

# Measuring Medical Homes

## Tools to Evaluate the Pediatric Patient- and Family-Centered Medical Home

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## LIST OF ABBREVIATIONS

AHRQ	Agency for Healthcare Research and Quality
ACES	Ambulatory Care Experiences Survey
AQA	Ambulatory Care Quality Alliance
AAFP	American Academy of Family Physicians
AAP	American Academy of Pediatrics
ACP	American College of Physicians
AMA	American Medical Association
AOA	American Osteopathic Association
CMHI	Center for Medical Home Improvement
CMS	Centers for Medicare and Medicaid Services
CAHMI	Child and Adolescent Health Measurement Initiative
CYSHCN	Children and youth with special health care needs
CCC	Children with Chronic Conditions Screener – 5-item, non-condition-specific screener developed by CAHMI and integrated into the CG-CAHPS
CSHCN	Children with special health care needs
CG-CAHPS	Clinician & Group - Consumer Assessment of Health Plans Study
CATCH	Community Access to Child Health program
COC	Components of Care
CPCI	Components of Primary Care Instrument
CAHPS®	Consumer Assessment of Health Plans Study
EHR	Electronic health record
FACCT	Foundation for Accountability – closed in 2004; activities now run by CAHMI
GPAQ	General Practice Assessment Questionnaire
GPAS	General Practice Assessment Survey
HIT	Health information technology
HRSA	Health Resources and Services Administration
IOM	Institute of Medicine
MCHB	Maternal and Child Health Bureau
MPOC	Measures of Processes of Care
MH	Medical home
MHFI	Medical home family index
MHI	Medical home Index
NCQA	National Committee for Quality Assurance
NDP	National Demonstration Project
NQF	National Quality Forum
NQMC	National Quality Measure Clearinghouse
NCRU	Neurodevelopmental Clinical Research Unit – McMaster University
P3C	Parent's perceptions of primary care
PCMH	Patient-centered medical home
PCPCC	Patient-centered primary care collaborative
PPC-PCMH™	Physician practice connections – patient-centered medical home
PCAS	Primary Care Assessment Survey
PCAT	Primary Care Assessment Tool
PHDS	Promoting Healthy Development Survey
PPC-PRS	Physicians Practice Connections Readiness Survey
RAND	Research And Development Corporation
RAPP	Research Association of Practicing Physicians
RBRVS	Resource-Based Relative Value Scale
S-CHIP	State Children's Health Insurance Program
YAHCS	Young Adult Health Care Survey

# Measuring Medical Homes:

## Tools to Evaluate the Pediatric Patient- and Family-Centered Medical Home

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The purpose of this monograph is to present various tools available and in use to identify, recognize, and evaluate a practice as a pediatric medical home. With increasing national interest in health care reform, the provision of medical homes for all is seen as a method to improve population health as well as reduce health inequities and health care expenditures. Because no one tool is recognized as the *de facto* tool to assess pediatric practices, a review of the relative merits of existing tools will help inform purchasers, payers, providers, and patients in evaluating pediatric practices. Many of the multistakeholder and single-payer medical home demonstration projects focus on adult populations and adult outcomes. An understanding of tools to assess pediatric practices may assist such pilots in incorporating and evaluating pediatric practices in both practice transformation and payment reform.

## Section I: The Patient- and Family-Centered Medical Home

### INTRODUCTION

Over the past 40 years, medical home has evolved from a place to store medical records of children with multiple health providers, to an approach to provision of primary care.<sup>1</sup> Primary care has been associated with decreased health care expenditures, improved population health, reduced disparities in health outcomes, and increased patient and family satisfaction with health care.<sup>2-15</sup> In an environment of rising health care costs, increasingly poor population health outcomes, and increasing dissatisfaction among healthcare providers, patients, and families, the medical home model is an attractive solution for increasing availability, quality, and payment for primary care services.

In pediatrics, medical home has been defined as “a headquarters or home base for care where the child and family feel comfortable in the health care process.”<sup>16</sup> The medical home concept has evolved into the patient- and family-centered medical home model. This model is

characterized by provision of patient- and family-centered primary care, innovations in practice, and payment reform.<sup>17</sup> With an exponential increase in medical home demonstrations with associated novel payment structures, evaluation of the demonstration projects is imperative to identify the most successful medical home model.<sup>18</sup> Measurement criteria for the effectiveness of interventions to transform practices, determine the degree of “medical homeness” achieved by a practice, and assess outcomes and impact are greatly needed.<sup>19,20,16</sup> The purpose of this monograph is to describe various evaluation tools currently available to medical practices and explore their utility to assess the degree to which a practice employs the medical home approach.

### ORIGIN OF THE MEDICAL HOME CONCEPT

The term “medical home” originated in pediatrics and initially focused on children and youth with special health care needs (CYSHCN). CYSHCN are defined by the Maternal and Child Health Bureau (MCHB) as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”<sup>21</sup> The first known published reference to the term “medical home” is in the 1967 *Standards of Child Health Care*, written by the American Academy of Pediatrics (AAP) Council on Pediatrics.<sup>1</sup> The concept of a “medical home” as a repository for medical records became a formal policy of the AAP in 1977.<sup>1</sup>

In the late 1970s, the concept of the “medical home” expanded and began to be characterized by “commitment to the individual, primary services, fulltime accessibility, service continuity, comprehensive record-keeping, competent medical management, and cost-effective care.”<sup>21</sup> The medical home gained widespread approval in several states and was subsequently recognized by the federal Maternal and Child Health Bureau (MCHB) Division of Services for Children with Special Health Care Needs.<sup>22</sup>

During the 1980s, many barriers to provision of a medical home for CYSHCN were identified. Specifically, a lack of interest by some pediatricians in provision of coordinated care for CYSHCN, a lack of reimbursement for the extraordinary time involved in provision of care for CYSHCN, poor coordination with tertiary care centers and medical subspecialists and surgical specialists, a poor relationship with the educational system, the pediatrician's loss of income for coordinated care, the pediatrician's loss of power in the relationship when providing family-centered care, and concerns about the spread of misinformation through parent support networks were cited.<sup>23</sup> The importance of "imaginative methods, backed by insurance and governmental funding, [that] must be developed and used to improve financing" for the care coordination and other needs of CYSHCN became apparent following implementation of the first medical home models.<sup>23</sup>

In 1990, recommendations for strategies to ensure a medical home for all children were suggested by physicians, including: (1) legislative policy to ensure funding and access, (2) public-private coordination to ensure availability of services, and (3) physician education and training to enhance skills and awareness.<sup>23</sup> In 1992, the AAP Ad Hoc Task Force on the Definition of the Medical Home published a definition of medical home as:

... medical care of infants, children, and adolescents [that] ideally should be accessible, continuous, comprehensive, family centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a relationship of mutual responsibility and trust with them.<sup>24</sup>

The AAP established a Division of Community Pediatrics in 1993 as well as the Community Access to Child Health (CATCH) program.<sup>1</sup> The CATCH program promotes and supports development of a medical home for every pediatric patient in a community. At that time, the Division of Community Pediatrics also developed a Medical Home Training Program. From 1994-1999, the MCHB awarded a cooperative agreement to the AAP to develop a project, the Medical Home Program for Children with Special Needs, which was to include an updated version of the Medical Home Training Program.<sup>1</sup> In addition, the National Center of Medical Home

Initiatives for Children with Special Needs (National Center) was established. In 1999, the AAP was awarded a 5-year cooperative agreement to support the National Center, now called the National Center for Medical Home Implementation, and the creation and maintenance of a Web site ([www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)). The current cooperative agreement focuses on establishing a medical home for all children and youth. Goals of the National Center include:

- Enhancing policies and operational standards through partnerships at the national level that guide implementation of the medical home.
- Providing resources and tools that increase implementation of the medical home at the practice level.
- Enhancing the collaboration for medical home system change at the state and community levels.
- Leveraging the AAP structure—chapters, committees, councils, and sections—to further maximize medical home implementation at all levels from local to national.<sup>25</sup>

In 2002, the AAP published a policy statement by the Medical Home Initiatives for Children with Special Needs Project Advisory Committee.<sup>26</sup> The policy reiterated the 1992 definition of a medical home and expanded the scope by including "desirable characteristics" of a medical home (see Table 1). The AAP also described comprehensive health care for infants, children, and adolescents to include: (1) family-centered care; (2) information sharing about relevant services; (3) provision of primary care; (4) continuously available ambulatory and inpatient care for acute illnesses; (5) continuity of care and organized transitions; (6) coordination with medical subspecialists and surgical specialists; (7) interaction with community resources, such as education programs; (8) care coordination, including a care plan implemented by a team; (9) maintenance of a confidential, accessible, and comprehensive child health record; and (10) provision of developmentally appropriate and culturally sensitive health assessments.<sup>26</sup>

TABLE 1. DESIRABLE CHARACTERISTICS OF A MEDICAL HOME<sup>26</sup>

**ACCESSIBLE**

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Care is provided in the child's or youth's community.

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All insurance, including Medicaid, is accepted.

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Changes in insurance are accommodated.

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Practice is accessible by public transportation, where available.

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Families or youth are able to speak directly to the physician when needed.

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The practice is physically accessible and meets Americans with Disabilities Act requirements.

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**FAMILY-CENTERED**

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The medical home physician is known to the child or youth and family.

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Mutual responsibility and trust exists between the patient and family and the medical home physician.

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The family is recognized as the principal caregiver and center of strength and support for child.

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Clear, unbiased, and complete information and options are shared on an ongoing basis with the family.

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Families, youth, and physicians share responsibility in decision making.

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The family is recognized as the experts in their child's care, and youth are recognized as the experts in their own care.

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**CONTINUOUS**

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The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood.

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Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the child or youth and family.

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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.

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**COMPREHENSIVE**

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Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.

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Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.

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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.

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Preventive, primary, and tertiary care needs are addressed.

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The physician advocates for the child, youth, and family in obtaining comprehensive care and shares responsibility for the care that is provided.

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The child's or youth's and family's medical, educational, developmental, psychosocial, and other service needs are identified and addressed.

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Information is made available about private insurance and public resources, including Supplemental Security Income, Medicaid, the State Children's Health Insurance Program (SCHIP), waivers, early intervention programs, and Title V State Programs for Children with Special Health Care Needs.

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Extra time for an office visit is scheduled for children with special health care needs, when indicated.

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**COORDINATED**

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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.

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Care among multiple providers is coordinated through the medical home.

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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.

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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 subspecialists, and mental health/developmental professionals.

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Families are linked to family support groups, parent-to-parent groups, and other family resources.

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When a child or youth is referred for consultation or additional care, the medical home physician assists the child, youth, and family in communicating clinical issues.

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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.

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The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.

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**COMPASSIONATE**

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Concern for the well-being of the child or youth and family is expressed and demonstrated in verbal and nonverbal interactions.

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Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth.

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**CULTURALLY EFFECTIVE**

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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.

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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.

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Written materials are provided in the family's primary language.<sup>26</sup>

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The AAP acknowledged in the 1992 policy that “efforts to establish medical homes for all children have encountered many challenges, including the existence of multiple interpretations of the ‘medical home’ concept and the lack of adequate reimbursement for services provided by physicians caring for children in a medical home.”<sup>26</sup> The 2002 policy was reaffirmed by the AAP in May 2008.<sup>27</sup>

## NATIONAL RESEARCH ON AND RESOURCES FOR THE MEDICAL HOME

In 1999, the MCHB and the National Center for Health Statistics conducted the first *National Survey of Children with Special Health Care Needs* over a 3-year period.<sup>28</sup> The purpose of the survey was to determine state prevalence estimates for children with special health care needs and to determine the status of health care received by these children. More than 373 000 parents were screened through a random-digit dialing telephone survey, from which 38 866 interviews were conducted, representing a minimum of 750 CSHCN per state. The results of the survey were utilized to determine whether CSHCN have access to a medical home. Medical home was defined by 5 components: (1) having a usual place for sick/well care, (2) having a personal doctor or nurse, (3) experiencing no difficulty in obtaining needed referrals, (4) receipt of needed care coordination, and (5) presence of family-centered care. Although 90.5% reported having a usual source of care and 89.0% reported having a personal doctor or nurse, only 39.8% reported receiving effective care coordination when needed. Families of children without a medical home were twice as likely to report a delay in or forgone care and an unmet health care need and were 3 times as likely to report an unmet need for family support services as were those with a medical home. Alternatively, families of CSHCN with a medical home were only one third as likely as those without a medical home to report an unmet need for therapeutic or supportive services.<sup>28</sup>

In 2004, results were published on a study assessing presence of a medical home for all children and CSHCN using existing population-based data sets, including the *National Survey of Children with Special Health Care Needs*, the *National Medical Expenditures Panel Survey*, the *Consumer Assessment of Health Plans Study (CAHPS®) Child Survey*, and the *CAHPS Child Survey – Children with Chronic Conditions*.<sup>29</sup> Of children not meeting criteria for

having a special health care need, 80.9% reported having a medical home, and of CSHCN, 72.5% reported having a medical home. However, of families of children without a special health care need, 62.3% reported receiving coordinated care, and of families of CSHCN, 66.5% reported receiving coordinated care.<sup>29</sup>

The Center for Medical Home Improvement (CMHI), originally located in the Hood Center for Children and Families at the Children’s Hospital at Dartmouth Hitchcock Medical Center, is part of the Crotched Mountain Foundation. With funding from MCHB, CMHI developed a toolkit titled *Building a Medical Home: Improvement Strategies in Primary Care for Children with Special Health Care Needs*.<sup>30</sup> The toolkit includes improvement steps, strategies, and measurement tools for practices.<sup>30</sup> CMHI suggests that the toolkit be utilized to guide practices through a baseline measurement, team formation, quality improvement structures for process implementation, and collaborative learning.<sup>31</sup>

In July 2009, the AAP and National Center for Medical Home Implementation, with funding from the MCHB, released a more comprehensive toolkit for development of a medical home for all pediatric patients. The *Building Your Medical Home* toolkit is available for free online and provides guidance to practices who are interested in moving forward with the development and improvement of a pediatric medical home with the goal of addressing and integrating high quality health promotion, acute care and chronic condition management in a planned, coordinated, and family-centered manner. The toolkit is designed to meet the standards defined in the National Committee for Quality Assurance (NCQA)’s *Physician Practice Connections – Patient-Centered Medical Home (PPC-PCMH™)*.<sup>25</sup> Topics within the toolkit include care partnership support, clinical care information, care delivery management, resources and linkages, practice performance measurement, and payment and finance.<sup>25</sup>

In 2008, a review of literature found that CYSHCN benefited from a medical home.<sup>20</sup> Homer et al. reviewed more than 33 articles reporting on 30 distinct studies of pediatric medical homes, but reported inconsistencies in the definition of medical home activities and in the assessment of outcomes. The authors recommended further studies incorporating the full AAP medical home construct and more rigorous study methods in evaluation of medical home models.<sup>20</sup>



## MEDICAL HOME CONCEPT GAINS WIDESPREAD SUPPORT

In 2002, leadership representing family medicine professional societies initiated a study to develop a strategy “to transform and renew the discipline of family medicine to meet the needs of patients in a changing health care environment.”<sup>32</sup> The results of this national demonstration project, published in 2004, included the need to promote a new model of practice, with the first characteristic identified as a “personal medical home” defined as “the practice serv[ing] as a personal medical home for each patient, ensuring access to comprehensive care through an ongoing relationship.”<sup>32</sup> Additional characteristics of the “New Model of Family Medicine” include: patient-centered care, a team approach, elimination of barriers to access, advanced information systems, redesigned offices, whole-person orientation, care provided within a community context, emphasis on quality and safety, and commitment to provide family medicine’s basket of services (see Appendix A). The medical home would serve as “the focal point through which all individuals – regardless of age, sex, race, or socioeconomic status – receive a basket of acute, chronic, and preventive medical care services.”<sup>32</sup> This national demonstration project served as the precursor to TransforMED, a consultative service for practice redesign and wholly owned subsidiary of the American Academy of Family Physicians (AAFP).

In 2006, the American College of Physicians (ACP) published a policy monograph titled *The Advanced Medical Home: A Patient-Centered, Physician-Guided Model of Health Care*.<sup>33</sup> Instead of being assessed by attributes of primary care, the proposal included evidence-based medicine and clinical decision support, delivery of care modeled after the chronic care model (a model of chronic disease care), ongoing care, enhanced access, key quality indicators, technology-driven care, and physician and practice performance feedback (see Appendix B). The society proposed voluntary certification and recognition of primary care and specialty medical practices that provide evidence of such attributes.<sup>33</sup>

In March 2007, the AAFP, the AAP, the ACP, and the American Osteopathic Association (AOA) endorsed the *Joint Principles of the Patient-Centered Medical Home*.<sup>34</sup> The group defined the patient-centered medical home (PCMH) as “an approach to providing comprehensive primary care for children, youth and adults” (see Appendix C). The principles or attributes of a PCMH include a personal physician, physician-directed medical practice,

whole-person orientation, coordinated and/or integrated care, quality and safety, enhanced access, and appropriate payment for the added value of the aforementioned attributes.<sup>34</sup>

Following announcement of the *Joint Principles*, stakeholders, including purchasers, payers, providers, and patient advocacy groups, rallied to identify new systems to deliver primary care and appropriate payment methodologies that provide greater remuneration for the delivery of cognitive services.<sup>18,35</sup> Stakeholders have cited rising health care costs, errors in and poor quality of health care, decreasing access, and dissatisfaction of providers and patients as factors supporting the need to identify new models of primary care.<sup>35</sup> The Patient-Centered Primary Care Collaborative (PCPCC), a coalition of more than 650 large employers, primary care societies, national health plans, consumer groups, and others formed in 2007 to address these issues. Several multistakeholder pilot and demonstration projects to test new models of primary care have begun across the country.<sup>18</sup> These pilot and demonstration projects often test transformational activities, such as implementation of new models of practice. The AAFP, AAP, ACP, and AOA developed guidelines for PCMH demonstration projects, endorsed by the PCPCC and described below.<sup>36</sup> Many of the pilots are relying on the National Committee for Quality Assurance (NCQA) *Physician Practice Connections-Patient-Centered Medical Home (PPC-PCMH)* recognition program as a method of identifying practices worthy of increased payment as a medical home.<sup>36</sup> However, many believe that the NCQA standards for recognition as a PCMH do not adequately reflect the attributes of a medical home.<sup>37-40,17</sup> For example, the PPC-PCMH recognition program includes minimal measures of continuity and comprehensiveness and lacks the patient and family perspective in assessment of whether the practice is a medical home.<sup>38</sup>

## AAP—THE “PATIENT- AND FAMILY-CENTERED MEDICAL HOME”

Although the AAP agreed to endorse the *Joint Principles* statement, it still acknowledges the importance of the original attributes in its 2002 medical home policy statement. Specifically, within pediatrics, the attributes of family-centeredness, compassion, and cultural effectiveness remain integral characteristics of the medical home. Family-centeredness is integral to pediatric care, as often the family members of the pediatric patient are

responsible for ensuring access and coordination of care for a child. Family-centered care is also particularly important in transitions within the health care system, from primary care to medical subspecialists and surgical specialists or hospitals. Therefore, the MCHB and the AAP both prefer to use the term “patient- and family-centered medical home,” rather than “patient-centered medical home,” when describing a medical home.

## MEASUREMENT GUIDELINES FOR PATIENT-CENTERED MEDICAL HOME DEMONSTRATION PROJECTS

In March 2009, the PCPCC endorsed measurement guidelines developed by the AAFP, the AAP, the ACP, and the AOA for patient-centered medical home demonstrations<sup>36</sup> (see Appendix D). The guidelines are intended to help demonstrations maintain consistency in measurement in line with the *Joint Principles* and to enable interpretation and evaluation across various demonstration projects. Of most relevance to evaluation of medical home projects is the method of practice recognition as a medical home as well as the type of data collected for the project evaluation. For example, the guidelines recommend use of nationally recognized criteria for recognition of a medical home, such as the criteria developed by the NCQA’s PPC-PCMH.<sup>36</sup> Such criteria guide the selection of and increased remuneration for practices within the medical home pilots. Guidelines endorsed by the PCPCC also recommend collection of descriptive data on the practice(s) and qualitative and quantitative data on process and outcome measures of clinical quality, measures of resources used, measures of patient/family experience of care, and measures of experience of participating physicians, practice staff, and payers within the model.<sup>36</sup>

## Section II: Measurement of the Pediatric Medical Home

### IMPORTANCE OF MEASURING THE MEDICAL HOME

Differentiating a practice that meets criteria as a medical home from one that does not is of great importance in determining (1) which activities successfully transform practices and (2) which degree of “medical home-ness” is associated with better outcomes and reduced health care expenditures. Furthermore, identification of

some standard measurement criteria is necessary for practices participating in multistakeholder PCMH pilot projects and ideal for all PCMH initiatives to reduce provider and practice reporting fatigue and allow for comparison of outcomes across projects.

Currently, different instruments are in use to recognize, as opposed to evaluate, practices as medical homes. For example, the PPC-PCMH is a tool used widely by payers for recognizing a practice as a PCMH and, thereby, potentially increasing reimbursement to such a practice. However, many other tools are in use to evaluate practices on the continuum of transformation to a medical home. Understanding the range of available tools may assist in the identification of strengths and weaknesses of each tool, particularly in terms of provision of care to pediatric patients and their families as well as gaps and areas of opportunity for improvements.

### RECOGNIZED CHALLENGES IN MEASURING THE PEDIATRIC MEDICAL HOME

Over the past 2 decades, the challenges related to operationalizing the attributes of a medical home for measurement have been recognized. Challenges to standardized measurement of the AAP definition of a medical home include the following factors:

- Incomplete empirical evidence and consensus regarding the absolute and relative costs and benefits of discrete components of the AAP definition of medical home;
- Lack of availability of comparable sources of data for measuring certain aspects of medical home in a consistent way across children and settings of care;
- Ongoing debate and uncertainty regarding how to measure specific concepts included in the AAP definition of medical home, such as “ongoing source of care,” continuity, and coordination of care; and
- Selecting which of the numerous concepts of medical home send the strongest signal and can be most feasibly and validly measured when data collection methods, such as parent surveys, must be made as parsimonious as possible.<sup>29</sup>

In addition to these challenges, it is difficult to assess: (1) the effectiveness of interventions to transform practices into medical homes and (2) the effectiveness of medical home models in improving specific or functional health outcomes due to the lack of standardization in measurement of medical home. In 2002, Cooley and other leaders in medical home implementation and

research stated that there was “an immediate need for large-scale, practice-based studies of the outcomes for children and youth, providers, and the health care system when such improvements in primary care are implemented.”<sup>31</sup> It is anticipated that additional PCMH pilot projects will contribute to the establishment of a more data-driven evidence base for the medical home concept.

## A CONCEPTUAL FRAMEWORK: MEDICAL HOME AS PRIMARY CARE

In a 2008 published review of outcomes associated with pediatric medical home models, the author posited:

One could legitimately ask whether the medical home [MH] as assessed through this review is different from primary care per se, as many of the specific activities studied – such as identification of a continuous provider over time – are indistinguishable from primary care. In our view, the medical home concept and the definition of primary care differ little. However, because the reality of primary care has come to differ so broadly from its ideal definition, and because the elements required to make primary care effective in improving outcomes for persons with chronic illness have been clarified, the reframing of primary care as the MH serves a useful purpose.<sup>20</sup>

In 1978, the Institute of Medicine (IOM) published a report and described primary care as accessible, comprehensive, coordinated, continuous, and accountable.<sup>41</sup> In 1996, the IOM defined primary care as “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal healthcare needs, developing a sustained partnership with patients, and practicing in the context of family and community”<sup>42</sup> (see Table 2). As the *Joint Principles* first and foremost define the PCMH as an “approach to providing comprehensive care,” tools to identify or evaluate a medical home should, minimally, include attributes of primary care.<sup>34</sup> In fact, most models of the medical home proposed by primary care professional organizations suggest that the determination of practices as a medical home should be based on the “conceptual underpinnings of primary care.”<sup>40</sup> Tools to measure the pediatric medical home, therefore, ideally should include all attributes of the AAP definition of a

medical home—namely accessible, continuous, comprehensive, family-centered, coordinated, and compassionate care.

TABLE 2. ATTRIBUTES OF PRIMARY CARE

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**COMPREHENSIVE.** Comprehensive care addresses any health problem at any given stage of a patient’s life.

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**COORDINATED.** Coordinated ensures the provision of a combination of health services and information that meets a patient’s needs. It also refers to the connection between, or the rational ordering of, those services, including the resources of the community.

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**CONTINUOUS.** Continuity is a characteristic that refers to care over time by a single individual or team of health care professionals (“clinician continuity”) and to effective and timely communication of health information (events, risks, advice, and patient preferences) (“record continuity”).

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**ACCESSIBLE.** Accessible refers to the ease with which a patient can initiate an interaction for any health problem with a clinician (eg, by phone or at a treatment location) and includes efforts to eliminate barriers such as those posed by geography, administrative hurdles, financing, culture, and language.

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Adapted from “Box 2-1 Definition of Primary Care” on page 32 of the IOM publication *Primary Care: America’s Health in a New Era*. Reprinted with permission from the National Academies Press, Copyright 1996, National Academy of Sciences.

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The quality of medical care, which is the focus of medical home pilot projects, can be evaluated by examining processes, structures, and outcomes.<sup>43,44</sup> Processes refer to the systems of care by a health care provider or within a practice, and structures refer to the material and social actions that are used to provide care.<sup>43</sup> Structures enable processes or behaviors to occur within a clinical setting. Process measures provide particularly useful feedback for quality improvement initiatives, such as PCMH pilots. Process measures are easier to measure than outcome measures, require less risk adjustment than outcome measures, and can be collected more quickly than outcome measures.<sup>45</sup> Consequently, many of the tools available to measure the pediatric medical home include a combination of both process and structure measures. Ideally, each attribute of a medical home should include measures of structures and the processes that are facilitated by the structures.

## **FACTORS TO CONSIDER WHEN SELECTING AN INSTRUMENT TO MEASURE THE PEDIATRIC MEDICAL HOME**

Several factors are important to consider in the selection of the appropriate instrument to measure pediatric medical homeness. Such factors are related to characteristics of the instrument, whether it is intended to assess provider, practice staff, or patient perspectives of medical homeness.

### ***Purpose of Tool***

When selecting a tool, it is essential to identify its original intent and purpose and then compare that with the current intent. Some tools are designed solely for educational rather than evaluative purposes. Some are designed for adult populations, although they may have been utilized with pediatric populations. Some may be designed to assess satisfaction with a provider or practice rather than experience with a provider or practice.

### ***Response Set***

The response set, or type of possible responses to a survey question, is also of critical importance when selecting a tool. Tools that measure frequency rather than strength are problematic in situations when respondents rarely visit a practice. For example, if a response set includes “sometimes” and “always,” how would one respond if he or she has only visited a clinic one time?

### ***Formats Available***

The format of the tool is also of great importance. The format could be intended for a provider, multiple providers (eg, care team), a clinic staffer, or a patient or patient’s family member. The availability of multiple formats, for example, one tool that can measure the perspective of several stakeholders, such as providers, staff, and patients, promotes alternative viewpoints and richer information for identifying strengths and weaknesses within a practice.

### ***Method of Completion***

Questionnaires can be self-completed or completed with the assistance of an interviewer. Self-completed questionnaires are generally less expensive in terms of data gathering, require less trained staff, introduce less “interview bias,” and offer more standardized questionnaire items. Self-completed questionnaires can be distributed by mail, in an office, or through the Internet. Questionnaires may also be completed with the assistance of an interviewer. The advantages to use of an

interviewer include the presence of another person sensitive to patients’ concerns, ability to clarify ambiguities or questions about the questionnaire, and establish a rapport, subsequently increasing respondent participation.<sup>46</sup> Interviews using a questionnaire can be conducted by phone or in person.

### ***Testing of Reliability and Validity***

A reliable and valid tool is important for use in assessment of a medical home. Understanding the methods used to develop a tool is of critical importance. Validity of a tool refers to how well concepts have been operationalized and whether the tool accurately assesses the concepts under study. Types of validity include face validity, content validity, predictive validity, concurrent validity, convergent validity, and discriminant validity. A helpful review of each type of validity can be found in the online book *Research Methods Knowledge Base* at <http://www.socialresearchmethods.net/kb/measval.php>. Reliability refers to the extent to which results are consistently reproducible when using the same methods. Types of reliability include interrater reliability, test-retest reliability, parallel-forms reliability, and internal consistency reliability. A helpful review of each type of reliability can be found online at <http://www.socialresearchmethods.net/kb/reotypes.php>.

### ***Populations Surveyed***

An understanding of populations surveyed by the tool and the performance of the tool within different populations can be important if generalizability is of interest. Examples of populations include the general population, population subgroups, patients in primary care facilities/practices, patients in specialty practices, physician managers, health systems professions, etc. Has the tool been used with diverse populations—for example, families of children both with and without special health care needs; families of different cultural, geographic, or socioeconomic backgrounds; or providers in practices of differing size and organizational structure? Does the tool have comparable versions for different types of respondents—for example, patients versus health care providers?

### ***Languages Available***

Availability of the tool in different languages might also be of interest depending on where a tool may be used. For example, if the tool is designed to be self-completed, is it available in languages other than English?

### **Length of Time to Complete**

Time needed to complete a survey tool is also of interest, particularly when considering how it might be used. For example, if a survey takes place during a clinic visit, a lengthy questionnaire may interfere with clinic flow. Also, lengthier questionnaires often suffer from low response rates or biased samples.

### **Resources Needed**

A description of the resources needed to implement a survey is also helpful. For example, if a questionnaire is designed solely for use with an interviewer, one must account for the expense of hiring, training, and paying an interviewer. Also, if a questionnaire is particularly lengthy, inclusion of an incentive for survey participants might be considered. Finally, if a questionnaire is paper-based rather than electronic, costs of data entry must also be considered. And for all surveys, resources for analysis and presentation are also necessary.

## **Section III: Tools to Measure the Pediatric Medical Home**

For the purposes of this monograph, tools were selected for review if their purpose is to explicitly assess pediatric medical homeness or if they include at least 2 of the attributes of the *Desirable Characteristics of a Medical Home* described by the AAP<sup>26</sup> (see Table 1). Tools were identified through a literature review using PubMed and through informal interviews with opinion leaders in the fields of maternal and child health and pediatrics. Tools designed for or used exclusively with adult populations were excluded from this review. The tools are presented alphabetically in this section. Each tool was reviewed thoroughly with presentation of the background, purpose, description, and development; examples of use of each tool are provided. An overview of each tool may also be viewed in Appendix E.

### **Consumer Assessment of Healthcare Providers and Systems (CAHPS) Child Primary Care Questionnaire 2.0 (beta)**

#### **BACKGROUND**

The CAHPS® is a suite of surveys developed by a consortium of public and private research organizations, which currently includes the Yale School of Public Health, RAND, and Westat, with the Agency for Healthcare

Research and Quality (AHRQ) as the primary funder and lead federal agency.<sup>47</sup> The first of the 3 CAHPS study initiatives began in October 1995 with the development of a standardized patient questionnaire designed to assess enrollees' experiences with health care services in organized health care plans.<sup>48</sup> Since 1995, the CAHPS Consortium has expanded the family of surveys to include instruments targeting specific populations, including survey products for clinicians and group practices, hospitals, in-center hemodialysis facilities, nursing homes, and behavioral health organizations.<sup>49</sup> [3]The most relevant survey instrument for measurement of a pediatric patient-centered medical home is the CAHPS Clinician & Group (C&G) Child Primary Care Questionnaire 2.0 (beta) released in October 2008 and meant to replace the C&G Child Primary Care Questionnaire 1.0 originally released in 2006. The CAHPS C&G Survey is also available for adult primary care and adult specialty care.

#### **PURPOSE**

CAHPS is an evolving family of survey instruments and reporting tools designed to measure important dimensions of health care performance from the consumer's point of view. The underlying purpose of the C&G Survey is to gather data to allow consumers to make objective comparisons between providers and clinics, to create incentives for practices to assess and improve patients' experiences with care, and to enhance public accountability by increasing the transparency of the quality of care provided in return for the investment.<sup>50</sup>

Rather than asking about satisfaction, which can vary with differing expectations, the CAHPS surveys assess experience by capturing the patient's perspective on how consistently certain actions were performed by healthcare providers. The CAHPS Child Questionnaires, including those that are part of the CAHPS C&G Survey, are intended to gather information from parents or guardians about the experience of care for their children 17 years of age or younger.<sup>51</sup>

#### **DESCRIPTION**

A core set of survey questions is common to all versions of a survey to ensure standardization and comparability; these items are applicable across various kinds of medical practices and patient populations. All of the CAHPS C&G Surveys have a standard core set of items covering the following 3 domains: access and timeliness of care, doctor-patient communication, and office staff helpful-

ness. Supplemental items for the *Primary Care* versions of the surveys inquire about issues such as: after-hours e-mail, being kept informed about appointment start, cost of care, doctor role, doctor thoroughness, health improvement, health promotion and education, health with problem or concerns, other doctors and providers at your doctor's office, provider communication, provider knowledge of specialist care, recommend doctor, shared decision making, wait time for urgent care, care from specialists in the last year, and most recent visit. In addition to yielding a global rating of care, the questionnaire measures a patients' intent to switch providers.

#### CHILD PRIMARY CARE QUESTIONNAIRE 1.0

Date of original release:	2006
Number of items/questions:	37 (additional 64 supplemental)
Number of pages:	11
Length of time to complete:	15-20 minutes
Languages available:	English and Spanish
Type of respondent:	Family/patient
Formats for completion:	Self- or interviewer-administered

#### Response Set:

The CAHPS Clinician & Group Survey and Reporting Kit offers detailed instructions for users to format and tailor the survey to their needs while maintaining standardization and comparability. All surveys in the CAHPS family use a 4-point Likert-like response scale, with response options of "never," "sometimes," "usually," and "always." The original *Child Primary Care Questionnaire 1.0* is also available with a 6-point scale, which adds "almost never" and "almost always" categories to the response options. The 6-point scale was endorsed by the National Quality Forum (NQF); however, because of strong user feedback, the newer C&G *Child Primary Care Questionnaire 2.0 (beta)* is only available in the 4-point scale to maintain consistency with the hospital and health plan surveys in the CAHPS family.<sup>47</sup>

Cost for use:	None. Permission required.
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#### CHILD PRIMARY CARE QUESTIONNAIRE 2.0 (BETA)

Date of original release:	2008
Number of items/questions:	54 (additional 24 supplemental)
Number of pages:	15
Length of time to complete:	20-25 minutes
Languages available:	English and Spanish
Type of respondent:	Family/patient
Formats for completion:	Self- or interviewer-administered

#### Response Set:

C&G *Child Primary Care Questionnaire 2.0 (beta)* is only available in the 4-point scale to maintain consistency with the hospital and health plan surveys in the CAHPS family.

Cost for use:	None. Permission required.
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The core items in the *Child Primary Care 2.0 (beta)* differ from those in the 1.0 version in several ways:

1. There are new items about experiences with developmental care and preventive care as well as an item on overall mental and emotional health status;
2. Items on communication between the doctor and the child have been moved from the supplemental item set into the core instrument;
3. Items to identify children with chronic conditions have been added.<sup>47</sup>

It was noted in the August 2008 reaffirmation<sup>27</sup> of the AAP policy statement "The Medical Home"<sup>26</sup> that the C&G *Child Primary Care Questionnaire 1.0* does not include questions related to a practice's provision of:

1. Care recognizing the diversity of a family and that parents are the constant in a child's life (though there are potentially relevant supplemental items from the *Health Plan Child Questionnaire 4.0* that might be incorporated into the 2.0 [beta]).
2. Care over an extended period of time to ensure continuity.
3. Care that involves provider interaction with early intervention programs, schools, early childhood education and child care programs, and other public and private community agencies to be certain that the special needs of the child and family are addressed (though items to identify children with special needs are included in the 2.0 [beta] supplemental questions, questions to address interaction with schools, etc are not). The CAHPS *Health Plan Child Questionnaire*, which could be incorporated into the 2.0 [beta], contains questions addressing these interactions.

4. Coordination services in which the family, the physician, and other service providers work to implement a specific care plan as an organized team.
5. An accessible, comprehensive, central health record that contains all pertinent information about the child, preserving confidentiality.
6. Developmentally appropriate and culturally competent health assessments and counseling to ensure successful transition to adult-oriented health care, work, and independence in a deliberate, coordinated way.<sup>26</sup>

The instruments in the CAHPS C&G Survey are compatible with the other questionnaires in the CAHPS suite of surveys. Survey administration guidelines, data analysis guidelines and programs as well as reporting measures are available in the CAHPS Clinician & Group Survey and Reporting Kit. Additional technical support is available through the CAHPS User Network and the National CAHPS Benchmarking Database.<sup>49</sup>

Note: An expanded set of items for Children with Chronic Conditions available for the *Child Questionnaire* in the CAHPS Health Plan Survey 4.0 can be adapted for use with the C&G Survey. The questionnaire includes items related to the major topics of access to prescription medicines, access to specialized services, family-centered care, and coordination of care and services and integrates a modified version of the *Children with Chronic Conditions (CCC) Screener*, developed in collaboration with the Child and Adolescent Health Measurement Initiative (CAHMI). The CCC Screener is a 5 item, non-condition-specific screener for identification of children who experience current health or health care use consequences because of a health condition that has lasted or is expected to last for at least 12 months.<sup>52</sup>

CAHPS technical specifications require a sample large enough to yield 300 completed questionnaires for a group (or health plan), and a minimum of 45 completed questionnaires is suggested for individual clinicians. Larger sample sizes may be required for valid information on children with chronic conditions.

## DEVELOPMENT

The questionnaire items were subject to cognitive, reliability, and validity testing, and the core items were found to perform consistently with the previous CAHPS questionnaires.

The C&G *Child Primary Care Questionnaire 2.0 (beta)* was developed in response to suggestions noted by the National Quality Forum (NQF) when officially endorsing the CAHPS C&G *Child Primary Care Questionnaire 1.0* in 2007. The NQF indicated that the instrument would benefit from the addition of questions about developmental and preventive care.<sup>47</sup> Additionally, it is meant to address The Commonwealth Fund's concern that the *Child Primary Care Questionnaire* needed to more accurately reflect the differences in pediatric and adult primary care. Thus, the 2.0 (*beta*) version was developed with emphasis placed on accessing and promoting a child's active development through comprehensive care, scheduled and preventive care, doctor-to-parent education, provision of care to CSHCN, increased morbidities in children, and the fact that pediatric patients are disproportionately affected by social and environmental health issues.<sup>50</sup>

The development of the new survey items for the beta version was spearheaded by the Yale CAHPS Team at the Yale School of Epidemiology and Public Health through the Center for Survey Research (CSR) at the University of Massachusetts Boston, where the revised version was developed and tested. The multistage development included the input of many stakeholders, including the AAP, as well as parents and guardians through focus groups and cognitive interviews. The field test was conducted in Massachusetts among parents or guardians of children seen at a doctor's office in the previous 12 months ( $n = 1000$ ). The field test included both English and Spanish versions administered via mailed (self-administered) questionnaires and telephone (interviewer-administered) modes.<sup>47</sup>

## EXAMPLES OF USES

Given that the C&G *Child Primary Care Questionnaire 2.0 (beta)* was recently released, the CAHPS Consortium is still in the process of identifying and compiling a list of users of the new survey. Currently, CAHPS cites 7 profiles of "CAHPS child survey sponsors," which demonstrate the variety of CAHPS Child Survey Projects either currently underway or recently completed using the CAHPS *Health Plan Survey*. The majority of these projects have been or are being conducted by states to evaluate the performance of health plans and providers participating in their state's Medicaid program. Participating states include Colorado, Kansas, Michigan, New Mexico, Pennsylvania, Utah, and Washington. Many have used the CCC Screener to identify children with special health

care needs. And a number of these states have published their findings in report card form in consumer guides. The Centers for Medicare & Medicaid Services (CMS) has been a major partner in the CAHPS program since 1996. Other partners include the Centers for Disease Control and Prevention and the National Institute for Disability and Rehabilitation Research.<sup>53</sup>

## OBTAINING A COPY OR PERMISSION TO USE

The CAHPS *Clinician & Group Survey and Reporting Kit*, as well as all of the other surveys in the CAHPS family, are available for free download at <https://www.cahps.ahrq.gov>

For more information about CAHPS or the *Child Survey*, contact the CAHPS Helpline toll free at (800) 492-9261 or e-mail [CAHPS1@ahrq.gov](mailto:CAHPS1@ahrq.gov).

## Components of Primary Care Instrument (CPCI)

### BACKGROUND

The *Components of Primary Care Instrument (CPCI)* was developed by Susan A. Flocke, PhD, Associate Professor of Family Medicine and Epidemiology and Biostatistics at Case Western Reserve University in 1996.<sup>54</sup> Support for instrument development was provided by a grant from the National Cancer Institute (1R01CA60862) and by a Robert Wood Johnson Foundation Generalist Physician Faculty Scholar Award to Kurt Stange, MD.<sup>54</sup>

### PURPOSE

The purpose of the scale is to measure 7 key aspects of the delivery of primary care from the perspective of patients. The 7 domains were based on the IOM definition of primary care and on additional domains based on the literature. The original domains included comprehensiveness, accumulated knowledge (by physician of patient), interpersonal communication, coordination of care, first-contact care, continuity of care, and longitudinality.<sup>54</sup> However, since the initial development of the tool, additional domains were added, including advocacy, family context, and community context.

## DESCRIPTION

### COMPONENTS OF PRIMARY CARE INSTRUMENT (CPCI)

Date of original release:	1996
Number of items/questions:	52
Number of pages:	2
Length of time to complete:	15 minutes in current form
Languages available:	English
Type of respondent:	Family/patient
Format for completion:	

The tool is designed to be completed in office, self-administered by individual patients immediately after a visit with a physician.

### Response Set:

The response format for the items is a 6-point Likert-type scale, ranging from 1 = strongly disagree; to 6 = strongly agree. The scale domains include: comprehensive care, accumulated knowledge, communication, patient preference for regular doctor, coordination of care, advocacy, family orientation, community orientation, duration of relationship, and continuity.<sup>54</sup>

Cost for use:	None. Permission required.
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## DEVELOPMENT

A description of the development of the scale can be found in the article, "Measuring Attributes of Primary Care: Development of a New Instrument" in the *Journal of Family Medicine*.<sup>54</sup> Briefly, the items were initially reviewed for content validity by primary care experts and pilot tested with 43 patients visiting a family physicians' practice. After modifications and additions were made, the scale was evaluated in a cross-sectional survey of patient visits to 138 family physician members of the Research Association of Practicing Physicians (RAPP) network located in a 50-mile radius of Cleveland and Youngstown, Ohio. Data collection occurred between October 1994 and August 1995, and research nurses administered the questionnaires as an exit interview. The patient sample consisted of consecutive patients visiting each physician within a day. Data collection occurred over 2 days at each site, separated by 4 to 5 months. The data collection included both adults and children (or their caregivers) for a total of 4454 patients and an 89% response rate. The scale was developed through exploratory factor analysis and correlation analysis (to evaluate internal consistency and the correlation with patient satisfaction).



## EXAMPLES OF USE

The CPCI has been used to assess the association between payment systems,<sup>55</sup> delivery of preventive services,<sup>56</sup> managed care restrictiveness,<sup>57</sup> physician style,<sup>58</sup> continuity of care,<sup>59</sup> and change in providers by elderly patients.<sup>60</sup>

## OBTAINING A COPY OR PERMISSION TO USE

Requests for copies or permission to use may be directed to Susan Flocke, PhD. The tool is available free of charge.

Susan A. Flocke, PhD  
Associate Professor of Family Medicine and Epidemiology  
and Biostatistics  
Case Western Reserve University  
1101 Cedar Avenue, suite 306  
Cleveland, Ohio 44106-7136  
E-mail: [susan.flocke@case.edu](mailto:susan.flocke@case.edu)  
Tel: (216) 368-3887  
Fax: (216) 368-4348

## Family-Centered Care Self-Assessment Tool

### BACKGROUND

The *Family-Centered Care Self-Assessment Tools* are a suite of tools including a *Provider Tool*, a *Family Tool*, and a *Users' Guide*. The tools were developed by Family Voices, Inc, a national, grassroots organization of families of CYSHCN and providers, with funding from the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services under Cooperative Agreement #U40MC00149-09-00. The tool was developed by a team with assistance from the Georgetown University Center for Child and Human Development and released in October 2008.

## PURPOSE

The purpose of the tools is to: (1) increase outpatient health care settings' and families' awareness about the implementation of family-centered care, and (2) provide an organized way for health care settings to assess current areas of strength and identify areas for growth, plan for future efforts, and track progress.<sup>61</sup>

## DESCRIPTION

As described in the *Users' Guide*:

The tool is not designed to provide a score, but is meant as an opportunity for reflection and quality improvement activities related to family-centered care within outpatient health care practices. The *Family Tool* can also be used by families to assess their own skills and strengths, the care their children and youth receive, and to engage in discussions within health care settings and with policy makers in organizations, health plans and community and state agencies about ways to improve health care services and supports. The tool is intended to assess care for all children and youth and also has some questions that are specific to the needs of children and youth with special health care needs and their families. Questions on the tool address the ten components of family-centered care and the key aspects of family/youth/provider partnerships. Examples of topics include: the *family/provider partnership*, *care setting practices and policies*, and *community systems of services and supports*.<sup>61</sup>

The *Provider* and *Family Tools* share many of the same questions, although framed from the different perspective of respondents. Also, the tool is not designed for implicit or explicit comparison between or rating of practitioners or facilities.

The accompanying *Users' Guide* includes a description for using the tool, including steps for implementing a family-centered care self-assessment process. The *Users' Guide* also includes a description of resources related to family-centered care.<sup>61</sup>

## FAMILY-CENTERED CARE SELF-ASSESSMENT TOOLS: FAMILY VERSION

Date of original release:	October 2008
Number of items/questions:	98
Number of pages:	8
Length of time to complete:	15-20 minutes
Languages available:	English
Type of respondent:	Family/patient

The tools are designed for use in the outpatient setting for all children and youth, although some questions are more pertinent for CYSHCN.

Format for completion:	Self-administered
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### Response Set:

The tools are not visit- or time-based, but rather refer to the relationship with the primary care provider. Both formats use a 4-point Likert scale ranging from "Never" to "Always." Some items in the *Family Tool* also include the option "Does Not Apply." The tools incorporate the 10 components of family-centered care identified by the Institute for Family-Centered Care.

Cost for use:	None.
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## FAMILY-CENTERED CARE SELF-ASSESSMENT TOOLS: PROVIDER VERSION

Date of original release:	October 2008
Number of items/questions:	105
Number of pages:	8
Length of time to complete:	15-20 minutes
Languages available:	English
Type of respondent:	Physician

Format for completion:	Self-administered
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### Response Set:

The tools are not visit- or time-based, but rather refer to the relationship with the primary care provider. Both formats use a 4-point Likert scale ranging from "Never" to "Always." The tools incorporate the 10 components of family-centered care identified by the Institute for Family-Centered Care.

Cost for use:	None.
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## DEVELOPMENT

In 2006, MCHB, Family Voices, and the National Center for Medical Home Initiatives at the AAP brought together an expert panel of family members, state and federal

policy makers, providers, and academicians to develop a set of indicators of family-centered care that could be measured and be useful to all stakeholders in all settings. The group met for 2 days in September 2006 and again on April 14, 2007 to begin this work. The group decided to create a set of 3 levels of indicators for each of the first 9 principles of family-centered care. The principles of family-centered care have little overlap with the attributes of primary care. During 2007 and into 2008 a work group of representing Family Voices and other key stakeholders continued to develop the tool and it was shared with providers and family members for feedback. On the basis of that feedback, the tool was reconceptualized to its current format. The current draft is being vetted with pediatric health care settings and family support and advocacy organizations and will be field tested in the future.

## EXAMPLES OF USES

Because the *Family-Centered Care Self-Assessment Tools* were released in October 2008, there are, as yet, no published reports of use. The tool is in the process of field testing as of summer of 2009.

## OBTAINING A COPY OR PERMISSION TO USE

The tools are available for download from the Family Voices Web site. Hard copies of the tools can also be ordered through the Web site. The tools are available free of charge.

Web site: <http://www.familyvoices.org/>

E-mail: [catalog@familyvoices.org](mailto:catalog@familyvoices.org)

Tel: (505) 872-4774

Tel: (888) 835-5669

## Medical Home Index (MHI) and Medical Home Family Index (MHFI)

## BACKGROUND

The *Medical Home Index (MHI)* and *Medical Home Family Index (MHFI)* were developed by W. Carl Cooley, MD, and Jeanne W. McAllister, RN, MS, MHA, at the Center for Medical Home Improvement (CMHI) within the Hood Center for Children and Families at the Children's

Hospital at Dartmouth Hitchcock Medical Center.<sup>30</sup> The *Medical Home Index* was developed in 2001 with funding from a grant (MCJ 33IS26 and H02 MC 00087) from the Maternal and Child Health Bureau of the Health Resources and Services Administration. CMHI recently released an *Adult Medical Home Index* and renamed the original indices the *Pediatric Medical Home Index* and the *Pediatric Medical Home Family Index*.

## PURPOSE

The purpose of the *MHI* is to assess a practice’s “medical homeness” to facilitate a process of change toward high levels of medical home achievement.<sup>30</sup> The tool can be used as a quality improvement tool, particularly when used in conjunction with the *MHFI*, as a measure toward the Healthy People 2010 goal for states that all CYSHCN will receive care in a “medical home,” to identify medical homes for payers for enhanced reimbursement, and as a research tool to associate level of “medical homeness” with outcomes.<sup>31</sup> Although the *MHI* and *MHFI* are companion tools, they are not parallel in content or response sets.

## DESCRIPTION

The *MHI* items are divided into 6 domains of practice activity including: organizational capacity, chronic condition management, care coordination, community outreach, data management, and quality improvement.<sup>30</sup> The *MHI* is designed for provision of care to CYSHCN.

### PEDIATRIC MEDICAL HOME INDEX (MHI)

Date of original release:	2001
Number of items/questions:	25
Number of pages:	11
Length of time to complete:	15-20 minutes
Languages available:	English
Type(s) of respondent:	Physician and clinic staff
Format for completion:	Self-administered
Response Set:	

Each item is scored across 4 levels of achievement as partial or complete depending on attainment of degree of activity in the practice at that level. The 4 levels of achievement correspond to a “continuum of quality” with 1 = basic pediatric care; 2 = responsive care; 3 = productive care; and 4 = comprehensive care.

Cost for use:	None. Permission required. Sharing of data requested.
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### PEDIATRIC MEDICAL HOME INDEX (MHI) – SHORT VERSION

Date of original release:	2001
Number of items/questions:	10
Number of pages:	4
Length of time to complete:	5-10 minutes
Languages available:	English
Type(s) of respondent:	Physician and clinic staff
Format for completion:	Self-administered
Response Set:	Same as the full version of the <i>MHI</i> .
Cost for use:	None. Permission required. Sharing of data requested.

### PEDIATRIC MEDICAL HOME FAMILY INDEX (MHFI)

Date of original release:	2001
Number of items/questions:	38
Number of pages:	3
Length of time to complete:	15-20 minutes
Languages available:	English and Spanish
Type(s) of respondent:	Family/patient
Format for completion:	Self-administered
Response Set:	

The responses set is a mix of frequency based responses ranging from *never*, *sometimes*, *often*, and *always*. Some responses are yes and no.

Cost for use:	None. Permission required. Sharing of data requested.
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## DEVELOPMENT

A description of the development of the tool can be found in the article, “The Medical Home Index: Development and Validation of a New Practice-Level Measure of Implementation of the Medical Home Model.”<sup>30</sup> The design of the tool was informed by the *Assessment of Chronic Illness Care Tool*, developed by the Improving Chronic Illness Care Program at the MacColl Institute for adult patients with chronic illness. Construct validity of the *MHI* was assessed by 23 national experts on the medical home concept. Pilot testing followed in 16 New England practices from September 2000 through February 2001, which included 90-minute interviews with lead physician and nonphysician staff members. In the second phase of pilot testing, a national sample of 27 practices participating in the federally funded medical home projects was selected from March

through September 2001. The MHI performed successfully on measures of interrater reliability and internal consistency reliability. Further information about the MHI validation process and benchmarking data can be found at <http://www.medicalhomeimprovement.org/knowledge/practices.html>. Because of the small sample size, a principal component analysis was not conducted.

The University of Illinois at Chicago Division of Specialized Care for Children developed tools, the *Medical Home Practice Survey* and the *Medical Home Family Survey*, modeled after the MHI. The *Medical Home Family Survey* is an online tool designed to take 15 to 20 minutes to complete and can be found at <http://www.uic.edu/hsc/dscc/survey/mhfamilysurvey.asp>.

## EXAMPLES OF USES

The MHI and MHFI have been utilized widely in quality improvement projects in pediatric practices. There are few published reports of results of use of the MHI, although one recent study found an association between high scores on the MHI and lower hospitalizations and emergency department use among patients.<sup>13</sup> A recent study in the *Journal of Ambulatory Care Management* reported a positive association between practices involved in transformational medical home activities and family reports of reduced primary care visits, reduced specialty visits, reduced hospitalizations, and decreased nights in the hospital as reported on the MHFI.<sup>15</sup>

## OBTAINING A COPY OR PERMISSION TO USE

The tools are available free of charge. Before using the tools, CMHI requests a description of the purpose of use. CMHI also requests deidentified practice and family data on completion of the tools.

Center for Medical Home Improvement:  
<http://www.medicalhomeimprovement.org/knowledge/practices.html>

American Academy of Pediatrics National Center for Medical Home Implementation  
(within the *Building Your Medical Home Toolkit*):  
<http://www.pediatricmedhome.org/>

## Medical Home Implementation Quotient (MHIQ)

### BACKGROUND

The *Medical Home Implementation Quotient (MHIQ)* was released in April 2008 by TransforMED, a wholly owned subsidiary of the American Academy of Family Physicians (AAFP). Development of the tool was led by Elaine M. Skoch, RN, MN, CNAA, EMBA, TransforMED Vice President of Performance Improvement and Education.

### PURPOSE

The purpose of the tool is as (1) an educational tool to assist practices in understanding the components of a medical home, (2) a method of identifying and evaluating areas of quality improvement within a practice, and (3) a guide in assessing performance related to the must pass elements of the NCQA PPC-PCMH recognition program.<sup>70</sup> The tool is meant to be a guide to becoming a medical home rather than as an evaluative tool.

### DESCRIPTION

The tool is a Web-based self-assessment tool composed of 9 modules including 10 to 32 questions per module. The tool can be completed by any professional in the practice. To use the tool, one must register for a free online account with TransforMED. The account then enables one to return to partially completed tools, assess current standings, track improvement in progress, and to send assessment results by e-mail to oneself. The Web site also includes a color-coded dashboard providing feedback on completed modules. Optional e-mail reminders to complete the form may also be set within an account. Modules included within the MHIQ are patient-centered medical home, practice management, health information technology, quality and safety, practice-based team care, continuity of care services, practice services, access to care and information, and care management. At the end of each module and after completion of the entire assessment, participants will receive tips for improving scores for the module as well as links for resources to improve the scores. The tool provides a score as well as the opportunity to compare MHIQ responses to the NCQA PPC-PCMH must pass elements.

## MEDICAL HOME IMPLEMENTATION QUOTIENT (MHIQ)

Date of original release:	April 2008
Number of items/questions:	9 modules of 13-32 questions
Number of pages:	Web-based
Length of time to complete:	Minimum of 15 minutes/module; average time-to-completion of 2-4 hours
Languages available:	English
Types of respondent:	Physician and clinic staff
Format for completion:	Self-administered
Response Set:	
The response set includes multiple choice responses as well as yes and no responses.	
Cost for use:	None. Free registration is required.

## DEVELOPMENT

The MHIQ was developed by Elaine M. Skoch, RN, MN, CNA, EMBA, Vice President of Performance Improvement and Education, TransforMED, following requests from practices for tools to assess where they may fall short in implantation and integration of the PCMH components. The tool was developed based on the TransforMED medical home model following the experience of TransforMED as the lead in a 24-month National Demonstration Project (NDP) from June 2006 to May 2008.<sup>70</sup> The tool has been vetted through a number of commissions of the AAFP and experts before release and was used with the NDP participating practices.<sup>70</sup> However, the tool has not been rigorously tested for validity and reliability.

## EXAMPLES OF USES

The MHIQ was originally piloted with NDP participating practices. The MHIQ is currently used within all practices participating in consultative services by TransforMED for assistance with transformational activities to become medical homes.<sup>70</sup> There are currently no published references on use of the MHIQ.

## OBTAINING A COPY OR PERMISSION TO USE

The tool is available free of charge and is copyrighted.

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The tool is available on the Internet for free use through TransforMED. Free registration is required. The Web site is <http://www.transformed.com/MHIQ/welcome.cfm>.

## Measure of Processes of Care (MPOC)

### BACKGROUND

The *Measure of Processes of Care* (MPOC – pronounced “em-pock”)<sup>62</sup> is a set of tools developed by Gillian King, PhD, at the Thames Valley Children’s Centre; and Peter L. Rosenbaum, MD, FRCP(C), and Susan King, MSc, of the Neurodevelopmental Clinical Research Unit (NCRU) at McMaster University in Ontario, Canada. The NCRU is funded by grants from The Ontario Mental Health Foundation and The Ontario Ministry of Health. The first of the 3 tools currently available, the MPOC-56, was published in November 1995. The MPOC was designed, as part of the work of the NCRU, to examine health care delivery and its impact on children with disabilities and their families. The survey items measure parents’ perceptions of the care they and their children receive from rehabilitation treatment centers charged with delivering family-centered health care services throughout Canada.<sup>63</sup> In 1998, a companion survey called the MPOC-SP meant to capture the provider perspective was released, and in 1999 the MPOC-20, a shortened version of the MPOC-56, was released.<sup>62</sup>

### PURPOSE

On the basis of the assumption that the interactions between health care providers and parents of CSHCN may significantly impact parental well-being, the survey is a self-report measure of parents’ perceptions of the extent to which specific provider behaviors occur and health care services are delivered. The authors’ intent was “to develop a comprehensive measure that tapped all the aspects or dimensions of care-giving valued by

parents,” for use in clinical and research settings geared toward program evaluation and total quality management.<sup>63</sup>

## DESCRIPTION

### MPOC-56

Date of original release:	November 1995
Number of items/questions:	56
Number of pages:	6
Length of time to complete:	15-20 minutes
Language(s) available:	English, French, Dutch, German, Finnish, Swedish
Type of respondent:	Family/patient
Format for completion:	Self-administered

#### Response Set:

Written at an eighth-grade reading level, the tool yields 5 scale scores in the areas of: enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care for the child and family, and respectful and supportive care. The authors selected these domains on the basis of a literature review of aspects of health care delivery deemed important to patients and families, and focus on client satisfaction, adherence to therapy and advice, and familial stress. Each of the 56 items uses a 7-point response set. The items within each domain are averaged (without weighting) to yield a scale score for each domain. The scale scores are ordinal, where a score of 7 = to a great extent; 4 = sometimes; 1 = never; and 0 = not applicable.<sup>64</sup>

It is, perhaps, worth noting that, in part because of the response set categories selected by the authors, the items throughout the questionnaire are positively worded, as the authors concluded it would have been linguistically awkward to pose negatively worded questions. Additionally, the authors wanted the items to reflect the extent to which parents experienced desired or positive provider behaviors, and report of a “negative” behavior would not be equivalent to a report of “positive” behaviors. Both the response set measuring the extent to which behaviors occur and the positively worded statements were deliberately chosen to examine the authors’ broader research interest examining the “possibility that ‘better’ care for parents of children with long-term health or developmental problems has a positive impact on parental mental health.”<sup>63</sup>

Cost for use:	None. Permission required. Can be downloaded from <a href="http://www.canchild.ca">http://www.canchild.ca</a> .
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### MPOC-20

Date of original release:	1999
Number of items/questions:	20
Number of pages:	3
Length of time to complete:	5-10 minutes
Language(s) available:	English
Type of respondent:	Family/patient
Format for completion:	Self-administered

#### Response Set:

The number of items was narrowed to 20, with 3 to 5 items remaining within each of the 5 domains. Items also use a 7-point response set, and the same scale scoring method as the MPOC-56 is used.

Cost for use:	None. Permission required. Can be downloaded from <a href="http://www.canchild.ca">http://www.canchild.ca</a> .
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### MPOC-SP

Date of original release:	1998
Number of items/questions:	27
Number of pages:	4
Length of time to complete:	10-15 minutes
Language(s) available:	English
Type of respondent:	Physician and clinic staff
Format for completion:	Self-administered

#### Response Set:

Uses a 7-point response scale and scale scoring method similar to the other MPOC questionnaires. It is important to note that the MPOC-SP measures the provider’s perceptions of his or her behavior; thus, it may be useful to pair the MPOC-SP with either the MPOC-56 or MPOC-20 measurement tools to gain a multiperspective, more exhaustive analysis of health care delivery in a particular setting.<sup>65</sup>

Cost for use:	None. Permission required. The MPOC-SP can be requested online from <a href="http://www.canchild.ca">http://www.canchild.ca</a> and will be sent electronically.
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## DEVELOPMENT

The development of the MPOC surveys was a lengthy process, which began with a literature review of components of care (COCs), the subsequent identification of 22 COCs by the research group, followed by 2 surveys of health care professionals and parents of children with

special health care needs to determine those COCs most valued by both groups. These surveys identified the 7 highest-ranking COCs, which were (in rank order): parent involvement, education/information, treatment of disability, accessible and available care, continuity and consistency of care, coordination of care, and family-centered approach to care. These categories were used as guidance in focus groups during which parents were asked to identify specific behaviors of health care providers they deem important. This, in combination with a literature review, generated a pool of more than 300 items pertaining to the top 7 COC domains. A draft version containing 101 items was pretested by 40 parents, assessed for readability, and determined to be at an eighth-grade reading level. It was then reviewed by senior staff at the participating Canadian rehabilitation centers in various disciplines of health care. The resulting 101-item questionnaire was then sent out to 1002 consenting families, of which 749 families (74.8%) responded and 653 were ultimately determined to be usable. Data from these surveys were analyzed, and a 49-item survey was developed.<sup>63</sup> However, given the correlations between the variables being examined, the data was reanalyzed using an oblique rotation, which the research team believed to more accurately reflect “reality.”<sup>63</sup> This yielded the MPOC-56, which is the published version of the *Measure of Processes of Care Survey Tool* released in 1995, and has been used among varied patient groups, including those with neurologic disabilities, acquired head injury, cleft palate, and functional constipation. This version has been distributed to individuals and organizations in over 23 countries, mainly in North America, Europe, and Asia. Additionally, it has been translated from English into French, Dutch, Swedish, Finnish, and German.<sup>66</sup> Psychometric testing on sample populations of parents with children ages 0 to  $\geq 17$  years has shown the MPOC-56 to be both reliable and valid. It has demonstrated good internal consistency (Cronbach’s alpha ranging from .63 to .96) and test-retest reliability (intraclass correlation coefficients ranging from .78 to .88) in a number of studies.<sup>62</sup>

In their original publication of the MPOC-56 tool, authors cautioned users about 2 potential limitations of the questionnaire. First, the authors recommended that parents responding to the questionnaire have at least 6 months of exposure to services in the clinical care setting being evaluated before completing the questionnaire. Users of the measurement tool were further cautioned against using survey scores to evaluate individual health care providers, because the tool was not devel-

oped, used, or validated for this purpose.<sup>63</sup> The second and perhaps most significant limitation for those seeking to use the tool as a measure of “medical homeness” is its inability to detect changes in parental experience over time. As the authors stated in their original publication of the MPOC-56, “to date MPOC has been developed and validated as a ‘discriminative’ measure.”<sup>67</sup> That is to say, our interest has been to be able to discern variations in parental experiences and perceptions of care and services received, in order to assess whether varying styles of care are viewed differently as measured by MPOC.”<sup>63</sup> Subsequent testing of the 1-year stability of the MPOC showed a tendency to score lower when repeated after 1 year. Its use as an evaluative instrument to track program intervention effectiveness or the method of health care delivery over time should be limited, because a statistically significant decrease in scale score may not necessarily correspond to a clinically relevant decrease.<sup>68</sup>

A shortened version, the MPOC-20, was developed in 1999 with the intent of improving the tool’s utility as well as its ability to discriminate between programs with different health care services delivery modes. Data from the initial pilot study conducted for the development of the MPOC-56 were reanalyzed, and the number of items was narrowed to 20, with 3 to 5 items remaining within each of the 5 domains. Psychometric testing was repeated using the data sets collected during the extensive pilot testing of the MPOC-56.<sup>66</sup> This analysis focused on reliability, validity, and discriminability. Subsequent testing has shown the MPOC-20 to be both reliable and valid.<sup>66</sup>

The MPOC-Service Provider (MPOC-SP) was developed in 1998 to measure the implementation of family-centered service in caring for children with chronic or special health care needs from a pediatric provider perspective. It can be used alone or in conjunction with the MPOC-56 parent questionnaire to gain the provider perspective on health care delivery in a clinical setting to be used in “initiatives of professional development, program evaluation, and research in the field of health service delivery.”<sup>69</sup> The MPOC-SP has also undergone extensive testing in the field as a discriminative measure, and has demonstrated good internal consistency (Cronbach’s alpha ranging from .76 to .88), test-retest reliability (intraclass correlation coefficients ranging from .79 to .99), and validity (i.e. including cross-disciplinary scale score comparisons and real-ideal comparison testing).<sup>65</sup>

## EXAMPLES OF USES

The MPOC questionnaires, including the MPOC-56, MPOC-20, and the MPOC-SP have been used extensively in at least 23 countries to evaluate family-centered care from the perspective of parents of children treated in rehabilitation centers as well as a variety of other pediatric care settings.

## OBTAINING A COPY OR PERMISSION TO USE

The MPOC-56 and MPOC-20 manual can be downloaded free of charge at [http://canchild.icreate3.esolutions-group.ca/en/measures/mpoc55\\_mpoc20.asp](http://canchild.icreate3.esolutions-group.ca/en/measures/mpoc55_mpoc20.asp).

Instructions for scoring are included in the manual. The MPOC-56 and MPOC-20 survey tools are included in the Appendix of the manual. Programming statements for use with SPSS-PC+ are available from the first author. A copy of the MPOC-SP can be requested by sending an e-mail to [canchild@mcmaster.ca](mailto:canchild@mcmaster.ca) and including the title of the measure (i.e., the MPOC-SP) in the message. A copy of the MPOC-SP will be mailed electronically.

## Primary Care Assessment Survey (PCAS)

### BACKGROUND

The *Primary Care Assessment Survey (PCAS)* was developed by Dana Safran, ScD, at The Health Institute of the New England Medical Center in 1994 with support from a grant from the Agency for Health Care Policy and Research (R01 HS08841).<sup>81</sup>

### PURPOSE

The purpose of the PCAS is to operationalize the 1998 IOM definition of primary care. The tool is for use in performance monitoring and planning at the level of the provider, practice, health plan, or delivery system.<sup>81</sup>

## DESCRIPTION

### PRIMARY CARE ASSESSMENT SURVEY (PCAS) - FULL VERSION

Date of original release:	1994
Number of items/questions:	51
Number of pages:	19
Length of time to complete:	7-15 minutes (self-administered) or 15-20 minutes (interviewer-administered)
Languages available:	English
Type of respondent:	Family/patient

The tool rates at a fifth grade reading level using the *Flesch-Kincaid Reading Ease Index*.<sup>81</sup>

Format(s) for completion:	Self-administered or interviewer-administered
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#### Response Set:

While the response set varies throughout the instrument, the most common response set is *very poor, poor, fair, good, very good, and excellent*.

The PCAS measures 7 domains of primary care performance through 11 summary scales, including: accessibility (organizational, financial), continuity (longitudinal, visit-based), comprehensiveness (contextual knowledge of patient, preventive counseling), integration, clinical interaction (clinician-patient communication, thoroughness of physical examinations), interpersonal treatment, and trust.

Cost for use:	None. Permission required.
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### PRIMARY CARE ASSESSMENT SURVEY (PCAS) - SHORT VERSION

Date of original release:	2000
Number of items/questions:	23
Number of pages:	7
Length of time to complete:	5-10 minutes
Languages available:	English
Type of respondent:	Family/patient

The tool rates at a fifth grade reading level using the *Flesch-Kincaid Reading Ease Index*.<sup>81</sup>

Format(s) for completion:	Self-administered
Response Set:	Same as full version of the PCAS
Cost for use:	None. Permission required.



## DEVELOPMENT

A description of the development of the PCAS can be found in the article “The Primary Care Assessment Survey: Tests of Data Quality and Measurement Performance.”<sup>81</sup> The tool was developed initially for a 2-year study comparing primary care performance of an indemnity insurance plan with 4 types of managed care plans offered to employees. The study included 6810 responses by mail and 394 responses by phone by adults employed in the Commonwealth of Massachusetts and enrolled in 1 of 12 health plans. The response rate was 68.5%. The tool performed highly on all analyses including tests of Likert scaling assumptions (item-convergent validity, item-discriminant validity, equal item variance, equal item-scale correlations, and score reliability) and evaluations on all scales (completeness of data, features of score distributions, and correlations among scales). The *Ambulatory Care Experiences Survey* (2002),<sup>82</sup> also developed by The Health Institute of the New England Medical Center, is a similar tool designed to evaluate patients’ experience with a specific physician. The tool was designed for use in any clinical specialty and is not specific to primary care.

## EXAMPLES OF USES

The questionnaire has been widely utilized in studies to assess the association between primary care characteristics and patient satisfaction, health risk behavior, medication adherence, and receipt of primary care services by Medicaid beneficiaries. In 2000, Ramsay *et al.* adapted the tool for use in general practice in Britain as the *General Practice Assessment Survey* (GPAS).<sup>83</sup> They further modified the tool, developing a shorter version, the *General Practice Assessment Questionnaire* (GPAQ).

## OBTAINING A COPY OR PERMISSION TO USE

The tool is available free of charge at <http://160.109.101.132/icrhps/resprog/thi/pcas.asp>. However, one must register on the Tufts Medical Center Institute for Clinical Research and Health Policy Studies Web site to receive the tool.

## Primary Care Assessment Tools (PCAT)

### BACKGROUND

The *Primary Care Assessment Tools* (PCAT) were developed by Barbara Starfield, MD, MPH, with the Child and Adolescent Health Policy Center in the Department of Maternal and Child Health at the Johns Hopkins University Bloomberg School of Public Health, with support from a grant (Federal Set-Aside Grant No. MCJ243A19) from the MCHB and a grant from the Henry J. Kaiser Family Foundation.<sup>84</sup> Additional support for field tests was provided by the District of Columbia’s Office of Maternal and Child Health through a Federal Set-Aside Grant MCJ42B032 from the MCHB. Further support for tool development was provided by the Primary Care Policy Center for the Underserved (funded by the Bureau of Primary Health Care) at the Johns Hopkins University Bloomberg School of Public Health.<sup>84</sup> The tools are copyrighted by the Primary Care Policy Center for Underserved Populations. The tools are also available for adults, in comparable form (differing only in the comprehensiveness domain because of the different needs of children and adults).

### PURPOSE

The PCAT is a suite of tools for elicitation of experiences with primary care by the extent and quality of primary care services as well as of primary health care systems.<sup>84</sup>

### DESCRIPTION

The PCAT includes comparable surveys of consumer-clients, facilities, providers, and health systems. The *Consumer-Client Tools* include expanded and short versions of both adult and child questionnaires. The *Facility* and *Provider Tools* also have both expanded and short versions. The *Health System Questionnaire* is currently in development. The PCAT includes tools such as a training manual for interviews, a sample consent form, a tally sheet for interviewers, a sample callback appointment sheet, and instructions for data analysis of each of the questionnaires. The survey contents are consistent with both the 1978 and 1996 IOM definitions of primary care, and include all of the components of primary care in each of the questionnaires.

## PCAT CHILD

	Full Version	Short Version
Date of original release:	1998	1998
Number of items/questions:	121	68
Number of pages:	14	11
Length of time to complete:	20-25 minutes	10-15 minutes
Language(s) available:	English, Spanish, French, Portuguese, Korean, and Mandarin Chinese (both People's Republic of China and Taiwan)	
Type of respondent:	Family/patient The reading level is high school.	
Formats for completion:	Self-administered or interviewer-administered (by mail, in-office, by phone, or in-person)	
Response Set:	<p>Although the response set varies in introductory and concluding sections, the majority of the response sets are <i>definitely, probably, probably not, definitely not, and not sure/don't remember</i>.</p>	
Cost for use:	None. Permission required.	

## PCAT PROVIDER

	Full Version	Short Version
Date of original release:	1998	1998
Number of items/questions:	153	70
Number of pages:	14	10
Length of time to complete:	20-25 minutes	10-15 minutes
Language(s) available:	English, Spanish, French, Portuguese, Korean, and Mandarin Chinese (both People's Republic of China and Taiwan)	
Type of respondent:	Physician	
Formats for completion:	Self-administered or interviewer-administered	
Response Set:	<p>Although the response set varies in introductory and concluding sections, the majority of the response sets are <i>definitely, probably, probably not, definitely not, and not sure/don't remember</i>.</p>	
Cost for use:	None. Permission required.	

## PCAT FACILITY

	Full Version	Short Version
Date of original release:	1998	1998
Number of items/questions:	153	70
Number of pages:	14	10
Length of time to complete:	20-25 minutes	10-15 minutes
Language(s) available:	English, Spanish, French, Portuguese, Korean, and Mandarin Chinese (both People's Republic of China and Taiwan)	
Type of respondent:	Clinic staff or provider	
Formats for completion:	Self-administered or interviewer-administered	
Response Set:	<p>Although the response set varies in introductory and concluding sections, the majority of the response sets are <i>definitely, probably, probably not, definitely not, and not sure/don't remember</i>.</p>	
Cost for use:	None. Permission required.	

## DEVELOPMENT

A description of the development of the tools can be found in the articles, "Measuring Consumer Experiences with Primary Care" and "Validating the Adult Primary Care Assessment Tool."<sup>85,86</sup> Both tools have been extensively tested for validity and reliability in such diverse populations as pediatric patients in Washington, DC, parents of children in health plans and the Healthy Kids subsidized insurance program in Florida, and adults in a health maintenance organization and health plans for low-income individuals in North Carolina.

## EXAMPLES OF USES

The tools have been used to examine the association between high ratings of primary care and group visits for patients with diabetes,<sup>87,88</sup> provision of primary care by family medicine preceptors,<sup>89</sup> practice features associated with primary care,<sup>90</sup> relationship of primary care to various health care reform strategies,<sup>91</sup> provision of primary care in health maintenance organizations and community health centers,<sup>92</sup> and racial and ethnic disparities in provision of primary care.<sup>93</sup> The tools have been used in Canada (Quebec), Brazil, Spain (Catalonia), South Korea, and China (both Taiwan and People's Republic of China).

## OBTAINING A COPY OR PERMISSION TO USE

The tools are available free of charge and can be downloaded from the Johns Hopkins University Primary Care Policy Center Web site ([http://www.jhsph.edu/pcpc/pca\\_tools.html](http://www.jhsph.edu/pcpc/pca_tools.html)). Permission for use is requested.

## Promoting Healthy Development Survey (PHDS)

### BACKGROUND

The Child and Adolescent Health Measurement Initiative (CAHMI) began development of the *Promoting Healthy Development Survey (PHDS)* in March 1998 with primary funding from The Commonwealth Fund. The David and Lucille Packard Foundation supported the initial pilot testing of the PHDS instrument, which was copyrighted in 1999.<sup>94,95</sup> Findings from the pilot testing, including the psychometric priorities of the PHDS, were published in "Assessing Health System Provision of Well-Child Care: The Promoting Healthy Development Survey."<sup>95</sup> The PHDS-PLUS, an enhanced telephone version, including items about the child and parent's health, health care utilization, etc. was developed from 1999-2000.<sup>94,96</sup> Reduced-item versions of the PHDS were developed for easier in-office survey administration and subsequently released under the name *ProPHDS* in 2001. An online version of the PHDS, called the *Online PHDS*, and a further reduced-item online version, called the *ProPHDS-5*, were released in November 2007. Providers using the *Online PHDS* can customize the content to include only specific sections of the PHDS and can choose to generate system-, plan-, office-, and/or provider-level feedback reports based on the survey data collected. The online versions of the survey also allow parents who complete the survey to receive a customized feedback report to help guide them on questions they should ask their child's health care provider at his or her next visit and provide links to educational resources.<sup>97,98</sup> The *Online PHDS* has provisional approval from the American Board of Pediatrics (ABP) to fulfill Performance in Practice (part 4) of the Maintenance and Certification requirements, requiring pediatricians to demonstrate competence in systematic measurement and improvement in patient care by surveying patients about their experience of care and completing ABP-approved QI projects and activities. The *Online PHDS* falls under the category of "Web-based improvement activities" defined by the ABP as a "self-paced, expert-devel-

oped quality improvement activities that physicians complete within their own practice setting. ABP-approved Web-based QI activities are ideal for pediatricians who do not have access to multipractice improvement initiatives."<sup>99</sup> The National Quality Forum (NQF) has endorsed the PHDS as a valid measure for system-, plan-, and provider-level "assessment of patients' experiences with preventive and developmental health care."<sup>96</sup>

### PURPOSE

The primary goal of the survey is to assess clinical processes of care and the quality of care experienced by children from 3 to 48 months old, specifically with regards to the recommended guidelines for the provision of developmental services set forth by the *Bright Futures* initiative of the AAP and MCHB.<sup>95</sup> The PHDS uses data obtained directly from parents regarding care their child has received "in the last 12 months" to generate quality measures, which are intended to aid health care providers, consumers, purchasers, and policy makers in assessing the degree to which practitioners and health plans provide helpful, family-centered anticipatory guidance and child and family psychosocial and developmental assessment services and follow-up.<sup>95</sup>

### DESCRIPTION

#### PHDS – FULL VERSION

Date of original release:	1999
Number of items/questions:	61
Number of pages:	16
Length of time to complete:	15-18 minutes
Languages available:	English and Spanish
Type of respondent:	Family/patient

Readability assessments indicate the PHDS is written at the eighth- to ninth-grade reading level.<sup>95</sup> A majority of the cognitive testing on the PHDS items over the last 11 years has been with parents of children enrolled in Medicaid.

Format(s) for completion:	Self-administered (mail)
Response Set:	

All versions of the PHDS incorporate the use of yes/no questions, as well as various Likert-like scales to score responses.

Measures of quality of care collected by the PHDS include: (1) anticipatory guidance and parental education by a doctor or other health provider; 2) health information; 3) developmental surveillance: ask about and address parents' concerns about their child's learning, development, and behavior; 4) standardized screening for developmental and behavioral delays; 5) follow-up for children at risk for developmental, behavioral, and social problems; 6) assessment of psychosocial well-being and safety in the family; 7) assessment of smoking, drug, and alcohol use in the family; 8) family-centered care (experience of care); and 9) helpfulness and effect of care provided.<sup>95</sup>

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Cost for use: None. Permission required.

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### PHDS-PLUS

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Date of original release:	2001
Number of items/questions:	128
Number of pages:	N/A
Length of time to complete:	12-15 minutes
Languages available:	English (most parts also available in Spanish as part of the NSECH)
Type of respondent:	Family/patient
Format(s) for completion:	Interviewer-administered (telephone)

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Response Set:

Yes/no questions, as well as various Likert-like scales to score responses. 78% of the items are derived from the original, full PHDS.<sup>100</sup>

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Cost for use: None. Permission required.

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### PRO-PHDS

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Date of original release:	2002
Number of items/questions:	21
Number of pages:	6
Length of time to complete:	5 minutes
Languages available:	English
Type of respondent:	Family/patient
Format(s) for completion:	Self-administered (mail/in-office)

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Ideal for in-office self-administration, this reduced-item version of the PHDS was developed in response to research demonstrating that, in order for in-office survey administration to be feasible, surveys must take no longer than 5 minutes for parents to complete.<sup>101</sup>

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Response Set:

Yes/no questions, as well as various Likert-like scales to score responses are used to collect descriptive information about parenting behaviors and issues in the family and captures information about 6 of the 9 PHDS measures of care—namely, anticipatory guidance and parental education, family-centered care, asking about and addressing parental concerns, follow-up for children at risk for developmental/behavioral delays, and assessment of the family. To further facilitate ease of administration, and avoid the age-specific skip patterns present in mail or telephone versions, 3 specific versions of the ProPHDS target distinct timeframes of child development for children younger than 4 years of age - Version 1 (3-8 months), Version 2 (9-17 months), and Version 3 (18-47 months).<sup>100</sup> Each of the versions consists of 21-items and is 6 pages long.

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Cost for use: None. Permission required.

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### ONLINE PHDS

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Date of original release:	2008
Number of items/questions:	Maximum of 66 items - Users can pick specific sections
Number of pages:	Web-based
Length of time to complete:	10-15 minutes - users can pick specific sections, therefore the survey length can be shorter
Languages available:	English
Type of respondent:	Family/patient

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Parents completing the online survey receive customized feedback.

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Format(s) for completion: Self-administered (online)

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Response Set:

The majority of the survey is tailored to the specific age of the child and focuses on the recommendations for the well-child care visits for children in that age group. Health care providers can set up custom versions of the online survey in order to meet their measurement needs.

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Cost for use: None. Permission required.

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## ONLINE PROPHDS-5

Date of original release:	2008
Number of items/questions:	15
Number of pages:	Web-based
Length of time to complete:	3-5 minutes
Languages available:	English
Type of respondent:	Family/patient
Format(s) for completion:	Self-administered (online)
Response Set:	
	An even more abbreviated version, focusing on 5 distinct aspects of care.
Cost for use:	None. Permission required.

Detailed sampling instructions for each survey version are provided for survey administration and evaluation at the group or provider level. In general, the sample size required is 15 to 20 completed surveys per health care provider.<sup>95</sup>

## DEVELOPMENT

A description of the development of the PHDS survey tool can be found in the article, "Assessing Health System Provision of Well-Child Care: The Promoting Healthy Development Survey."<sup>95</sup> Further summaries regarding the testing, validation and implementation of the PHDS can be found on the National Quality Forum Web site and the Agency for Healthcare Research and Quality (AHRQ) Child Health Care Quality Toolbox (<http://www.ahrq.gov/chtoolbox/measure6.htm>). A description of the psychometric properties for each of the PHDS measures can be found on the National Quality Measures Clearinghouse (NQMC) Web site ([http://www.qualitymeasures.ahrq.gov/summary/summary.aspx?ss=1&doc\\_id=10365](http://www.qualitymeasures.ahrq.gov/summary/summary.aspx?ss=1&doc_id=10365)).

As reported in PEDIATRICS, pilot testing of the survey was conducted with a diverse group of families in 3 managed care organizations serving families in California (2 of 3) and Ohio ( $n = 1478$ ) via mail administration. The response rate ranged from 32% to 45%. In-depth cognitive testing of the draft survey was conducted with 15 families representing a range of racial, income, and education groups, as well as different types of health insurance coverage, age of child, age and sex of parent, and number of children in the family. Psychometric analyses demonstrated that the PHDS quality measures scales have strong construct validity

and internal consistency.<sup>95</sup> Psychometric testing of the measures was reconfirmed with each pilot and with each new version of the PHDS developed. The PHDS measures are included in the National Quality Measures Clearinghouse (NQMC) and described in-depth in the AHRQ Child Health Care Quality Toolbox.

## EXAMPLES OF USES

More than 45 000 surveys have been collected to date by 10 Medicaid agencies, 4 health plans, and over 50 pediatric practices and nationally through the National Survey of Early Childhood Health (NSECH).<sup>96</sup> Further information regarding the components of the PHDS that have been incorporated in the NSECH can be found at <http://www.healthychild.ucla.edu/NSECH.asp>.

## OBTAINING A COPY OR PERMISSION TO USE

To obtain a copy of the PHDS or find more information about this tool developed by CAHMI, visit <http://www.cahmi.org>.

The PHDS is copyrighted, nonproprietary tool that is available at no charge, provided the user includes the copyright information on the survey tool. Users are encouraged to complete the CAHMI Users Form available on the CAHMI Web site so they receive updates and improvements to the tool, thereby insuring they are using the most updated version. Questions about the PHDS can be directed to CAHMI at (503) 494-1930 or [cahmi@ohsu.edu](mailto:cahmi@ohsu.edu).

## Physicians Practice Connections – Patient-Centered Medical Home (PPC-PCMH)

### BACKGROUND

The Physicians Practice Connections – Patient-Centered Medical Home (PPC-PCMH) was developed and funded by the National Committee for Quality Assurance (NCQA) in 2008.<sup>78</sup> The PPC-PCMH has been endorsed by the ACP, the AAFP, the AAP, the AOA, and other specialty professional societies, as well as the PCPCC. It has been endorsed by the National Quality Forum under the title Medical Home System Survey.

## PURPOSE

The purpose of the PPC-PCMH is to evaluate practices to recognize those meeting requirements as medical homes. Additionally, it was designed to develop standardized measures of a medical home for payers, for evaluation across PCMH demonstration projects, and for practices participating in projects with multiple payers.<sup>78</sup>

## DESCRIPTION

The 2008 PPC-PCMH is a self-scoring, Web-based survey tool completed by members of a practice. The application materials and description of standards and guidelines are available for free online. However, the actual survey tool costs \$80 to access for 1 to 4 users. The tool requires 40 to 80 hours to complete. The tool is composed of 9 standards, including questions pertaining to access and communication, patient tracking and registry functions, care management, patient self-management support, electronic prescribing, test tracking, referral tracking, performance reporting and improvement, and advanced electronic communication.

### PHYSICIANS PRACTICE CONNECTIONS - PATIENT-CENTERED MEDICAL HOME (PPC-PCMH)

Date of original release:	2008
Number of items/questions:	166
Number of pages:	Web-based
Length of time to complete:	40-80 hours
Languages available:	English
Type(s) of respondent:	Physician and clinic staff
Format for completion:	Self-administered

#### Response Set:

The tool includes 10 must-pass elements. In order to be recognized as a level 1, practice must score 15-49 points and pass 5 of the 10 must-pass elements with a performance level of at least 50%. To be recognized as level 2, a practice must score 50-74 points and pass all of the must-pass elements with a performance level of at least 50%. To achieve level 3 recognition, a practice must score 75 points or more and all 10 of the must-pass elements with a performance of at least 50%. Once the tool is complete, the practice members submit data and supporting documentation to the NCQA to be scored by the NCQA. At least 5% of the practices will then require an onsite audit by NCQA to validate documentation and survey responses. Once NCQA provides final results to the practice, information about the physicians, the practice, and the level of performance is available on the NCQA Web site for data users, including health plans and physician directory publishers. Information on practices that do not pass any level is not reported.<sup>78</sup>

Cost for use:	\$80 to access for 1-4 users
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## DEVELOPMENT

The PPC-PCMH was developed by the National Committee for Quality Assurance (NCQA) in 2008. The tool was developed based on the concepts of and evidence for the *Chronic Care Model* and informed by the experience of NCQA with the Bridges to Excellence program. Pilot testing of the *Physician Practice Connections Readiness Survey (PPC-RS)*, a precursor to the PPC-PCMH, found that self-reports alone should not be used for pay-for-quality efforts or public reporting<sup>79</sup> and that practice systems as measured by the PPC-RS are associated with high quality care for diabetes.<sup>80</sup> The initial instrument elements were developed using the 6 sigma process with a panel of experts, including clinicians, purchasers, medical directors, and systems experts. The NCQA staff worked closely with leaders of the ACP, AAFP, AAP, and AOA to develop the PPC-PCMH. A modified version of the PPC-PCMH, the *PPC-PCMH CMS Version* was released in 2009 for the CMS and includes new elements, such as a comprehensive health assessment and a module on giving patients information on the role of the medical home.

## EXAMPLES OF USES

The PPC-PCMH is currently be used extensively as a tool to identify practices as a PCMH in order to provide increased payment by payers, particularly in PCMH pilot projects.<sup>18</sup> For example, multipayer pilots in Colorado, Pennsylvania, New York, and Rhode Island, statewide pilots in Maine, Pennsylvania, and Vermont, single-payer initiatives by EmblemHealth, CIGNA, Humana, UnitedHealthcare, and Priority Health and governments, such as CMS (Medicare), New York City, Louisiana, Colorado, New Hampshire, Rhode Island, and Vermont are using the PPC-PCMH standards for practice recognition as a PCMH.<sup>18</sup>

## OBTAINING A COPY OR PERMISSION TO USE

The tool costs \$80 to access for 1 to 4 users. The tool can be found on the NCQA Web site at <http://www.ncqa.org/tabid/629/Default.aspx>.

# Parent's Perceptions of Primary Care (P3C)

## BACKGROUND

The *Parent's Perceptions of Primary Care (P3C)* tool was developed by Michael Seid, PhD, and the Center for Child Health Outcomes at the Children's Hospital and Health Center in San Diego, California.<sup>71</sup> Development of the tool was supported by a grant from the Agency for Healthcare Research and Quality (R01 HS10317) and the Substance Abuse and Mental Health Services Administration.

## PURPOSE

The purpose of the tool is a measure of pediatric primary care quality that is brief, practical, reliable, and valid; can be used irrespective of insurance status or presence of an established clinician-patient relationship; and is useful to patients and pediatricians, policy makers, and health system leaders.<sup>71</sup>

## DESCRIPTION

### PARENT'S PERCEPTIONS OF PRIMARY CARE (P3C)

Date of original release:	2001
Number of items/questions:	23
Number of pages:	1
Length of time to complete:	5-10 min
Languages available:	English, Spanish, Vietnamese, and Tagalog
Type of respondent:	Family/patient
Format for completion:	Self-administered

The tool has also been used via mail, telephone, and in-person interviews.

### Response Set:

The response scale for 21 of 23 items on the tool are a 5-point Likert scale with 0 = never; 1 = sometimes; 2 = often; 3 = almost always; and 4 = always. The tool does not refer to a specific time period of care. The scale yields scores on a 0-100 scale with 100 indicating higher scores of primary care. The scale yields both an overall index scale as well as subscale scores measuring continuity, access, contextual knowledge, communication, comprehensiveness, and coordination. The P3C is based on the IOM definition of primary care.

Cost for use:	None. Permission required.
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## DEVELOPMENT

A description of the development of the tool can be found in the article "Parents' Perceptions of Primary Care: Measuring Parents' Experiences of Pediatric Primary Care Quality."<sup>71</sup> After initial modifications to the instrument, additional pilot testing with 15 parents at an elementary school using cognitive interviewing methodology occurred.<sup>70</sup> The resulting instrument included 23 items. To validate the tool, 228 classes from 18 elementary schools within a large, urban school district, including children in kindergarten through sixth grade, were asked to participate. The classes represented a variety of language and heterogeneity of socioeconomic status. Students were asked to take the tool home and to ask parents to complete the tool. The response rate was 66% and included 3371 parents. The tool scored well in terms of feasibility, internal consistency, reliability, and validity using factor analysis and comparison between groups of children and with other tools.<sup>71</sup>

## EXAMPLES OF USES

The development of the P3C included a diverse population of parents in one geographic area of southern California, including those speaking Spanish, Vietnamese, and Tagalog, and of different socioeconomic backgrounds. The tool has also been used to assess primary care of children of Latino farm workers in Imperial County, California, and San Diego County, California, recruited from Head Start Centers.<sup>72</sup> The tool has been used to assess the association between access and primary care experiences in an urban community sample in California,<sup>73</sup> between barriers to care for children with asthma and primary care experiences in federally qualified health centers in San Diego County, California,<sup>74</sup> and between the effects of race/ethnicity, language, and potential access and primary care experiences in San Diego County, California.<sup>75</sup> The tool has also been used in residency practices in the Continuity Research Network across the country.<sup>76,77</sup>

## OBTAINING A COPY OR PERMISSION TO USE

The tool is available free of charge.

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## Young Adult Health Care Survey (YAHCS)

### BACKGROUND

The *Young Adult Health Care Survey (YAHCS)* was developed by the Child and Adolescent Health Measurement Initiative (CAHMI) in 1999 through funding from The David and Lucile Packard Foundation and The Commonwealth Fund. Given the well-documented gaps in health care quality and preventive services for adolescents, the high prevalence of health risk factors among teenagers, and the acknowledged need for teen-specific provider training and access to care strategies, the YAHCS was developed to inform quality improvement efforts in the field of adolescent health care. Endorsed by the National Quality Forum (NQF) for system and plan-level measurement, the quality measures derived from the YAHCS were intended to address the gap in standardized quality measures assessing the content of care provided to young adults as well as complement existing measures of well-child visit rates and the number of preventive care visits for teenagers. The YAHCS provides relevant and actionable data that can be used to assess whether young adults receive nationally recommended preventive health care services and guide quality improvement efforts targeting America's 40 million adolescents.<sup>102</sup>

### PURPOSE

The central purpose of the YAHCS is to complement existing performance measurement methods, and provide a comprehensive, actionable assessment of the quality of preventive care provided to adolescents, specifically with regard to adolescent preventive counseling and screening guidelines.<sup>102</sup>

## DESCRIPTION

The YAHCS is a teen survey that assesses whether young adults (ages 14 and older) are receiving nationally recommended preventive services on the basis of the recommended guidelines of a number of medical professional associations, including the American Medical Association's *Guidelines for Adolescent Preventive Services*.<sup>103</sup>

### YOUNG ADULT HEALTH CARE SURVEY (YAHCS)

Date of original release:	1999
Number of items/questions:	56 items
Number of pages:	7 pages
Length of time to complete:	10-15 minutes
Language(s) available:	English and Spanish
Type(s) of respondent:	Family/patient

Readability analyses indicate the YAHCS to be written at the sixth- to eighth-grade reading level.<sup>102</sup> For provider-level reporting, CAHMI recommends 15-30 completed surveys.<sup>104</sup>

Format for completion:	Self- or Interviewer-administered (mail or telephone)
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#### Response Set:

Using the data collected through the survey, composite quality measures can be tabulated for each of the 8 aspects of recommended preventive care emphasized in the YAHCS. The 8 categories are strongly aligned with adolescent preventive care guidelines set forth by the AMA, AAP, AAFP, and MCHB and the goals and objectives of *Healthy People 2010*.<sup>102</sup> They include: preventive screening and counseling on risky behaviors, sexual activity and sexually transmitted diseases (STDs), weight, healthy diet, and exercise, and emotional health and relationship issues; private and confidential care; helpfulness of counseling; communication and experience of care; and health information. A ninth, global, comprehensive quality measure can be calculated to assess the number of teenagers who received all the components of recommended care measured in the survey. The YAHCS gathers additional information regarding the quality of care findings for specific groups of young adults, which can be useful for quality improvement and community assessment.<sup>105</sup>

Cost for use:	None. Tool is copyrighted but nonproprietary.
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## DEVELOPMENT

The YAHCS was developed by CAHMI in 1999, following the implementation of the S-CHIP program in 1997. The YAHCS development and implementation was peer reviewed by the CAHMI Young Adult Health Care



Advisory Group which involves consumers, providers, researchers, policy makers, and other stakeholders. Testing of the survey was conducted through 35 cognitive interviews of teenagers, a formal readability assessment and pilot testing field trials in a total of 6 sites, both commercial and public, in California, New York, and Florida ( $n = 4060$ ). Telephone ( $n = 1767$ ) and mail ( $n = 2293$ ) administration methods were used, yielding an average response rate of 40.3% of adolescents whose parents waived authorization (6.45% of parents refused to allow their adolescent to participate). Findings from the pilot field trials in the 6 health plans showed YAHCS quality measures have strong construct validity and strong internal consistency.<sup>102</sup> In each subsequent implementation of the YAHCS, psychometric analyses were conducted and similar findings regarding the strong reliability and validity of the tool were confirmed.<sup>105</sup> The YAHCS has been endorsed by the National Quality Forum<sup>103</sup> and the quality measured derived from the YAHCS are included in the National Quality Measure Clearinghouse (NQMC).<sup>106</sup>

## EXAMPLES OF USES

Beyond the original field testing in California, New York, and Florida, the YAHCS has been used by several counties, state Medicaid and S-CHIP agencies, and health plans.<sup>105</sup> Components of the YAHCS were used nationally in the FACCT *Young Adult Online Survey* about teen health and health care sponsored by the Robert Wood Johnson Foundation.<sup>107</sup>

## OBTAINING A COPY OR PERMISSION TO USE

To obtain a copy of the YAHCS or find more information about this tool developed by CAHMI, visit <http://www.cahmi.org>.

The YAHCS is copyrighted, nonproprietary tool that is available at no charge, provided the user includes the copyright information on the survey tool. Users are encouraged to complete the *CAHMI Users Form* available on the CAHMI Web site so they receive updates and improvements to the tool, thereby insuring they are using the most updated version. Questions about the YAHCS can be directed to CAHMI at (503) 494-1930 or [cahmi@ohsu.edu](mailto:cahmi@ohsu.edu).

# Section IV: Future Directions in Measurement of the Pediatric Medical Home

## ASSESSING THE TOOLS AGAINST THE ATTRIBUTES OF THE PEDIATRIC MEDICAL HOME

All of the tools were reviewed and scored against the elements described in the *Desirable Characteristics of a Medical Home* (see Table 1). Each attribute of a pediatric medical home was rated as a “-” if no element within the attribute was included in the tool, a “+” if one element was in the tool, and “++” if 2 or more elements were included in the tool.

**TABLE 3. PEDIATRIC MEDICAL HOME ATTRIBUTES OF AVAILABLE TOOLS**

Tool	Accessible	Family Centered	Continuous	Comprehensive	Coordinated	Compassionate	Culturally Effective
CAHPS Child Primary Care Questionnaire 2.0	-	++	+	++	++	+	+
CPCI	-	++	+	++	++	+	-
FCCT	++	++	+	+	++	++	++
MHI	-	++	+	-	++	-	+
MHFI	++	++	+	-	++	+	+
MHIQ	-	++	+	++	++	-	++
MPOC – 56	-	++	++	++	++	++	-
MPOC – 20	-	++	+	++	++	++	-
PCAS	++	++	++	++	++	++	+
PCAS – Short Form	+	++	+	++	++	++	-
PCAT – Child Expanded Tool	+	++	++	++	++	++	++
PCAT – Child Short Tool	+	++	+	++	++	+	++
PHDS	-	++	+	++	+	++	++
PPC-PCMH	+	++	+	+	++	-	++
P3C	+	++	+	++	++	+	+
YAHCS	-	++	-	+	-	+	+

- No elements from the AAP *Desirable Characteristics of a Medical Home* included in attribute
- + if at least one element from AAP *Desirable Characteristics of a Medical Home* included in attribute
- ++ if more than one element from AAP *Desirable Characteristics of a Medical Home* included in attribute

## DISCUSSION OF RESULTS

Across all tools assessed, coordination and family-centered care were the most represented attributes of the pediatric medical home (see Table 3). Accessibility and compassion were the least represented attributes, likely because of the level of specificity used in the examples of accessibility within the *Desirable Characteristics of a Medical Home* described by the AAP and the difficulty in developing a measure of compassion. The *Family-Centered Care Self-Assessment Tool* and the *Primary Care Assessment Tools (PCAT)* contained the most elements of the pediatric medical home as defined by the AAP.

None of the tools included more than one element of all domains as defined by the *Desirable Characteristics of a Medical Home*. However, this may be partly because the elements described within the AAP practice accessibility domain, such as acceptance of all insurance and accessibility by public transportation, are quite specific. It should also be noted that some elements described in the IOM definition of accessibility, such as cultural and language accessibility and accessibility by phone, are included under different attributes within the AAP medical home definition.

Although most tools were rigorously tested for validity and reliability within different populations, a few, such as the *Medical Home Implementation Quotient (MHIQ)* and the *Family-Centered Care Self-Assessment Tool*, either were not rigorously field tested or are in the process of field testing at this time.

Although the AAP *Desirable Characteristics of a Medical Home* includes specific operationalized items, not all are included in all tools. Ideally, the *Desirable Characteristics* could be incorporated and field tested within existing tools. Through additional psychometric testing, one could determine whether the *Desirable Characteristics* fit within the ascribed medical home attributes, defined by the 4 primary care attributes: comprehensiveness, coordination, continuity, and accessibility.

## DIFFICULTIES IN MEASUREMENT

Primary care is difficult to measure in many ways. The outcomes of primary care are less specific than disease-oriented preventive or treatment programs. Primary care addresses a wider range of patient needs, beyond disease-oriented preventive or treatment programs, and

patients often have multiple problems for which desirable outcomes are contested.<sup>108</sup> The challenge for many of the medical home demonstrations undertaken to date is further complicated by the need to understand the processes and structures within primary care and how these relate to population level outcomes, such as morbidity and mortality. Understanding the downstream affect of transformational activities within a practice is essential to improving a medical home. Many of the tools assessed can assist in measuring changes within the medical home over time and yield results to guide future process changes and transformational activities.

Measurement of “medical homeness” is further complicated by the differing definitions of a medical home being used in the field. Although the Medical Home Initiatives for Children with Special Needs Project Advisory Committee operationalized the AAP definition of the medical home through the *Desirable Characteristics*, the *Joint Principles* created a shared definition of the patient- and family-centered medical home, but provided little guidance on operationalizing and measuring how well a practice meets this shared definition. As the Iowa Center for Evaluation Research stated after reviewing the evidence for medical homes, “Without adequate and standardized methods for measuring this concept, it is not possible to determine what practices have achieved a medical home. Research on the outcomes related to the adoption of a medical home is even more problematic to determine when there is no accepted definition. Because of the lack of standardization and the previous ambiguity of the definition, it is not always clear that the researchers are measuring the same construct.”<sup>109</sup> Thus, without a standardized definition of what constitutes a medical home, it is difficult to develop a standardized measure of “medical homeness.”

## IMPORTANCE OF MEASUREMENT

Despite the acknowledged difficulties in measurement of a medical home, measurement and tools for measurement are critically important. Purchasers, payers, providers, and patients need to be able to determine whether new practice and payment models are successful as measured by changes in practice that affect patient and provider satisfaction, population health indicators, and value to society. The tools included in this guide are also of interest as a means to evaluate the merit of current medical home pilot and demonstration

projects, particularly those focused on or including pediatric populations. The tools for measurement are of critical importance in achieving standardized assessment of components pursuant to achieving better health, lower costs, and improved equity.

Although measurement is important, understanding the relationship between practice change as a result of transformational activities and payment reform requires time. Behavioral and organizational change is difficult and changes in health status and population health are often slow. Therefore, sufficient time for measurement is essential in order to judge the return on investment for all stakeholders in the medical home pilot and demonstration projects. As has been noted, "A criticism of current pilot demonstration evaluations is the pressure on researchers to demonstrate a business case, or lack thereof, in short order. In this regard, health care reform may do well to heed the lessons of the recent collapse of the financial sector: remaining too focused on short-term gains is alluring but in the end may provide foolhardy."<sup>17</sup>

## NEXT STEPS

Identifying tools with immediate practical relevance for providers, families, and patients is also of critical importance. Years may be required to further assess the true value of many of the medical home pilot and demonstration projects. Therefore, having immediately useful information available from comparable practice surveys will encourage patients, families, and providers to remain engaged in the evaluation process as well as provide critical information that can actually affect the transformational process through provision of quality improvement reports. Tools that are available in parallel formats for both providers and families or patients, such as the *Family-Centered Care Self-Assessment Tool* and the *Primary Care Assessment Tool (PCAT)*, are of value for quality improvement purposes as the same questions are asked from the perspective of the provider or patient/family member. By identifying variation both within and between the provider and patient/family groups, practices can immediately identify areas of strength and opportunities for improvement.

## RECOMMENDATIONS

1. Reach consensus on specific elements to be included within each attribute of the medical home. Are those within the *Desirable Characteristics of a Medical Home* optimal for defining and measuring a pediatric medical home? Are the primary care domains and subdomains the same for adults and children, recognizing that specific items may have to differ, and that it might be useful to have other (nonprimary care) components of care that are relevant only for children or other specific age groups? Consistency across different age groups would be useful for characterizing health services across the lifespan.
2. Develop new or expand existing tools to incorporate appropriate constructs for evaluating the pediatric medical home.
3. Develop new or expand to parallel formats for existing tools to incorporate perspectives from multiple stakeholders, such as providers, staff, families, and patients, and for use as quality improvement tools.
4. Advocate for greater inclusion of pediatric practices in the medical home pilot and demonstration projects currently underway, with a concomitant effort to incorporate evaluation tools measuring attributes relevant to pediatric medical homes.

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## Appendix A. Characteristics of the New Model of Family Medicine

CHARACTERISTIC	DESCRIPTION
Personal medical home	The practice serves as a personal medical home for each patient, ensuring access to comprehensive, integrated care through an ongoing relationship
Patient-centered care	Patients are active participants in their health and health care. The practice has a patient-centered, relationship-oriented culture that emphasizes the importance of meeting patients' needs, reaffirming that the fundamental basis for health care is "people taking care of people"
Team approach	An understanding that health care is not delivered by an individual, but rather by a system, which implies a multidisciplinary team approach for delivering and continually improving care for an identified population
Elimination of barriers to access	Elimination, to the extent possible, of barriers to access by patients through implementation of open scheduling, expanded office hours, and additional, convenient options for communication between patients and practice staff
Advanced information systems	The ability to use an information system to deliver and improve care, to provide effective practice administration, to communicate with patients, to network with other practices, and to monitor the health of the community. A standardized electronic health record (EHR), adapted to the specific needs of family physicians, constitutes the central nervous system of the practice
Redesigned offices	Offices should be redesigned to meet changing patient needs and expectations, to accommodate innovative work processes, and to ensure convenience, comfort, and efficiency for patients and clinicians
Whole-person orientation	A visible commitment to integrated, whole-person care through such mechanisms as developing cooperative alliances with services or organizations that extend beyond the practice setting, but which are essential for meeting the complete range of needs for a given patient population. The practice has the ability to help guide a patient through the health care system by integrating care—not simply coordinating it
Care provided within a community context	A culturally sensitive, community-oriented, population-perspective focus
Emphasis on quality and safety	Systems are in place for the ongoing assessment of performance and outcomes and for implementation of appropriate changes to enhance quality and safety
Enhanced practice finance	Improved practice margins are achieved through enhanced operating efficiencies and new revenue streams
Commitment to provide family medicine's basket of services	A commitment to provide patients with family medicine's full basket of services—either directly or indirectly through established relationships with other clinicians

## Appendix B. Components of the Advanced Medical Home Model

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Acknowledgment that the best quality of care is provided not in episodic, illness-oriented, complaint-based care—but through patient-centered, physician-guided, cost-efficient, longitudinal care that encompasses and values both the art and science of medicine.

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Attributes include promotion of continuous healing relationships through delivery of care in a variety of care settings according to the needs of the patient and skills of the medical provider.

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Physicians are partners in coordinating and facilitating care to help patients navigate the complex and often confusing health care system by providing guidance, insight and advice in language that is informative and specific to patients' needs.

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Patients will have a personal physician working with a team of health care professionals in a practice that is organized according to the principles of the advanced medical home. In most cases, primary care physicians, with their office care team, are ideally suited to provide principal care and be a patient's care coordinator. However, a medical specialist with his/her office care team can fulfill the role if he/she so chooses.

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Personal physicians advocate for and provide guidance to patients and their families as they negotiate the complex health care system.

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## Appendix C. Joint Principles of the Patient-Centered Medical Home

Personal physician	Each patient has an ongoing relationship with a personal physician trained to provide first contact, continuous and comprehensive care.
Physician directed medical practice	The personal physician leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of patients.
Whole-person orientation	The personal physician is responsible for providing for all the patient's health care needs or taking responsibility for appropriately arranging care with other qualified professionals. This includes care for all stages of life: acute care, chronic care, preventive services, and end-of-life care.
Care is coordinated and/or integrated	Care is coordinated and/or integrated across all elements of the complex health care system (eg, subspecialty care, hospitals, home health agencies, nursing homes) and the patient's community (eg, family, public, and private community-based services). Care is facilitated by registries, information technology, health information exchange, and other means to ensure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.
Quality and safety	Quality and safety are hallmarks of the medical home: <ul style="list-style-type: none"> <li>• Practices advocate for their patients to support the attainment of optimal, patient-centered outcomes that are defined by a care planning process driven by a compassionate, robust partnership between physicians, patients, and the patient's family</li> <li>• Evidence-based medicine and clinical decision-support tools guide decision making</li> <li>• Physicians in the practice accept accountability for continuous quality improvement through voluntary engagement in performance measurement and improvement</li> <li>• Patients actively participate in decision-making, and feedback is sought to ensure patients' expectations are being met</li> <li>• Information technology is utilized appropriately to support optimal patient care, performance measurement, patient education, and enhanced communication</li> </ul>

- Practices go through a voluntary recognition process by an appropriate nongovernmental entity to demonstrate that they have the capabilities to provide patient centered services consistent with the medical home model
- Patients and families participate in quality improvement activities at the practice level

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Enhanced access	Enhanced access to care is available through systems such as open scheduling, expanded hours and new options for communication between patients, their personal physician, and practice staff.
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Payment	<p>Payment appropriately recognizes the added value provided to patients who have a patient-centered medical home. The payment structure should be based on the following framework:</p> <ul style="list-style-type: none"> <li>• It should reflect the value of physician and nonphysician staff patient-centered care management work that falls outside of the face-to-face visit.</li> <li>• It should pay for services associated with coordination of care both within a given practice and between consultants, ancillary providers, and community resources.</li> <li>• It should support adoption and use of health information technology for quality improvement;</li> <li>• It should support provision of enhanced communication access, such as secure e-mail and telephone consultation;</li> <li>• It should recognize the value of physician work associated with remote monitoring of clinical data using technology.</li> <li>• It should allow for separate fee-for-service payments for face-to-face visits. (Payments for care management services that fall outside of the face-to-face visit, as described above, should not result in a reduction in the payments for face-to-face visits).</li> <li>• It should recognize case mix differences in the patient population being treated within the practice.</li> <li>• It should allow physicians to share in savings from reduced hospitalizations associated with physician-guided care management in the office setting.</li> <li>• It should allow for additional payments for achieving measurable and continuous quality improvements.</li> </ul>
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## Appendix D. Guidelines for Patient-Centered Medical Home (PCMH) Demonstration Projects.

### COLLABORATION AND LEADERSHIP

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The project is open to input from all relevant stakeholders. Examples of relevant stakeholders include professional societies, payers, local larger employers/purchasers, health care-oriented community groups, including patient advocacy groups, and representatives from local/regional quality improvement programs.

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The project ensures that the leaders of local/regional primary care professional organizations are adequately briefed about the project.

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The project identifies an entity that is responsible for convening all participants and coordinating the activities of the project.

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### PRACTICE RECOGNITION

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The project uses the National Committee for Quality Assurance (NCQA) Physicians Practice Connections (PPC) PCMH tool, or a similar, consensus-based recognition process that includes validation of PCMH practice attributes defined in the “Joint Principles.”

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The project includes participation of a range of practice size and its representative of the area in which the project is taking place.

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The project clearly outlines the responsibilities of all participating parties, including providers, payers, patients/families, and other relevant stakeholders.

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### PRACTICE SUPPORT

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The project provides participating practices with sufficient financial and nonfinancial support to at least cover the costs of the PCMH recognition approval process; additional physician, clinical staff, and administrative staff work associated with the project; and implementation of the practice infrastructure required to provide services consistent with the PCMH care model.

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The project encourages the incorporation of and support for health information technology (HIT) solutions to facilitate: care management and care coordination by the medical team; patient and family access to educational material and electronic communications; and/or performance reporting (including the patient/family experience, quality outcomes and improvement, and health care resource utilization).

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The project design maximizes the number of patients in each participating practice covered by the demonstration project. This can be accomplished in multiple ways, including the participation of multiple payers and the use of broad criteria for patient participation (eg, child, adult, and elderly participants; patients with chronic and nonchronic conditions).

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### REIMBURSEMENT MODEL

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The project's payment model is broadly consistent with the following:

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A prospective, bundles component that covers physician and administrative staff work and practice expenses linked to the delivery of services under the PCMH model not covered by the most current Medicare RBRVS system.

A visit-based fee component for services delivered as part of a face-to-face visit and that are already recognized by the most current Medicare RBRVS system.

A performance-based component based on the achievement of defined quality and efficiency goals as reflected on evidence-based quality, cost of care and patient experience measures.

The payment model should recognize difference in the level of the PCMH care provided and patient case/mix complexity.

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## ASSESSMENT AND REPORTING OF RESULTS

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The project provides evidence supporting that it is of sufficient duration to reasonably expect the impact of the model to be demonstrated.

The project contains a commitment to an external evaluation to ensure the integrity and credibility of the project's data and reports.

The project contains a commitment to transparency of the data set, including the selection, use and reporting of results from clinical metrics, financial measures, and the application of proprietary measures of performance.

The project includes, at a minimum, the following data collection categories:

Descriptive data of the participating patients and practices.

Process and outcome measures of clinical quality with preference for those measures approved by the AQA and the National Quality Forum (NQF).

Measures of resources used, which can include cost of care to the payer and patient, and net effect of the care model on the financial performance of the participating practices.

Measures of patient/family experience of care with a preference for nationally recognized measures

Measures of the experience and/or satisfaction of participating physician, practice staff, and payers with the model.

The project measures the qualitative and quantitative (ie, resource utilization) effects of the PCMH delivery and payment model on the broader health care community (eg, subspecialty and specialty practices, hospital/emergency department care).

The project includes a process to broadly and publicly disseminate its results.

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## Appendix E. Tools At-a-Glance Table

TOOL NAME		DATE OF ORIGINAL RELEASE	NUMBER OF ITEMS/ QUESTIONS	NUMBER OF PAGES	LENGTH OF TIME TO COMPLETE	LANGUAGE AVAILABLE	TYPE(S) OF RESPONDENT			FORMAT FOR COMPLETION		COST FOR USE
							PHYSICIAN	CLINICAL STAFF	FAMILY/ PATIENT	SELF-ADMIN	INTERVIEWER-ADMIN	
CAHPS® C&G	Child Primary Care 1.0	2006	37 (additional 64 supplemental)	11	15-20 minutes	English & Spanish			X	X	X	None. Permission required
	Child Primary Care 2.0 (beta)	2008	54 (additional 24 supplemental)	15	20-25 minutes				X	X	X	
CPCI		1996	52	2	15 minutes	English			X	X		None. Permission required
Family-Centered Care Self Assessment Tools	Family Version	October 2008	98	8	15-20 minutes	English			X	X		None.
	Provider Version		105	8	15-20 minutes		X		X			
MHI	MHI	2001	25	11	15-20 minutes	English	X	X		X		None. Permission required. Sharing of data requested.
	MHFI		38	3	15-20 minutes				X	X		
	MHI-Short Version		10	4	5-10 minutes		English	X	X		X	
MHIQ		April 2008	9 modules of 13-30 questions	Web-based	Minimum of 15 minutes/module; average time-to-completion of 2-4 hours	English	X	X		X		None. Free registration is required.
MPOC	MPOC-56	November 1995	56	6	15-20 minutes	English, French, Dutch, German, Finnish, Swedish			X	X		None. Permission required. The MPOC-SP will be sent to you electronically.
	MPOC-20	1999	20	3	5-10 minutes	English			X	X		
	MPOC-SP	1998	27	4	10-15 minutes	English	X	X		X		
PCAS	Full Version	1994	51	19	7-15 minutes (self-admin) or 15-20 minutes (inter-viewer-admin)	English			X	X	X	None. Permission required
	Short Version	2000	23	7	5-10 minutes				X	X	X	
PCAT	PCAT Child	1998	121	14	20-25 minutes	English, Spanish, French, Catalan, Portuguese, Korean & Mandarin Chinese (both People's Republic of China & Taiwan)			X	X	X	None. Permission required
	PCAT Child Short Version	1998	68	11	10-15 minutes				X	X	X	
	PCAT Provider	1998	153	14	20-25 minutes		X			X	X	
	PCAT Provider Short Version	1998	70	10	10-15 minutes		X			X	X	
	PCAT Facility	1998	153	14	20-25 minutes			X		X	X	
	PCAT Facility Short Version	1998	70	10	10-15 minutes			X		X	X	
PHDS	Full Version	1999	61	15	15-18 minutes	English, Spanish			X	X <sup>(mail)</sup>		None. Tool is copyrighted, but non-proprietary. Available at no charge. Permission required.
	PHDS-PLUS	2001	128	N/A	12-15 minutes				X		X <sup>(telephone)</sup>	
	Pro-PHDS	2002	21	4	5 minutes				X	X <sup>(mail/in office)</sup>		
	Online PHDS	2008	Maximum of 66 questions - users can pick specific sections	Web-based	10-15 minutes **					X <sup>(online)</sup>		
	ProPHDS-5	2008	5		Web-based 3-5 minutes				X	X <sup>(online)</sup>		
PPC-PCMH™		2008	166	Web-based	40-80 hours	English	X	X		X		\$80 to access for 1-4 users
P3C		2001	23	1	5-10 min	English, Spanish, Vietnamese & Tagalog			X	X		None. Permission required
YAHCS		1999	56	7	10-15 minutes	English & Spanish			X	X	X	None. Permission required

\*\*Users can choose to complete only specific sections, thereby shortening the survey length

