

Review of Quality Measures of the Most Integrated Health Care Settings for Children and the Need for Improved Measures: Recommendations for Initial Core Measurement Set for CHIPRA

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ABSTRACT

OBJECTIVE: To identify, assess, and make recommendations for inclusion of measures that assess the domain of "most integrated health care setting," with a specific focus on measures of the medical home, one particular mechanism for integrating care, to identify gaps in measurement; and to make recommendations for new measure development.

METHODS: We developed a conceptual framework for care integration and reviewed literature on measures assessing the presence and quality of the medical home to determine their validity, reliability, and feasibility as a proxy for care integration.

RESULTS: We identified 2 broad approaches to assessing the extent to which patients receive care that fulfills the aims of the medical home: 1) organizational assessment of practice systems and processes thought associated with achieving these desired aims (viz, the National Committee for Quality Assurance Physician Practice Connections—Patient Centered Medical Home measure and the Medical Home Index, and 2) direct assessment by patients/families of their experience of care in targeted dimensions. Based on concerns about the absence of reliability data and the feasibility of applying the practice audit/self-assessment approach on a population level for the

purpose of state reporting, as well as the limited data linking performance on the specific measures with important child outcomes, we did not recommend any of the measures of organizational assessments of practice systems for inclusion in the core set as an indicator of care integration. In contrast, measures of the medical home based on items from the National Survey of Child Health on a population level or the Consumer Assessment of Healthcare Providers and Systems for practice- and state-level assessment are more feasible, have known reliability and performance characteristics, and more closely reflect the aims of the medical home, including care integration.

CONCLUSIONS: Measures of health care integration as captured by the experience of care in a medical home can best be assessed for state-level performance through patient/family experience surveys. Better measures of care integration, care coordination, and integration of mental, developmental, and physical health into a comprehensive care system are high-priority topics for measure development.

KEYWORDS: integrated health care; medical home

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THE QUALITY PROVISIONS of Public Law 111-3, the Children's Health Insurance Program Reauthorization Act, under Title IV, Section 401(a), require identification of a core set of health care quality measures for a specified set of topics for children enrolled in Medicaid and Children's Health Insurance Program (CHIP). The legislation specifies that this measurement set should enable states to report on "the quality of children's health care under such titles across the domains of quality, including clinical quality, health care safety, family experience with health care, health care in the most integrated setting, and elimination of racial, ethnic, and socioeconomic disparities in health and health care."^{1(p123,stat73)}

This report was prepared to inform the Agency for Healthcare Research and Quality (AHRQ) National Advisory Council for Healthcare Research and Quality Subcommittee on Children's Healthcare Quality Measures for Medicaid and CHIP Programs (SNAC) about potential measures of the "most integrated health care setting" for inclusion in its recommendations for an initial core measurement set. Based on the short time available for identification and assessment of measures, a preliminary finding that no direct measures of care integration were suitable for Children's Health Insurance Program Reauthorization Act (CHIPRA) use, and the salience of the medical home concept to the SNAC, AHRQ, and Centers for

Medicare & Medicaid Services (CMS), this report focuses on measures of the patient-centered medical home as an example of a “most integrated health care setting.”

CONCEPTUAL FRAMEWORK FOR ASSESSING CARE INTEGRATION AND THE MEDICAL HOME

Health care delivery in the United States is fragmented.^{2,3} Most providers work independently without adequate access to information from others. Changes in insurance impair continuity. Behavioral health operates parallel to physical health services. For children with special health care needs, overlapping programs exist. State-level responsibilities are frequently divided among multiple agencies.

This fragmentation makes achieving the 6 aims for health care (safety, effectiveness, efficiency, equity, timeliness, and patient centeredness) difficult.² Fragmentation impedes safety and effectiveness when information is not promptly transmitted; decreases patient centeredness by increasing the burden on families; impairs efficiency by fostering duplication of effort; and results in delay. Because of this cross-cutting impact, the Institute of Medicine (IOM) now considers coordination a key attribute of quality (“Ensure patients receive well-coordinated care within and across all health care organizations, settings, and levels of care”^{4(p9)}), joining the long-standing objective established by the Division of Special Health Care Needs of the Maternal and Child Health Bureau that “Services for children with special health care needs and their families will be organized in ways that families can use them easily.”⁵ Integration is “the combining and coordinating of separate parts or elements into a unified whole.”⁶ It is a somewhat broader concept than coordination, which is “the harmonious functioning of parts for effective results.”⁷

Two broad strategies, with some conceptual overlap, have been used to promote health care integration. One is the creation of integrated delivery systems, with a single organization encompassing different elements of the continuum of care—primary, specialty and home care, acute care, rehabilitation care, and long-term hospital care (vertical integration). Perhaps because organizational consolidation does not necessarily entail establishing systems for coordination and communication, these integrated delivery systems as a whole have not been found to have a consistent relationship to functional integration or other dimensions quality of care, although certain integrated delivery systems are considered models of high-performing health care.^{3,8–10}

Another complementary strategy to make whole or integrate the different elements of the health care system is to strengthen the capabilities of a single site whose purpose includes both provision of comprehensive care when possible and active coordination of that care when multiple providers, sites, and programs need be engaged. The IOM Committee on the Future of Primary Care defined primary care as “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the

context of family and community.”^{11(p15)} In 2002, the American Academy of Pediatrics (AAP) defined a medical home as care that is accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.¹² AAP reaffirmed this policy statement in 2008.¹³ The AAP policy statement highlights provision of care by a “designated physician.” However, we use a broader concept to incorporate personal physician or nurse. Table 1 lists the desirable characteristics of a medical home, replicated from the AAP policy statement of 2002. Similarly, the Joint Principles of the Patient Centered Medical Home emphasize that care is coordinated and/or integrated and that the site provides a whole person orientation.¹⁴ Primary care as formulated in the family/patient-centered medical home emphasizes its role in care management and coordination of health care delivery, and thus approaches the concept of integration.

At the initial meeting of the SNAC, the committee directed the research team to focus on measurement of the medical home as a specific approach to measuring care integration. The specific objective of this article is to identify the current state of measures for the medical home as a basis for recommendations to include in the initial core set of quality measures for Medicaid and CHIP programs, as well as to identify opportunities to further develop and improve quality measurement of integration.

METHODS

We initially undertook a search of PubMed and Medline to identify measures of integration. After identifying a limited set of measures that assessed organizational integration (eg, sharing common business office functions),¹⁵ we focused our subsequent research on identifying existing measures of the patient-centered medical home. To do so, we undertook searches of PubMed and Medline bibliographic databases and conducted Web research of key public and private health care–related agencies and foundations, initiatives, and professional associations (including AHRQ); AAP; Center for Healthcare Strategies (CHCS); Center for Medical Home Improvement (CMHI); Commonwealth Fund; IOM; Maternal and Child Health Bureau; National Academy for State Health Policy; National Center for Medical Home Implementation; National Committee for Quality Assurance (NCQA); National Quality Measures Clearinghouse; National Quality Forum (NQF); and Patient Centered Primary Care Collaborative. Terms used in the search included: integrated care, integrated delivery system, family-centered and patient centered medical home, care coordination, comprehensive care, care transition, care planning, integration of mental health and primary care, chronic care management, referral management, child health, and quality measures.

We applied definitions of validity, reliability, and feasibility consistent with the definitions used by the SNAC.¹⁶ Specifically, validity was assessed by comparing the elements assessed through the instrument against the criteria (adopting the second component of the SNAC’s definition—the measure should truly assess what it

Table 1. Desirable Characteristics of a Medical Home***Accessible**

- Care is provided in the child's or youth's community.
- All insurance, including Medicaid, is accepted.
- Changes in insurance are accommodated.
- Practice is accessible by public transportation, where available.
- Families or youth are able to speak directly to the physician when needed.
- The practice is physically accessible and meets Americans With Disabilities Act 10 requirements.

Family Centered

- The medical home physician is known to the child or youth and family.
- Mutual responsibility and trust exists between the patient and family and the medical home physician.
- The family is recognized as the principal caregiver and center of strength and support for child.
- Clear, unbiased, and complete information and options are shared on an ongoing basis with the family.
- Families and youth are supported to play a central role in care coordination.
- Families, youth, and physicians share responsibility in decision making.
- The family is recognized as the expert in their child's care, and youth are recognized as the experts in their own care.

Continuous

- The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood.
- Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the child or youth and family.
- The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.

Comprehensive

- Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.
- Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.
- Preventive care is provided that includes immunizations, growth and development assessments, appropriate screenings, health care supervision, and patient and parent counseling about health, safety, nutrition, parenting, and psychosocial issues.
- Preventive, primary, and tertiary care needs are addressed.
- The physician advocates for the child, youth, and family in obtaining comprehensive care and shares responsibility for the care that is provided.
- The child's or youth's and family's medical, educational, developmental, psychosocial, and other service needs are identified and addressed.
- Information is made available about private insurance and public resources, including Supplemental Security Income, Medicaid, the State Children's Health Insurance Program, waivers, early intervention programs, and Title V State Programs for Children With Special Health Care Needs.
- Extra time for an office visit is scheduled for children with special health care needs, when indicated.

Coordinated

- A plan of care is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the care of the patient.
- Care among multiple providers is coordinated through the medical home.
- A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.
- The medical home physician shares information among the child or youth, family, and consultant and provides specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals.
- Families are linked to family support groups, parent-to-parent groups, and other family resources.
- When a child or youth is referred for a consultation or additional care, the medical home physician assists the child, youth, and family in communicating clinical issues.
- The medical home physician evaluates and interprets the consultant's recommendations for the child or youth and family and, in consultation with them and subspecialists, implements recommendations that are indicated and appropriate.
- The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.

Compassionate

- Concern for the well-being of the child or youth and family is expressed and demonstrated in verbal and nonverbal interactions.
- Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth.

Culturally Effective

- The child's or youth's and family's cultural background, including beliefs, rituals, and customs, are recognized, valued, respected, and incorporated into the care plan.
- All efforts are made to ensure that the child or youth and family understand the results of the medical encounter and the care plan, including the provision of (para)professional translators or interpreters, as needed.
- Written materials are provided in the family's primary language.

Physicians should strive to provide these services and incorporate these values into the way they deliver care to all children. (Pediatricians, pediatric medical subspecialists, pediatric surgical specialists, and family practitioners are included in the definition of "physician.") Although the AAP Policy Statement highlights provision of care by a "designated physician," we use a broader concept to incorporate personal physician or nurse.

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purports to measure) for the medical home as defined by the AAP.^{12,13} Reliability refers to the consistency in arriving at the same conclusion either across time or across reviewers, or, more technically, the degree to which the measure is free from random error. Because

the legislation required measures be developed for voluntary use by state Medicaid and CHIP programs, health plans, and providers, and required that state program data be reported to Congress, our definition of feasibility emphasized the ease and cost of applying the

measure in the context of use by state Medicaid and CHIP programs. As stated in the SNAC report,¹⁶ a measure will be considered feasible if: 1) the data necessary to score the measure are available to state Medicaid and CHIP programs, and 2) detailed specifications are available for the measure.

RESULTS

Measures reviewed include the following: the Physician Practice Connections—Patient-Centered Medical Home (PPC-PCMH), a survey tool developed by the NCQA to assess the structure or the capabilities of a practice via a self-assessment of whether structures and processes are in place that would enable the practice to function in a manner consistent with the goals of the patient centered medical home; the Medical Home Index (MHI), developed to identify structures and processes of a medical home as a part of the improvement process for a physician practice, along with a partner measure; the Medical Home Family Index (MHFI), which was developed to measure and incorporate family experiences of care; the National Survey of Child Health (NSCH)/National Survey of Children with Special health Care Needs (NSCSHCN); the Consumer Assessment of Healthcare Providers and Systems (CAHPS)—Child; the Primary Care Assessment Tool (PCAT); and the Parent's Perceptions of Primary Care (P3C) tool. A summary comparison is provided in Table 2.

NCQA's PPC-PCMH

The NCQA PPC-PCMH is an auditable self-report by practices assessing whether systems and processes are in place that the developers assert will lead to care consistent with the medical home framework. The practice is assessed against 9 standards: access and communication, patient tracking and registries, care management, patient self-management support, electronic prescribing, test tracking, referral tracking, performance reporting and improvement, and advanced electronic communications.¹⁷ Overall performance is scored and categorized into 3 levels. This 3-level scoring implicitly acknowledges that, for most practices, meeting these reporting standards will be a staged process.

The standards of the PPC-PCMH were aligned with the Joint Principles of the Medical Home¹⁴ and the measure has been endorsed by American Academy of Family Physicians (AAFP), American College of Physicians (ACP), American Osteopathic Association (AOA), and the AAP for use in demonstration projects. NCQA led a rigorous process with a team of experts to identify the best available empirical evidence in the areas of medical home, patient-centered care, cultural competence, and the chronic care model to identify core elements and items that are actionable by a physician practice. The PPC-PCMH has also been endorsed as a medical home measure by the NQF.¹⁸

The PPC-PCMH contains 166 items, of which 46% assess practice report of their use of information technology, 14% assess care for 3 specific chronic diseases the practice identifies as important to their patient panel, 13% reflect systems for coordinating care, 9% assess accessibility, 5% relate to

performance reporting, and 4% are about tools for organizing clinical data. Use of nonphysician staff and collection of data on patient's experience of care are each reflected in 2% of items, and 1% of items represent each domain of preventive service delivery, continuity of care, and patient communication preferences.¹⁷

Although the tool captures the practice's capacity for chronic care management, care plans, and guidelines, as now constructed, it does not address the comprehensiveness of care or capture information on processes of coordination and communication between primary care and specialists; nor does it emphasize the patient and family centeredness of care or the role of coordination with community resources and services.*

It places substantial emphasis on the presence of systems such as electronic health records and the function of those systems, such as electronic prescribing.¹⁹ High scores reflect the presence of these systems and their self-reported use (eg, report use of a registry system to track performance) rather than documenting processes of care (eg, the proportion of patients receiving a particular treatment or the actual proportion of patients with a condition tracked through a registry system) or outcomes (blood pressure levels, hemoglobin A1C, growth, function). NCQA drafted a plan for the evolution of the PPC-PCMH to address many of these concerns, including ways to assess patient centeredness, capture the experience of the patient/family, and measure the relationships with specialists, hospitals, and community organizations.²⁰

The AAP has developed a crosswalk between the NCQA PPC-PCMH Recognition Program key elements and building blocks of a tool kit to support the development of a pediatric medical home. For example, while adult and family practices might focus on chronic care management on conditions such as arthritis, cardiovascular disease, cancer, diabetes, hypertension, and obesity, pediatric practices may focus on chronic care management of attention deficit disorder, asthma, and obesity.

In terms of validity, the PPC-PCMH measure addressed 4 of 6 elements of the AAP Medical Home concept, although whether self-assessment by a practice of the presence of systems translates into actual performance is unknown. In terms of reliability, one study using the Physician Practice Connections Readiness Survey, a predecessor to the PPC-PCMH, found agreement with on-site audits varied by type of respondent ranging from 40.9% to 96.7% among lead physicians and from 33.9% to 81.9% for reports from other medical office staff, and varied by type of items as well.²¹

*On January 31, 2011, NCQA published new standards for Patient-Centered Medical Home for 2011 (PCMH 2011), which include increased attention to coordination across primary care and specialists, integration of behavioral health and primary care, meaningful use, and quality improvement; it also expands patient-centered components. An optional module of Recognition in Patient Experience is also included. This module proposes use of a medical home version of the CAHPS Clinician & Group Survey—Child Version (currently in development and field testing). This report focuses on the components of the PPC-PCMH version that was available at the time the SNAC convened (summer 2009).

Table 2. Comparison of Current Medical Home Measures on Purpose, AAP Characteristics of Medical Home, Source, Format, Length, and Use*

	CAHPS	NSCH	PPC-PCMH	MHI	MHFI	PCAT	P3C
Purpose	Assess experiences of care and measure how parents perceived actions by health care providers and dimensions of the medical home	Survey parent experiences of care and components of the medical home	Measure practice structures and capacity of the Medical Home	Measure practice capacity and facilitate change and quality improvement	Assess outcomes of medical homeness through parent experiences of care	Measure experiences of quality of primary care	Measure pediatric primary care quality
AAP characteristics of medical home	Measure incorporates elements of accessible, family centered, comprehensive, coordinated, compassionate, and culturally effective	Measure incorporates elements of family-centered, comprehensive, coordinated, compassionate, and culturally effective	Measure incorporates elements of accessible, family centered, coordinated, and culturally effective. (The 2011 Standards expand measure of coordination between primary care and specialists, coordination with community resources, and increasing patient-centered components).	Measure incorporates elements of family centered, continuous, comprehensive, coordinated, and culturally effective	Measure incorporates elements of accessible, family centered, coordinated, compassionate, and culturally effective	Measure incorporates elements of family centered, continuous, coordinated, compassionate, and culturally effective	Measure incorporates elements of accessible, family centered, comprehensive, coordinated, and culturally effective
Source	Parent	Parent	Clinical and Office Staff	Clinical and Office Staff	Parent	Clinical and Office Staff Parent	Parent
Type of measure (structure, process, and/or outcome)†	Process and outcome	Process and outcome	Structure and process	Structure and process	Process and outcome	Structural, process and outcome	Process and outcome
Format	Interview and self-administered	Interview and phone administered	Self-administered	Self-administered	Self-administered	Interview or self-administered	Self-administered
Length	54 items	41 plus demographic and developmental items	166 items	25 items	38 items	153 items 121 items	23 items
Current use	Surveys of experiences of care, including medical home components, measuring health plans, state Medicaid programs; Medical Home measure at practice level using CAHPS Clinician and Group Version in development	Survey of experiences of care—national and state trends	NCQA PCMH recognition program and measure of medical home demonstration projects	Quality improvement projects in pediatric practices	Quality improvement projects in pediatric practices	Research of primary care quality	Assess primary care quality with different groups

*Data included information from Malouin RA, Merten SL. *Measuring Medical Homes: Tools to Evaluate the Pediatric and Family-Centered Medical Home*. National Center for Medical Home Implementation. Elk Grove Village, Ill: American Academy of Pediatrics; 2010. Available at: <http://www.medicalhomeinfo.org/downloads/pdfs/MonographFINAL3.29.10.pdf>. Accessed August 5, 2010. AAP = American Academy of Pediatrics; CAHPS = Consumer Assessment of Healthcare Providers and Systems; NSCH = National Survey of Child Health; PPC-PCMH = Physician Practice Connections—Patient-Centered Medical Home; MHI = Medical Home Index; MHFI = Medical Home Family Index; PCAT = Primary Care Assessment Tool; P3C = Parent's Perceptions of Primary Care.

†Definitions used for structure, process, and outcomes are as follows: *structure of care* is a feature of a health care organization or clinician relevant to its capacity to provide health care; *process of care* is a health care service provided to, on behalf of, or by a patient; and *outcome of care* is a health state of a patient resulting from health care and patient experiences of care.

Recommendations in a report for the Patient Centered Primary Care Collaborative²² suggest the PPC-PCMH might be used as one of a number of performance measures by a purchaser—eg, the percentage of children enrolled in Medicaid and CHIP who have had a primary care visit by a physician practice recognized by PPC-PCMH level 1, 2, and 3, respectively. However, although the tool is widely used in medical home demonstration programs,²³ a priori considerations raise concerns about the feasibility of the use of the PPC-PCMH for routine use by states in assessing quality of care for children. The data are time and resource intensive to collect and primarily are self-reported by practices, subject to audit. Few states have reliable mechanisms of assigning Medicaid and CHIP beneficiaries to specific practices, which would be necessary to link to practice certification. Additionally, although a growing number of practices are pursuing NCQA recognition through the PPC-PCMH, the absolute number of certified practices that serve children is still exceedingly small. Thus, although states could deem practices as medical homes consistent with a particular level of performance on the assessment, they would not at this time be able to determine the proportion of children who receive their care in a medical home.

MHI AND MHFI

The Center for Medical Home Improvement developed a model of medical home improvement for primary care to better meet the needs of children with special health care needs (CSHCN). Central to this model, the MHI is a tool developed to determine the extent to which a practice follows care processes, consistent with the criteria for the medical home.^{24,25} Construct validity was developed by a team of experts on medical home and pilot tested on over 40 practices. The measure was demonstrated to have strong interrater reliability and internal consistency.²⁴ Practices that scored higher on the MHI have demonstrated fewer hospitalizations and lower emergency department use among their patients.²⁶ This MHI enables practices to undertake a self-assessment along components of the medical home across 6 domains, including organizational capacity, chronic condition management, care coordination, community outreach, data management, and quality improvement. Items assess processes related to access, continuity, coordination, community outreach, family-centered care, and one item of cultural competence. Each item has multiple ($n = 4$) levels of response, each of which is specified with detailed text. For example, one item under care coordination ranges from level 1 (“family coordinates care without specific support; they integrate office recommendations into their child’s care”) to level 4 (“staff offer a set of care coordination activities; their level of involvement fluctuates according to family needs/wishes. A designated care coordinator ensures the availability of these activities including written care plans with ongoing monitoring”).

The Center for Medical Home Improvement developed a companion instrument, the MHFI, to incorporate a process and outcome measure of parent experiences of

care. The MHFI captures parent experiences of the organizational capacity, chronic condition management, and care coordination at the practice. One study found an association between the MHI and child health outcomes (hospitalization and emergency department use).²⁶ Neither of 2 studies found an association of MHFI measures of medical home characteristics with these outcomes.^{26,27}

Despite evidence for validity (both criterion and predictive) and reliability, substantial obstacles remain to the MHI’s widespread use in state level quality assessment. The use of the MHI has been limited to measuring the care of CSHCN (an adult tool has also been developed). The same logistical concerns raised in considering the PPC-PCMH tool also apply to the use of this tool in the context of the initial core measures, ie, the attribution of patients to practices at a state level and the reliability in common use (as opposed to research settings).

The Family MHI has been subject to far less testing than other consumer survey assessments, and applies to a narrower population. These other surveys are reviewed below.

PROCESS AND OUTCOME MEASURES: FAMILY EXPERIENCES OF MEDICAL HOME

Consumer (for children, parent) surveys enable respondents to report their perception of integration and coordination.²⁸ Consumer surveys capture patient reports of care processes (ie, whether an event took place) as well as reports of patient experience including ratings of care and potentially of patient outcomes (such as satisfaction with care or pain).

We identified 2 surveys that have been specifically applied to the assessment of the medical home, the NSCH/NSCSHCN and the CAHPS Health Plan Survey—Child.²⁹ A comparison of the items and components of the medical home is provided in a [Supplementary Table](#).

We also identified 2 other tools measuring parent experiences of primary care that were developed on the basis of the IOM definition of primary care, which is broadly consistent with the AAP dimensions of the medical home. These are the PCAT and the P3C.

NSCH AND NSCSHCN

Details of development and standardization of the NSCH and the NSCSHCN, as well as the survey data, are available online (<http://www.nschdata.org>; <http://childhealthdata.org>; <http://www.cahmi.org>). A medical home composite score is derived from 19 items of the survey that assess 5 of the 7 components of the medical home as defined by the AAP.¹² The composite measure for medical home includes personal doctor or nurse, usual source of care, family-centered care, access to needed referrals, and care coordination. To qualify as having a medical home, a child must have a personal doctor or nurse and meet the criteria for adequate care on every needed component. The NSCH also incorporates items measuring a parent’s experience of culturally effective care. Although items and composites of the medical home from earlier versions of the NSCH and NSCSHCN diverged to highlight specific population needs, the items on the 2 national surveys have now been harmonized. The

Supplementary Table includes a list of specific items measuring dimensions of the medical home using these surveys. Methodology and specification of the data and composite scores for a medical home measure have been well documented in a manual for the NSCH.³⁰ This measure has been endorsed by the NQF.³¹

CAHPS—CHILD

The CAHPS survey instrument represents another widely used measure of experiences of care. Items from the survey are also grouped together to measure experiences of integration of care as defined in the medical home. The CAHPS development process began in 1995 and has been led by an AHRQ-funded research consortium including Harvard Medical School, RAND, the Research Triangle Institute, American Institute of Research, Yale University School of Public Health, and Westat. All CAHPS surveys go through a thorough and rigorous development process including the instrument itself, as well as the protocol for fielding the survey and the analysis and reporting of data. All survey instruments are tested with different consumers and/or patient groups including cognitive testing to confirm that survey respondents understand and use the questionnaire as intended; findings from the testing are utilized to make improvements in wording. Access to survey instruments, including sampling and scoring, and the benchmarking database is available online (<https://www.cahps.ahrq.gov/default.asp>).

The CAHPS Health Plan Survey 4.0 (all versions) and the Clinician & Group Survey 1.0 (all versions) have been endorsed by the NQF. NCQA's Committee on Performance Measurement has also accepted the CAHPS Health Plan Survey 4.0. However, there are limited data on psychometric properties of these dimensions, as now constituted, reported in the peer-reviewed literature. The composites of the CAHPS Health Plan Survey have been designed and tested with internal consistency reliability of 0.70 or greater.³² Data on the testing of reliability of composites from the CAHPS Clinician and Group Survey have also been found to be consistent with these findings (Detailed information and review on the CAHPS Clinician & Group Survey measures are presented in the report from Co, Sternberg, and Homer on "Measuring Patient and Family Experiences of Health Care for Children" in this supplement).³³

The CAHPS Health Plan Survey 4.0 Child Medicaid Questionnaire includes similar, but not precisely identical, items to capture measures of the dimensions of the medical home.³¹ Core items of the CAHPS Health Plan Survey 4.0 Child Medicaid Questionnaire for measuring a medical home include 3 of the composite scores: Getting Needed Care and Getting Care Quickly, which measure access, and How Well Doctors Communicate, which represents a component of family centered care.

Item sets for children with chronic conditions have been incorporated into this version, and its administration is recommended for all children (Dale Shaller, MPA, Principal, Shaller Consulting, Managing Director, National CAHPS Benchmarking Database, January 2010, personal communication). These items include measures of Parents'

Experience With Getting Needed Information About Their Child's Care; Parents' Experience With the Child's Personal Doctor or Nurse; Parents' Experience With Shared Decision-making; Coordination of Care; and Parents' Experience With Getting Prescription Medicines. Supplemental items include measuring experiences of culturally effective care. A list of specific items of the CAHPS Health Plan Survey 4.0 used to measure dimensions of the medical home is included in a Supplementary Table.

Although the CAHPS Health Plan Survey measures many of the dimensions of medical home, the items on getting specialized services does not provide a measure of whether children receive developmental screenings and assessments, whether the specialists and primary care providers communicate with each other, or whether there is a shared unified care plan for CSHCN. Additionally, the measure only touches on the broader concepts of integration with the community (eg, help with getting counseling and coordination with school). These topics will be included in the CAHPS Clinician and Group Survey for Medical Home (still in development and field testing).

PCAT

The PCAT—Child is another measure developed to assess the quality of primary care for children.^{34,35} The tools are organized around the primary dimensions of primary care. The instrument assesses first contact care (accessibility and utilization), continuity, comprehensiveness, and coordination. Additionally, there are scales for family centeredness, community orientation, and cultural competence. These components and scales are consistent with the dimensions of the medical home. An initial study published findings of good general reliability and validity on the primary dimensions for the child version, though the psychometric properties of the supplemental scales were questionable.³⁴ In addition to the child edition, there is also a facility/provider survey, and a survey for health systems is in development. A manual has been developed that details standardization for administration and scoring.³⁵ The PCAT has largely been interviewer administered, though a self-administration version of the tool is available. No current studies are available that detail or study how the facility/provider and the child surveys can be used to measure medical home from the different perspectives.

The PCAT has been used in research settings and for program assessment and improvement, though the measure has not been widely used by states for accountability purposes (although it has been applied to assess delivery of primary care in specific programs, such as Florida's Children's Medical Services).

P3C

The P3C is a tool, developed by Michael Seid and the Center for Child Health Outcomes and Children's Hospital and Health Center at San Diego, California, to measure experience of quality pediatric primary care based on the IOM definition.³⁶ Study demonstrated good internal consistency, reliability, and validity. The components of P3C are also consistent with the dimensions of the medical

home. No studies of large scale use and broader application to medical home or integration of care have been published to date.

FEASIBILITY OF CONSUMER SURVEY APPROACH

Established processes and procedures exist for the administration of consumer surveys on a population wide level (eg, NSCH or NSCSHCN). Surveys are also commonly administered at a plan level. The same feasibility concerns exist in attributing patients to individual practices, but an assessment of the overall level to which patients (children) experience the attributes of the medical home in general or the care coordination and integration elements in particular is feasible through existing survey mechanisms. Although feasible, surveys are considered expensive and obtaining high levels of response in Medicaid populations is a particular challenge.³³

MEASURES IN DEVELOPMENT

Substantial activity is already underway to develop more defined process and outcome measures that will strengthen this area substantially over the next several years. A Patient-Centered Medical Home version of the CAHPS Clinician and Group Survey is currently in development and field testing.³⁷ NCQA is developing a measurement set that will look specifically at the area of care coordination, care planning, and referral management.^{38,39} NQF also solicited measures related to care coordination⁴⁰ and has recently endorsed a composite measure by Child and Adolescent Health Measurement Initiative of receiving effective care coordination when needed.⁴¹

To better address the concept of whole person integration in care, NCQA is field testing a more comprehensive measurement approach to primary care for children with an emphasis on prevention and whole child and family orientation.

DISCUSSION AND RECOMMENDATIONS

We found 2 broad, and likely complementary, approaches to measurement of medical home: practice self-assessment of systems, and reported processes and consumer (parent) reporting of their experiences of the processes and outcomes of care.

Both the PPC-PCMH and MHI instruments capture important elements of the pediatric medical home as defined by the AAP. The MHI measure hews more closely to the criteria but is more narrowly focused on children and youth with special health care needs alone (consistent with the initial framing of the medical home concept). One cross-sectional study supports an association of the MHI score with risk of hospitalization or emergency department use; no study yet supports such an association for the PPC-PCMH in children. Preliminary reports of Patient Centered Primary Care Collaborative demonstration projects indicated positive results for practices with PPC-PCMH recognition for adults.⁴² However, reliability of these measures as they would be applied in practice is inconsistent.²¹ Feasibility concerns mitigate against recommending the immediate

use of either of these measures for state level assessment of quality of care for children. Practices report that the effort entailed in undertaking the PPC-PCMH assessment is substantial. Few states have the capability of assigning Medicaid and CHIP patients to particular practices, particularly in fee for service settings. Very few sites caring for children have undergone PPC-PCMH certification.

Data from the NSCH and CAHPS Health Plan Survey 4.0 Child Medicaid Questionnaire are already available for many states, and the samples can be expanded to capture subgroups or to track performance over time.

In comparing the 2 surveys (NSCH and CAHPS Health Plan Survey 4.0–Child Medicaid Survey), each has strengths and drawbacks. Both capture many similar items and dimensions of the medical home (Supplementary Table). The CAHPS Health Plan Survey 4.0 Child Medicaid Questionnaire provides more items inquiring about the parent's experience of different aspects of family centered care and access. Although both surveys have extensive detailed instructions on sampling, administration, coding, and reporting, and they have been found to be useful as measures of a medical home, detailed specification on use of data for a medical home measure has been documented into a manual only for NSCH.³⁰ Data on the medical home measure using the NSCH are already reported on a state-by-state basis,⁴³ but the samples are small, and it is administered at infrequent intervals. The CAHPS measure is in much wider use. Preliminary 2009 data indicated Medicaid plans in at least 25 states—representing care for over 68 000 children—already use the CAHPS Health Plan Survey 4.0 Child Medicaid Questionnaire,⁴⁴ although not all of those states may have included the Children with Chronic Conditions item set, which is important to measurement of medical home. (Use of this item set is recommended going forward.) The 2009 CHIPRA legislation also mandates use of CAHPS in Medicaid and CHIP.

The much wider and more frequent administration of CAHPS, as well as the requirement for the use of CAHPS elsewhere in the CHIPRA legislation, makes the use of this survey to assess “most integrated setting” more feasible. The application of the CAHPS survey for this purpose would be strengthened by the development of a manual for use of the CAHPS Health Plan Survey for measuring dimensions of the medical home, similar to that developed by Bethell and colleagues for the NSCH.³⁰ Additional studies providing cross-validation with other measures would also be desirable. The CAHPS Benchmarking Database and NCQA have been working together to minimize differences; nonetheless small difference in protocols, analysis, and reporting still exist (eg, CAHPS adjusts scores for differences in case mix, whereas NCQA does not do a case mix adjustment).⁴⁵ Going forward, for the purposes of comparability of scores for Medicaid and CHIP across states, using one set of standards would be beneficial.

LIMITATIONS

This report has substantial limitations. Although we sought to be comprehensive in our initial identification of measures of integration, we may have failed to identify

such instruments. Because we were asked to identify measures ready for use, we did not explore bundles of measures now being assembled as the concept of “accountable care organizations” is evolving to capture the dimension of integration. We did not have opportunity to explore measures that considered the integration of mental and physical health services, another dimension of integration that we view as important.

Several overlapping criteria for medical home exist, including the original AAP criteria, the Joint Principles, the dimensions highlighted by AHRQ and others. A comprehensive review would have assessed these criteria against all.

We contacted numerous experts in the development of this review; however, because our contacts were not systematic and we did not use a formal protocol for these interviews, we have not included their assessments and recommendations in this report.

Finally, this field is evolving so rapidly that the instruments, measures, and data available at the time of our initial assessment and recommendations will no longer accurately capture the state of the art of the field. Nonetheless, given constraints imposed by the requirements of the CHIPRA legislation and its rapid implementation by CMS and AHRQ, the methods were suitable to the task at hand.

CONCLUSION

Good evidence supports the value of the delivery of care to children through the medical home.⁴⁶ For the short term, we recommend the use of the consumer survey–based measures of medical home as can be derived from CAHPS and the NSCH. Yet the medical home, of itself, is likely only a partial solution (albeit a critically important one) to the delivery of care in the most integrated health care setting. Measurement of a medical home at best is an indirect indicator of whether care is integrated, ie, whether the patient and family experience care as a whole and whether it strengthens their capabilities as whole people. Further measure development should focus on improved and more specific measures of care coordination and integration both across the health care system and between health care and community systems; better measures of integration of mental, developmental, and physical health into a comprehensive whole system; and composite measures that build on the systems assessments embodied in approaches such as the MHI and PPC-PCMH together with measures of consumer experience and care processes and outcomes.

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REFERENCES

1. Public Law 111-3. Children’s Health Insurance Program Reauthorization Act of 2009, Title IV, Sec 401. Available at: http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111_cong_public_laws&docid=f:pub1003.111.pdf%20%2C%20A0. Accessed March 1, 2010.
2. Institute of Medicine. Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press; 2001.
3. Shih A, Davis K, Schoenbaum S, et al. *Organizing the US Health Care Delivery System for High Performance*. New York, NY: The Commonwealth Fund; August 2008.
4. National Priorities Partnership. *National Priorities and Goals: Aligning Our Efforts to Transform America’s Healthcare*. Washington, DC: National Quality Forum. Available at: <http://www.nationalprioritiespartnership.org/ShowContent.aspx?id=886>; 2008. Accessed January 2, 2010.
5. Maternal and Child Health Bureau. *Achieving and Measuring Success: A National Agenda for Children With Special Health Care Needs*. Available at: <http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>. Accessed March 1, 2010.
6. Dictionary.com. Integration. Available at: <http://dictionary.reference.com>. Accessed January 1, 2010.
7. Merriam-Webster.com. Coordination. Available at: <http://www.merriam-webster.com/dictionary/coordination>. Accessed January 28, 2011.
8. Burns LR, Pauly MV. Integrated delivery networks: A detour on the road to integrated health care? *Health Aff*. 2002;21:128–143.
9. Burns LR, Muller RW. Hospital-physician collaboration: landscape of economic integration and impact on clinical integration. *Milbank Q*. 2008;86:375–434.
10. Kautz CM, Gitell JH, Weinberg DB, et al. Patient benefits from participating in an integrated delivery system: impact on coordination of care. *Health Care Manage Rev*. 2007;32:284–294.
11. Institute of Medicine. In: Donaldson M, Yordy K, Vanselow N, eds. *Defining Primary Care: An Interim Report*. Washington, DC: National Academies Press; 1994.
12. Policy Statement. American Academy of Pediatrics. The medical home. *Pediatrics*. 2002;110:184–186.
13. American Academy of Pediatrics. AAP publications reaffirmed and retired, February and May 2008. *Pediatrics*. 2008;122:450.
14. American Academy of Family Physicians (AAFP), American Academy of Pediatrics (AAP), American College of Physicians (ACP), and American Osteopathic Association (AOA). Joint principles of the patient-centered medical home. March 2007. Available at: <http://www.medicalhomeinfo.org/joint%20Statement.pdf>. Accessed August 16, 2009.
15. Solberg LI, Asche SE, Shortell SM, et al. Is integration in large medical groups associated with quality? *Am J Manage Care*. 2009; 15:e34–e41.
16. Appendix A-8. Description of the Second Modified Delphi Process to Rate and Select Valid, Feasible, and Important Quality Measures. In Background Report for the Request for Public Comment on Initial, Recommended Core Set of Children’s Healthcare Quality Measures for Voluntary Use by Medicaid and CHIP Programs. December 2009. Rockville, Md: Agency for Healthcare Research and Quality. Available at: <http://www.ahrq.gov/chipra/corebackground/corebackapa8.htm>. Accessed January 28, 2011.
17. National Committee for Quality Assurance. Standards and guidelines for physician practice connections—patient-centered medical home (PPC-PCMH). 2008. Available at: <http://www.ncqa.org/tabid/631/Default.aspx>. Accessed March 1, 2010.
18. National Quality Forum. Medical Home System Survey. NQF endorsed standards. Available at: http://www.qualityforum.org/Measures_List.

- aspx#k=Medical%2520home&e=1&st=&sd=&s=&p=1. Accessed June 3, 2010.
19. Ginsburg P, Pham HH, O'Malley M, et al. Making medical homes work: moving from concept to practice. Center for Studying Health System Change. *Policy Perspective*. 2008;(1):1–20.
 20. National Committee for Quality Assurance. Planned evolution of PPC-PCMH requirements. 2009. Available at: <http://www.ncqa.org/tabid/631/Default.aspx>. Accessed March 1, 2010.
 21. Scholle SH, Pawlson LG, Solberg LI, et al. Measuring practice systems for chronic illness care: accuracy of self-reports from clinical personnel. *Jt Comm J Qual Patient Saf*. 2008;34:407–416.
 22. Bailit M, Hughes C. *The Patient Centered Medical Home: A Purchasers Guide*. Washington, DC: Patient Centered Primary Care Collaborative; 2008.
 23. Kaye N, Takach M. *Building Medical Homes in State Medicaid and CHIP Programs*. National Academy for State Health Policy. New York, NY: The Commonwealth Fund; June 2009.
 24. Cooley WC, McAllister JW, Sherrieb K, Clark RE. The Medical Home Index: development and validation of a new practice-level measure of implementation of the medical home model. *Ambul Pediatr*. 2003;3:173–180.
 25. Cooley WC, McAllister JW. Building medical homes: improvement strategies in primary care for children with special health care needs. *Pediatrics*. 2004;113:1499–1506.
 26. Cooley WC, McAllister JW, Sherrieb K, Kuhlthau K. Improved outcomes associated with medical home implementation in pediatric primary care. *Pediatrics*. 2009;124:358–364.
 27. McAllister JW, Sherrieb K, Cooley WC. Improvement in the family centered medical home enhances outcomes for children and youth with special healthcare needs. *J Ambul Care Manage*. 2009;32:188–196.
 28. Institute of Medicine. Committee on Quality of Health Care in America. *Envisioning the National Health Care Quality Report*. Washington, DC: National Academies Press; 2003.
 29. Bethell CD, Read D, Brockwood K. Using existing population-based data sets to measure the American Academy of Pediatrics definition of medical home for all children and children with special health care needs. *Pediatrics*. 2004;113:1529–1537.
 30. Child and Adolescent Health Measurement Initiative. Measuring medical home: using data elements from the National Survey of Children With Special Health Care Needs or the National Survey of Children's Health. 2008. Available at: <http://www.childhealthdata.org>. Accessed March 1, 2010.
 31. National Quality Forum. Measure of medical home for children and adolescents. Available at: <http://www.qualityforum.org/MeasureDetails.aspx?SubmissionId=84#k=Medical%2520home&e=1&st=&sd=&s=n&so=a&P=1&mt=&cs=>. Accessed February 1, 2011.
 32. CAHPS surveys and tools to advance patient-centered care. Available at: <https://www.cahps.ahrq.gov/default.asp>. Accessed March 1, 2010.
 33. Co JP, Sternberg SB, Homer CJ. Measuring patient and family experiences of health care for children. *Acad Pediatr*. 2011;11(suppl 3):S59–S67.
 34. Cassidy CE, Starfield B, Hurtado MP, et al. Measuring consumer experiences with primary care. *Pediatrics*. 2000;105(4 pt 2):998–1003.
 35. Starfield B, Shi L. *Manual for the Primary Care Assessment Tools*. Baltimore, Md: John Hopkins University; 2009.
 36. Seid M, Varni JW, Bermudez LO, et al. Parents' perceptions of primary care: measuring parents' experiences of pediatric primary care quality. *Pediatrics*. 2001;108:264–270.
 37. Consumer Assessment of Healthcare Providers and Systems. CAHPS Patient-Centered Medical Home Survey. Available at: https://www.cahps.ahrq.gov/content/products/CG/PROD_CG_PCMH.asp?P=1021&s=213. Accessed February 8, 2011.
 38. National Committee for Quality Assurance. NCQA 2009 programs and initiatives: case statement. Available at: http://www.ncqa.org/Portals/0/Sponsor/2009_Case_Statement.pdf. Accessed March 1, 2010.
 39. Scholle SH, Sampsel SL, Davis NEP, Schor EL. *Quality of Child Health Care: Expanding the Scope and Flexibility of Measurement Approaches*. New York, NY: The Commonwealth Fund; May 2009.
 40. National Quality Forum. Endorsing preferred practices and performance measures for measuring and reporting care coordination. Available at: http://www.qualityforum.org/projects/care_coordination.aspx#t=1&s=&p=. Accessed March 1, 2010.
 41. National Quality Forum. Children who receive effective care coordination of healthcare services when needed. Available at: <http://www.qualityforum.org/MeasureDetails.aspx?SubmissionId=116#k=care+coordination>. Accessed February 8, 2011.
 42. Grumbach K, Grundy P. *Outcomes of Implementing Patient Centered Medical Home Interventions: A Review of the Evidence from Prospective Evaluation Studies in the United States*. Washington, DC: Patient Centered Primary Care Collaborative; 2010.
 43. Child and Adolescent Health Measurement Initiative. National Survey of Children's Health Data Resource Center. Available at: <http://nschdata.org/DataQuery/DataQueryResultsAllStates.aspx?q=502&r1=999&r2=-1>. Accessed March 1, 2010.
 44. CAHPS Health Plan Survey database—survey respondents and health plan samples by state. Available at: https://www.cahps.ahrq.gov/CAHPSIDB/Public/Files/Doc3_Health_Plan_Samples_by_State_2009.pdf. Accessed March 1, 2010.
 45. The CAHPS Health Plan Survey database compared to NCQA Quality Compass. CAHPS Health Plan Survey Database—methodology. Available at: https://www.cahps.ahrq.gov/CAHPSIDB/Public/Files/Doc4_CAHPSHP_Methodology_Sep09.pdf. Accessed March 1, 2010.
 46. Homer CJ, Klatka K, Romm D, et al. A review of the evidence for the medical home for children with special health care needs. *Pediatrics*. 2008;122:e922–e937.

Supplementary Table. Comparison of Survey Items of NSCH, NS-CSHCN, and CAHPS Health Plan Survey 4.0 Child Medicaid Questionnaire to Assess the AAP Definitional Components of Medical Home*

Medical Home Components	2005–6 NS-CSHCN	2007 NSCH	CAHPS Health Plan Survey 4.0 Child Medicaid Questionnaire	CAHPS Health Plan Survey 4.0 Child Supplemental Items
Established relationship with a specific provider	C4Q02A: Child has <i>one or more</i> health care providers considered to be personal doctor or nurse	K4Q04: Child has <i>one or more</i> health care providers considered to be personal doctor or nurse (PDN)	9. A personal doctor is the one your child would see if he or she needs a check-up or gets sick or hurt. Does your child have a personal doctor?	PD2. Since your child joined this health plan, how often was it easy to get a personal doctor for him or her that you are happy with?
Accessible	(Not asked about in way defined via AAP definition of medical home)	(Not asked about in way defined via AAP definition of medical home)	14. Is your child able to talk with doctors about his or her health care?	In the last 6 months: T2. When you phoned your child's health plan to get help with transportation, how often did you get it? T3. How often did the help with transportation for your child meet your needs?
Family centered	During past 12 months, how often did all child's doctors and other health providers: C6Q02: Spend enough time with child? C6Q03: Listen carefully to parent? C6Q05: Provide needed information? C6Q06: Help parents feel like partner in child's care?	During past 12 months, how often did all child's doctors and other health providers: K5Q40: Spend enough time with child? K5Q41: Listen carefully to parent? K5Q43: Provide needed information? K5Q44: Help parents feel like partner in child's care?	In the last 6 months: CC1. How often did you have your questions answered by your child's doctors or other health providers? CC2. Did your child's doctor or other health provider tell you there was more than one choice for your child's treatment or health care? CC3. Did your child's doctor or other health provider talk with you about the pros and cons of each choice for your child's treatment or health care? CC4. When there was more than one choice for your child's treatment or health care, did your child's doctor or other health provider ask you which choice was best for your child? 11. How often did your child's personal doctor explain things in a way that was easy to understand? 12. How often did your child's personal doctor listen carefully to you? 13. How often did your child's personal doctor show respect for what you had to say? 15. How often did your child's personal doctor explain things in a way that was easy for your child to understand? 16. How often did your child's personal doctor spend enough time with your child?	In the last 6 months: C4. How often did your child's doctors or other health care providers make it easy for you to discuss your questions or concerns? C5. How often did you get the specific information you needed from your child's doctors or other health providers? H2. Did your child's doctor or other health provider tell you there was more than one choice for your child's treatment or health care? H3. Did your child's doctor or other health provider talk with you about the pros and cons of each choice for your child's treatment or health care? H4. When there was more than one choice for your child's treatment or health care, did your child's doctor or other health provider ask which choice you thought was best for your child?

(Continued)

Supplementary Table. Comparison of Survey Items of NSCH, NS-CSHCN, and CAHPS Health Plan Survey 4.0 Child Medicaid Questionnaire to Assess the AAP Definitional Components of Medical Home* (*Continued*)

Medical Home Components	2005–6 NS-CSHCN	2007 NSCH	CAHPS Health Plan Survey 4.0 Child Medicaid Questionnaire	CAHPS Health Plan Survey 4.0 Child Supplemental Items
Continuous Comprehensive Access to Care	<p>(Not asked about in survey)</p> <p><i>A) Referrals for specialist care</i></p> <p>During past 12 months:</p> <p>C5Q11: Needed a referral to see any doctors or receive any services?</p> <p>C4Q07: If yes, any problems getting the referral that was needed?</p> <p><i>B) Usual sources for care</i></p> <p>C4Q0A: Is there a place child usually goes when he/she is sick?</p> <p>C4Q0B: If yes, what kind of place is it?</p> <p>C4Q0D: Is there a place child usually goes for routine preventive care?</p> <p>C4Q01: If yes, Is this the same place that child goes for routine preventive care?</p> <p>C4Q02: If no, What kind of place does child go for routine preventive care?</p>	<p>(Not asked about in survey)</p> <p><i>A) Referrals for specialist care</i></p> <p>During past 12 months:</p> <p>K5Q10: Needed a referral to see any doctors or receive any services?</p> <p>K5Q11: If yes, any problems getting the referral that was needed?</p> <p><i>B) Usual sources for care</i></p> <p>K4Q01: Is there a place child usually goes when he/she is sick?</p> <p>K4Q02: If yes, what kind of place is it?</p>	<p>(Not asked about in survey)</p> <p>In the last 6 months:</p> <p>4. When your child needed care right away, how often did your child get care as soon as you thought he/she needed?</p> <p>6. Not counting the times your child needed care right away, how often did you get an appointment for health care at a doctor's office or clinic as soon as you thought your child needed?</p> <p>19. Did you try to make any appointments for your child to see a specialist?</p> <p>20. How often was it easy to get appointments for your child with specialists?</p> <p>24. In the last 6 months, how often was it easy to get the care, tests, or treatment you thought your child needed?</p> <p>CC9. In the last 6 months, how often was it easy to get special medical equipment or devices for your child?</p> <p>CC12. In the last 6 months, how often was it easy to get this therapy for your child?</p> <p>CC15. In the last 6 months, how often was it easy to get this treatment or counseling for your child?</p> <p>CC17. In the last 6 months, did your child's personal doctor talk with you about how your child is feeling, growing, or behaving?</p> <p>CC20. Does your child's personal doctor understand how these medical, behavioral, or other health conditions affect your child's day-to-day life?</p> <p>CC21. Does your child's personal doctor understand how your child's medical, behavioral, or other health conditions affect your family's day-to-day life?</p>	<p>In the last 6 months:</p> <p>H1. How often did you and your child's doctor or other health provider talk about specific things you could do to prevent illness in your child?</p> <p>20. How often was it easy to get appointments for your child with specialists?</p> <p>AH2. How often was it easy to get the after hours care you thought you needed for your child?</p> <p>CO2. When you phoned during regular office hours, how often did you get the help or advice you needed for your child?</p> <p>CO4. When you phoned after regular office hours, how often did you get the help or advice you needed for your child?</p> <p>WC4. Did you get an appointment for your child's visit for a check-up, or for shots or drops, as soon as you thought he or she needed it?</p> <p>In the last 6 months:</p> <p>AR1. Not counting the times your child needed health care right away, how many days did you usually have to wait between making an appointment and your child actually seeing a health provider?</p> <p>AR2. How often did your child have to wait for an appointment because the health provider you wanted him or her to see worked limited hours or had few available appointments?</p>

Coordinated	<p><i>A) Help with care coordination</i> During past 12 months: C5Q12: Does anyone help to arrange or coordinate child's care? C5Q17: Did family need extra help arranging or coordinating child's health care? C5Q09: If yes, how often got as much help as needed arranging or coordinating child's health care?</p> <p><i>B) Provider communication</i> C5Q10: How satisfied with communication between child's doctors and other providers? C5Q05: Needed doctors or other providers to communicate with child's school or other programs? C5Q06: If yes, how satisfied with that communication?</p>	<p><i>A) Help with care coordination</i> During past 12 months: K5Q20: Does anyone help to arrange or coordinate child's care? K5Q21: Did family need extra help arranging or coordinating child's health care? K5Q22: If yes, how often got as much help as needed arranging or coordinating child's health care?</p> <p><i>B) Provider communication</i> K5Q30: How satisfied with communication between child's doctors and other providers? K5Q31: Needed doctors or other providers to communicate with child's school or other programs? K5Q32: If yes, how satisfied with that communication?</p>	<p><i>A) Help with care coordination</i> CC7. In the last 6 months, did you get the help you needed from your child's doctors or other health providers in contacting your child's school or day care? CC18. In the last 6 months, did anyone from your child's health plan, doctor's office, or clinic help coordinate your child's care among these different providers or services? Did anyone from your child's health plan, doctor's office, or clinic help you get: CC10. Special medical equipment or devices for your child? CC13. Therapy [special therapy, such as physical, occupational, or speech] for your child? CC16. This treatment or counseling for your child (for an emotional, developmental, or behavioral problem)?</p> <p>(Addressed in the Family-Centered Care component questions)</p>	<p><i>A) Help with care coordination</i> In the last 6 months: H6/OHP2. How often did your child's personal doctor seem informed and up-to-date about the care your child got from these doctors or other health providers? OHP3. Did anyone from your child's health plan, doctor's office, or clinic help coordinate your child's care among these doctors or other health providers? OHP5. How satisfied are you with the help you got to coordinate your child's care? R1. How often was it easy to get a referral to a specialist that your child needed to see?</p> <p>(Addressed in the Family-Centered Care component questions)</p> <p><i>B) Language services</i> In the last 6 months: C1. How often did you have a hard time speaking with or understanding your child's personal doctor because you spoke different languages? C2. How often did your child have a hard time speaking with or understanding your child's personal doctor because you spoke different languages? I1. Did you need an interpreter to help you speak with your child's doctors or other health providers? I2. When you needed an interpreter to help you speak with your child's doctors or other health providers, how often did you get one? I3. Did your child need an interpreter to help you speak with your child's doctors or other health providers? I4. When your child needed an interpreter to help you speak with your child's doctors or other health providers, how often did your child get one?</p>	
Compassionate	(Addressed in the Family-Centered Care component questions)	(Addressed in the Family-Centered Care component questions)	(Addressed in the Family-Centered Care component questions)	(Addressed in the Family-Centered Care component questions)	
Culturally effective	<p><i>A) Respect for diversity</i> During past 12 months, how often were child's doctors and other health providers: C6Q04: Sensitive to family's values and customs?</p> <p><i>B) Language services</i> During past 12 months: S5Q13: Needed an interpreter to help speak with child's doctors or nurses? S5Q13A: If yes, how often able to get someone other than a family member to help speak with child's doctors or nurses?</p>	<p><i>A) Respect for diversity</i> During past 12 months, how often were child's doctors and other health providers: K5Q42: Sensitive to family's values and customs?</p> <p><i>B) Language services</i> During past 12 months: K5Q45: Needed an interpreter to help speak with child's doctors or nurses? K5Q46: If yes, how often able to get someone other than a family member to help speak with child's doctors or nurses?</p>			

*Source: Personal communication, Christine Bethel, Child and Adolescent Health Measurement Initiative, Oregon Health & Science University, 2009 and 2010.

NSCH = National Survey of Children's Health; NS-CSHCN = National Survey of Children with Special Health Care Needs; CAHPS = Consumer Assessment of Healthcare Providers and Systems; AAP = American Academy of Pediatrics.