health care quality.

- Quality measures for preventive services deserve particular attention for children and adolescents because most individuals in these age groups are generally healthy and because early interventions may prevent the onset of serious health disorders as the child or adolescent becomes an adult.
- Standardized measures of child health and the quality of relevant health care are important for all child health problems, but especially for preventable, ongoing, or serious health conditions.
- Variations persist in data elements pertaining to race, ethnicity, income, wealth, and education. Core data elements for socioeconomic status need to be identified that can feasibly be collected in a standardized manner, while introducing a life-course approach that can be applied across multiple data sets.
- The health of other family members, especially parents and other caregivers, may directly affect the health of children and adolescents, as well as their access to and use of health care services. Family-focused measures are a new frontier for research in the development of measures.
- With respect to social determinants of health, data are needed to determine those elements that offer timely potential for prediction of disparities.
- Race/ethnicity, socioeconomic status, primary language spoken at home, and parental English proficiency all affect disparities in health and health care and therefore are relevant topics for data collection for all children and adolescents.
- Measures of health literacy are important for adults' ability to understand information that is relevant for children's healthy development and in assuring adolescents' understanding of their own health status, and deserve greater recognition in the identification of future research priorities and the testing of new measures in national surveys.
- Biological influences on the health of children and adolescents are an important focus for measures of health and health care quality; also important are measures of behaviors and levels of functioning. Measures focused on the needs of the "whole child," as opposed to individual clinical concerns, can address the distinct needs of children and adolescents, including their unique epidemiology, their dependent status, and their developmental stages.
- Measures of care transitions are important, especially for children with special health care needs.
- New areas of focus entail place-based measurement, targeting selected geographic regions and population groups at the state, county, and even neighborhood levels.

Methodological Areas That Deserve Attention

- Many data sources cannot be used to assess the status of specific groups of children and youth, particularly vulnerable populations who are at risk of poor health outcomes because of their health conditions or social circumstances.
- Implementing an integrated approach involves choosing specific criteria for selecting reference groups. The selection of reference group criteria would benefit from interactions with state and local health officials, as well as those concerned with the health and health care quality of children and adolescents in their region, particularly underserved populations. The selection of criteria could also be guided by the

perspectives of families, consumers, and users, as well as those involved in data collection.

- Greater transparency is necessary to expose the strengths and limitations of different surveys in tracking the status of key child and adolescent populations of interest; in identifying appropriate reference groups over time; and in implementing innovative measurement practices that can adapt to changing conditions, changing populations, and opportunities for health improvement.
- Linking or aggregating databases offers opportunities to reduce variations among multiple data sources and to decrease the burden of data collection on individual states, providers, health plans, and households.
- While it is often difficult to connect data from the clinical records of children and adolescents enrolled in public health insurance plans to population health surveys and administrative data sets, such efforts will increase understanding of the social context and life-course influences that may affect children's health status and their access to and use and quality of health care services.
- Longitudinal data (with multiple observations for the same children/families over time) would enrich the quality of measures used in population health surveys and health care quality studies.
- Electronic data capture and linkage would greatly enhance future measurement activity. Expanding data collection beyond geographic and claims information to capture state-level policy and community-level characteristics would enable analysis of the variability and impact of coverage, eligibility, and payment policies. Special attention will be needed to ensure that advances in electronic data capture adhere to existing privacy and confidentiality guidelines and laws. Ongoing attention will also be needed to resolve emerging issues related to privacy and confidentiality in future measurement efforts.
- While electronic health records have potential for significant retrieval of selected variables across multiple records, they do not necessarily offer conceptual or metric precision. The data are locked in a multitude of disparate systems designed for purposes other than analyses of health and health care quality.

A STEPWISE APPROACH

The above conclusions provide the foundation for a stepwise approach to improving data sources and measures of health and health care quality for children and adolescents that in turn serves as a frame for the committee's recommendations. This approach is designed to stimulate and support collaborative efforts among federal and state agencies and key stakeholder groups in five key areas:

- 1. Set shared health and health care quality goals for children and adolescents in the United States;**
- 2. Develop annual reports and standardized measures based on existing data sets of health and health care quality that can be collected and used to assess progress toward those goals;**
- 3. Create new measures and data sources in priority areas;**
- 4. Improve methods for data collection, reporting, and analysis; and**
- 5. Improve public and private capacities to use and report data.**

Each area requires attention to specific strategies, which are detailed below in the committee's recommendations. Some of these strategies represent actions that can be taken now; others require a longer-term effort. They are aimed at aligning the areas of measurement of the health of children and adolescents that are emerging in population health surveys and longitudinal studies—areas that go beyond health conditions to assess health functioning, health potential, and health influences—with existing efforts to measure health care quality for children and adolescents.

RECOMMENDATIONS

Step 1: Set Goals

Setting national and state-level goals for the health of children and adolescents would prioritize the next generation of health care quality measures and clarify the relative roles of health care services and improvements in health care quality in achieving those goals. These goals could be derived as a set of critical objectives for children and adolescents from such sources as Healthy People 2010 and Healthy People 2020. They could also be reported as part of the annual national quality strategy and national prevention strategy reports prepared by the Secretary of HHS.

In determining priority areas for these goals, the committee built on earlier work that goes beyond the traditional focus on such indicators as morbidity, mortality, and chronic and acute conditions and identified seven priority areas to inform the setting of goals for health and health care quality for children and adolescents:

- childhood morbidity and mortality,
- chronic disease conditions,
- preventable common health conditions (especially mental and behavioral health and oral health),
- functional status,
- end-of-life conditions,
- health disparities, and
- social determinants of health.

In addition, the committee recommends an overarching emphasis on a *life-course perspective* that is integral to all seven priority areas listed above. Because a life-course perspective provides a framework for understanding how health and disease patterns emerge within an individual's social and physical environments as the result of the accumulation of the effects of risk factors and determinants across the life span and across generations, it necessitates focusing on measures in each of the seven priority areas at various life stages within childhood and adolescence, as well as the transition to adulthood.

None of the seven priority areas is fully distinct; however, each presents unique measurement challenges and opportunities that merit separate consideration. Most existing measures focus primarily on the first two areas and draw extensively on administrative data sets. Yet important initiatives have emerged within population health surveys, longitudinal studies, and other research studies that provide data sources and opportunities to develop new measures in the

remaining five areas. These initiatives warrant increased support because of their capacity to inform the next generation of health care quality measures, especially in areas that involve disparities, social determinants of health, and the life course, as well as the emerging health information technology (HIT) infrastructure. The use of such resources will require extensive collaboration among multiple agencies and the public and private sectors, as well as study participants and key consumers of the data.

It should be noted that the committee directed many of its recommendations to the Secretary of HHS to allow for flexibility and discretion at the highest levels. However, specific actions are also necessary within designated agencies to foster accountability for implementation. An initial action agenda for the implementation of each recommendation is therefore proposed in the full report.

Recommendation 1: The Secretary of Health and Human Services (HHS) should convene an interagency group to establish national health and health care quality goals for children and adolescents within a life-course framework.

Step 2: Develop Annual Reports and Standardized Measures Based on Existing Data Sets

Efforts to monitor and improve the health of children and adolescents are hampered by both the lack of annual reports that focus on child and adolescent health and health care quality and the absence of standardized measures and variation in salient data sources. Of particular concern are the lack of consistent measurement of disparities in health and health care quality to support the development of targeted interventions at the national and state levels and the retention of unnecessary or obsolete measures resulting from the adoption of nonstandardized core measure sets.

Existing Opportunities to Include Children and Adolescents in Annual HHS Reports

The Secretary of HHS is already required to make annual reports on health care quality and disparities, as well as on national prevention initiatives. These reports provide valuable opportunities to include specific consideration of children and adolescents and to draw attention to the ways in which their needs may differ from those of older populations.

Standardized Measurement of Disparities in Health and Health Care Quality

Pervasive and persistent disparities exist in health and health care by race/ethnicity, socioeconomic status, special health care needs, primary language spoken at home, and parental English proficiency for all children and adolescents. Traditionally, such disparities have been measured through racial, ethnic, and geographic data. Assessment of children's and adolescents' health will benefit from efforts to (1) standardize definitions and measures of these characteristics, (2) routinely include socioeconomic data (minimally household income as an increment of the federal poverty level and educational attainment of parents), and (3) introduce data on language proficiency. All of these actions will be increasingly important in response to the growing poverty rate of younger populations. The percentage of U.S. children and adolescents (under age 18) who lived in poverty increased from 18 percent in 2007 to an estimated 20.7 percent in 2009. The percentage is even higher among younger children (under

age 6) and among children in selected geographic areas, such as rural communities or central city regions.

The increasing racial and ethnic heterogeneity of younger populations also deserves consideration. Compared with U.S. adults, U.S. children and adolescents are disproportionately of nonwhite race/ethnicity—a fact of particular significance because poor and minority children have disproportionately high special health care needs compared with their nonpoor and white counterparts. Children and adolescents in these groups also are more frequently insured through public health plans. For example, more than 40 percent of African American and one-third of Latino children have public insurance such as Medicaid or CHIP. Thus the development of health indicators that can provide a basis for considering the health status of these groups in relation to the general population of children and adolescents is a particularly urgent need.

Recommendation 2a: The Secretary of HHS should include specific measures of the health and health care quality of children and adolescents in annual reports to Congress as part of the Secretary’s national quality and prevention strategy initiatives.

Recommendation 2b: These measures should include standardized definitions of race/ethnicity, socioeconomic status, and special health care needs, with the goal of identifying and eliminating disparities in health and health care quality within a life-course framework. Identifying and reducing disparities in health and health care will require collecting data on race/ethnicity, socioeconomic status, special health care needs, primary language spoken at home, and parental English proficiency for all children and adolescents.

A Periodic Review Process

The purpose of a periodic review of health and health care quality measures is to ensure that the system for child and adolescent health and health care quality measurement is achieving its information goals (public transparency, timeliness, accessibility, and quality); to identify obsolete, unnecessary, or redundant measures; to highlight emerging candidates for new measures; and to identify areas that deserve consideration in the development of valid and reliable measures in keeping with new health goals for children and adolescents. The review process provides an opportunity to address the need for effective and valid data collection approaches to ensure that respondents (especially parents and adolescents) are clear about the meaning and intent of questions being asked.

Recommendation 3: The Secretary of HHS should develop a strategy for continuous improvement of the system for collecting, analyzing, and reporting health and health care quality measures for children and adolescents. This strategy should include periodic review of those measures that are used, recommended, or required by the federal government.

Step 3: Create New Measures and Data Sources in Priority Areas

Ideally, child and adolescent health and health care quality measures and data sources should support analyses that can demonstrate how changes in funding levels for public insurance programs (such as Medicaid or CHIP) or in eligibility requirements, enrollment levels, or service procedures affect health outcomes, health care costs, and school achievement. They should make it possible to examine specific conditions and issues that are of particular importance to vulnerable and underserved children and adolescents, especially those served by Medicaid and CHIP. Such measures and data sources should also support analyses of whether and how the organization and delivery of health care achieve public goals of effectiveness, efficiency, safety, timeliness, equity, and patient-centeredness. Finally, they should be flexible enough to include possible emerging threats to child and adolescent health.

Collectively, the seven priority areas identified earlier can serve as a framework for assessing the comprehensiveness of any set of measures for child and adolescent health and health care quality. For example, in early 2010 the Secretary of HHS recommended a set of core measures of health care quality for children and adolescents that includes a strong emphasis on preventive services. These measures address only minimally oral health, mental and behavioral disorders, and substance use. Yet dental caries are the most prevalent childhood infectious disease, and some costly adult health outcomes (such as tobacco addiction and obesity) have their origins in youth. Early interventions to address these health issues in children and adolescents can help prevent such problems as coronary heart disease and diabetes. Thus, the life-course perspective advocated by the committee can pay dividends in savings to the health care system by addressing problems before they appear later in life.

The new National Prevention Strategy mandated in the Affordable Care Act of 2010 offers an opportunity to improve the quality of data sources for the measurement of preventive services for these and other conditions for children and adolescents. This effort will require collaboration among multiple agencies within HHS, as well as among multiple public- and private-sector stakeholders. Such will also be the case for measures targeting end-of-life conditions, health disparities, and social determinants of health.

Recommendation 4: The Secretary of HHS should develop new measures of health and health care quality focused on preventive services with a life-course perspective. These measures should focus on common health conditions for children and adolescents, especially in the areas of oral health and mental and behavioral health, including substance abuse.

Recommendation 5: The Secretary of HHS should support interagency collaboration within HHS to develop measures, data sources, and reporting focused on relationships between the social determinants of health and the health and health care quality of children and adolescents.

Recommendation 6: The Secretary of HHS should encourage interagency collaboration within HHS to introduce a life-course perspective that strengthens the capacity of existing data sources to measure health conditions, levels of functioning, and health influences (including access to and quality of care) for children and adolescents.

Recommendation 7: The Secretary of HHS should place priority on interactions between HHS agencies and other federal agencies to strengthen the capacity to link data sources in areas related to behavioral health and the social determinants of health and health care quality.

Step 4: Improve Data Collection, Reporting, and Analysis

Several strategies can be used to improve data sources and methods for data collection, reporting, and analysis: (1) data aggregation strategies, including the use of registries and data linkage opportunities; (2) the development of mechanisms to foster greater transparency of performance indicators; (3) the use of unique identifiers that allow analysts to link data on the same child from different administrative data sets to obtain a more robust profile of the family and neighborhood characteristics and his or her health and educational outcomes; and (4) greater use of longitudinal studies, which follow the same cohort of children over time to monitor their health conditions and the health care services they receive.

Creating opportunities to link data across multiple health care settings, as well as connecting health and health care data to education and human service data systems, would improve timeliness and facilitate analysis of the multiple factors that affect the well-being of children and adolescents. The success of such efforts will depend on both methodological and technical advances and the resolution of privacy and data sharing issues, as well as specific guidance from federal data collection agencies to create constructive remedies.

Likewise, longitudinal measurement fosters child-centered analysis, breaking down the divisions among data created by the different silos of the health care system and other service settings that engage the child and his or her family. Longitudinal measures are especially useful in monitoring care transitions, assessing whether the child's or adolescent's needs were identified and met within an appropriate care setting and developmentally tailored, and determining both the short- and long-term outcomes of care. While it may not be feasible to introduce longitudinal approaches into health care quality measures, longitudinal studies can identify specific data elements that merit consideration in the creation of new quality measures.

Finally, timely and transparent data systems can help engage parents in data collection efforts through explanation of the purpose of the effort and how the data will be used to assist their own and other children and adolescents throughout the country. This engagement and broad awareness are critical for ensuring that all segments of the population, including marginalized populations, will be fully represented in survey and administrative data sources.

Recommendation 8: The Secretary of HHS should identify significant opportunities to link data across health care, education, and human service settings, with the goal of improving timeliness and fostering greater transparency as to the multiple factors that affect the health of children and adolescents and the quality of services (including health care, educational, and social services) aimed at addressing those factors.

Recommendation 9: The Secretary of HHS should promote policy, research, and convening efforts that can facilitate linkages among digital data sets while also resolving legal and ethical concerns about privacy and data sharing.

Step 5: Improve Public and Private Capacities to Use and Report Data

The ultimate goal of improving data collection and reporting efforts is to develop national and state-based data collection systems, measures, and reports that are compatible and that provide a basis for comparing the health and health care quality of children and adolescents across different health plans and different states and other regions of the United States. It is therefore important to create conditions that will allow states to develop measures that are useful for their own purposes while moving toward a core set of national, standardized measures in key areas. It will also be important to develop an integrated approach that can blend measures of the health status of children and adolescents (drawn from population health surveys) with measures of health care quality for those services that are actually used by children, adolescents, and their families (drawn from administrative data sources or private health records). Measures are needed with which to compare the quality and utilization of services with the types and severity of children's health needs due to chronic health disorders or risk factors that make them vulnerable to adverse health outcomes. Measures are also needed to provide more precise information about the short- and long-term effects of preventive services within a life-course framework.

Efforts to build federal and state capacity for place-based measures (e.g., through geographic positioning data) can resolve some of the current difficulties in integrating health measures, social and physical environment measures, and other measures of influence that occur in health care settings. Such efforts will require innovative approaches to compiling and extracting data from existing surveys and databases. They will also require a conceptual framework with the ability to prioritize and operationalize key measures of social context, health influences, and preventive services. Necessary as well are criteria that can be used to designate the appropriate reference groups of common interest. At the same time, collaboration needs to be strengthened between those who collect the data and those who are expected to use the data to shape current and future interventions. Fostering this collaboration involves investing in the capacity of communities, states, providers, consumers, and others to use the data effectively to drive decision making in light of limited resources; to monitor changes given the introduction of new policies or investments over time; and to understand the importance of tailoring interventions to the needs of different racial/ethnic, geographic, and other segments of the population and tracking longitudinally how disparities respond to changes in health care resources, processes, and policies. Some states are prepared to serve as laboratories for the creation of new measures for difficult-to-measure indicators or difficult-to-reach populations, and they would benefit from the development of incentives that encourage voluntary compliance in these areas. The emerging HIT infrastructure offers an opportunity to emphasize the distinct needs of children and adolescents and to link those needs to family data in health information exchanges, as well as to supplement traditional electronic health information with data from other sources (including parents). These linked data sets will need to track children across public and private data sources, as well as link with public health information systems through birth certificates and newborn screening data sets.

Recommendation 10: The Secretary of HHS should establish a timetable for all states to report on a core set of standardized measures that can be used in the health information technology infrastructure to assess health and health care quality for children and adolescents. Congress and HHS should formulate alternative strategies (through incentive awards, demonstration grants, and technical assistance, for example) that

would enable states to develop the necessary data sources and analyses to meet such requirements.

FINAL OBSERVATIONS

The direction of policy and resources toward improving the health and health care quality of children and adolescents in recent years is an encouraging sign that the distinct needs and health priorities of these populations are being recognized. Opportunities are available now to incorporate these needs and priorities into emerging population wide health care quality initiatives while also enhancing separate data collection and analysis and research initiatives that address the unique characteristics and developmental requirements of these younger populations. Exploiting these opportunities will require strong national and state-based leadership. Much can be done with existing efforts, supplemented by modest additional resources, to go beyond traditional boundaries to incorporate data elements that can deepen our understanding of the complex interactions among health, health care quality, and the social determinants of health. Innovations in technology and data gathering methods enhance the potential to develop new measures that can inform our understanding of important health disparities, preventable health conditions, and the social determinants of health and enable a life-course approach to the assessment of health and health care quality for our nation's youth.