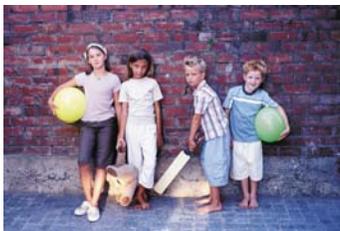

Methodology for Medical Home in the 2007 NSCH

Excerpt from

Measuring Medical Home: A Resource Manual for Researchers and Analysts

<http://medicalhomedata.org/ViewDocument.aspx?item=436>



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CAHMI – The Child and Adolescent Health Measurement Initiative

II. ASSESSMENT OF THE MEDICAL HOME CONCEPT

While the American Academy of Pediatrics' (AAP) initial work in defining the medical home provides a strong conceptual foundation, the measurement of this multi-layered concept is a complex undertaking.¹² As noted in the 2002 AAP policy statement: "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 system supports and structures to enable services to be provided by physicians according to the medical home definition."⁹ In spite of these challenges, the seven components and corresponding 37 characteristics of the AAP definition of the medical home remain the starting point for operationalizing and assessing the concept through the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health.

2.1 Overview of the Surveys

2001 NS-CSHCN: The National Survey of Children with Special Health Care Needs (NS-CSHCN) was first implemented in 2001-2002. The survey collects data for children with an ongoing health condition for which they require an above routine need or use of health care and related services (CSHCN). It is designed to provide reliable prevalence estimates nationally and separately for each state and the District of Columbia. Among the rich set of questions asked of parents participating in this telephone survey are those specifically developed to enhance information regarding states' progress toward meeting the Title V performance measures for CSHCN, including the presence of a medical home. At the time of the 2001 survey's development, a standardized method to measure medical home was not available. Working closely with child health researchers on the national technical expert panel for the survey, the development team drew upon research led by the Child and Adolescent Health Measurement Initiative (CAHMI). This project was funded by the David and Lucile Packard Foundation in order to develop and test what became the first Consumer Assessment of Health Providers and Systems Survey for Children with Chronic Conditions (CAHPS-CCC) included in the National Committee on Quality Assurance's HEDIS.³ Based on this and other measurement tools, a core set of questions with potential for assessing concepts outlined in the AAP's definition of medical home were identified and/or developed and tested for use in the NS-CSHCN. In May 2004, standardized estimates of medical home prevalence for the population of CSHCN in each state

and nationally were reported for the first time using data collected through the 2001 NS-CSHCN.^{13,14} This manual describes the methods used to create those estimates.

2003 NSCH: The first National Survey of Children's Health (NSCH) was conducted in 2003, two years after the initial implementation of the NS-CSHCN. This survey also includes data elements for assessing the medical home. The sample for the NSCH is taken from the U.S. population of non-institutionalized children age 0-17 years, rather than only CSHCN. The NSCH's focus on all children, not just children with special health care needs, presented additional challenges for medical home measurement because the health care needs of these two populations are quite different. Researchers from the Child and Adolescent Health Measurement Initiative (CAHMI) and National Center for Health Statistics worked in conjunction with Maternal and Child Health Bureau and its Technical Expert Panel to specify a medical home measurement approach that built upon what was learned from the 2001 NS-CSHCN.² A draft set of questions were developed and included in the pretest for the 2003 NSCH. Results from the pretest were analyzed and used to identify the final set of questions fielded in the medical home section of the 2003 survey.² The 2003 NSCH assesses the same components of the AAP medical home definition as evaluated by the NS-CSHCN; however, the anchoring of the assessment and the specific aspects of care assessed within each definitional component differ in important ways. These differences and similarities are discussed in later sections of this manual.

2005/06 NS-CSHCN: The second administration of the National Survey of Children with Special Health Care Needs (NS-CSHCN) took place during 2005-2006, providing yet another opportunity to refine medical home measurement. The national technical expert panel evaluated the methods used in the 2001 version of the NS-CSHCN and made several changes to the medical home questions for the 2005/06 administration of the survey. The effective care coordination and access to needed referrals topics underwent the most substantial revisions. These changes are described in greater detail in later sections. The 2009/2010 NS-CSHCN is currently being administered and uses the same survey items to measure Medical Home as in the 2005/06 NS-CSHCN.

2007 NSCH: Prior to the second administration of the NSCH in 2007, MCHB's national Technical Expert Panel (TEP) once again reviewed the methods and content used in the 2003 survey. On the basis of this evaluation, the TEP recommended a set of revisions that would

bring the medical home content and assessment approach for the 2007 NSCH in line with that used by the 2005/06 NS-CSHCN. This alignment of methodologies also responded to State MCH leaders' request for medical home estimates for their CSHCN populations at intervals more frequent than the NS-CSHCN's four-year cycle. Table 4 provides a crosswalk comparing the medical home questions from the 2007 NSCH with those used by the 2005/06 NS-CSHCN. The replication of 2005/06 NS-CSHCN medical home content and question design in the 2007 NSCH allows the same scoring parameters to be applied to both surveys – leading to directly comparable medical home results for the CSHCN population on a biennial basis. However, they differ in important ways that are further described below.

2.2 Overview of Methods and Content Used to Assess Medical Home

Table 2 provides an overview of the sampling, assessment focus, and number of survey items used to measure components of the medical home concept in the NS-CSHCN and the NSCH. Both surveys assess the same components of the AAP medical home definition; however, they vary in the number of questions devoted to specific topics. The surveys also differ with regard to the specific aspects of care assessed within each definitional component (see Table 4). Due to methodological issues related to defining, documenting and interpreting continuity of care, neither survey measures this concept directly. For similar reasons of complexity and validity using a consumer-reported methodology, neither assess the physical and financial accessibility of the medical home practice as characterized by the AAP definition.^{††}

TABLE 2: Overview of medical home measurement in two national child health surveys

	NS-CSHCN 2001	NS-CSHCN 2005/06	NSCH 2003	NSCH 2007
Total sample	38,866	40,723	102,353	91,432
Per State sample	≈ 750	≈ 800	≈ 2,000	≈ 1,800
Population addressed	CSHCN only 0-17 yrs	CSHCN only 0-17 yrs	All children [†] 0-17 yrs	All children [†] 0-17 yrs
Focus of assessment	All child's doctors and other health providers	All child's doctors and other health providers	Child's personal doctor or nurse	All child's doctors and other health providers
Number of survey questions addressing topics within AAP medical home definitional component:				
Established relationship with a specific health care provider	1	1	1	1
ACCESSIBLE^{††}	The concept of "accessible" is addressed in under "comprehensive" and "coordinated" care.			
FAMILY-CENTERED	4	4	2	4
CONTINUOUS	0	0	0	0
COMPREHENSIVE	6	7	9	4
COORDINATED	5	6	2	6
COMPASSIONATE	The concept of "compassionate care" is addressed in the context of the family-centered care questions asked in each of the surveys.			
CULTURALLY EFFECTIVE	1	3	2	3
Total	17	21	16	18

[†] The CSHCN Screener included in the NSCH allows stratification of results for children with and without special health care needs

^{††} The Accessible component of the AAP definition encompasses the physical and financial accessibility of the medical home, including handicap accessibility, community level availability of care, accessibility by public transportation, acceptance of Medicaid or other insurance types. Topics related to timely access to needed care or services are addressed under the Comprehensive component of the definition.

Table 3 briefly summarizes the questions used in each survey to address the various components of medical home, highlighting relevant differences in content, wording, anchoring, and skip patterns. In addition, Table 3 describes the criteria used to determine which respondents are asked the questions related to having a medical home. In the NS-CSHCN and in the 2007 NSCH, parents of sampled children have the opportunity to answer all relevant medical home questions. By contrast, only those respondents in the 2003 NSCH reporting that the child has a personal doctor or nurse are asked the subsequent questions relating to the medical home. This variation represents the most important substantive difference across the surveys.

TABLE 3: Across surveys comparison of methods and content for assessing medical home

	2001 and 2005/06 NS-CSHCN; 2007 NSCH	2003 NSCH
Established relationship with a specific health care provider	<ul style="list-style-type: none"> - 2001 asks if child has a relationship with a <u>single</u> provider, not one or more providers - 2005/06 and 2007 use the same wording as 2003 NSCH question asking about <u>one or more providers</u> 	<ul style="list-style-type: none"> - Question asks parents if there is <u>one or more health providers</u> who function as child's "personal doctor or nurse"
ACCESSIBLE	<p><i>The Accessible component of the AAP definition addresses the physical and financial accessibility of the medical home practice, including the accessibility of medical home practices by persons with disabilities, community-level availability of care, accessibility by public transportation, and acceptance of Medicaid and other types of insurance. Neither survey asks about these topics.</i></p> <p><i>Topics related to the availability and timely access of needed care and services are included under the Comprehensive component of the AAP definition.</i></p>	
FAMILY-CENTERED	<ul style="list-style-type: none"> - Family-centered care questions ask about care from all child's doctors and other health providers - In 2001 and 2005/06, these questions are only asked for sampled children with 1 or more doctor visits during past 12 months - In 2007, these questions are asked only for sampled children who used one or more of the following services during the past 12 months: preventive medical care, preventive dental care, mental health care, needed or received care from specialist doctors 	<ul style="list-style-type: none"> - Family-centered care questions focus <u>only</u> on care from child's personal doctor or nurse (PDN) - Family-centered care questions are asked <u>only</u> for sampled children with one or more PDNs
CONTINUOUS	<p><i>Topics within this component are not assessed by either survey due the methodological difficulties of measuring continuity of care over time in a reliable way using cross-sectional, point in time data.</i></p>	
COMPREHENSIVE	<ul style="list-style-type: none"> - 2001 and 2005/06 questions ask whether child has usual sources of care for both sick and preventive care. - 2007 asks only about usual source for sick care - Asked for <u>all</u> children in sample 	<ul style="list-style-type: none"> - Asks about access to urgent care and phone advice from PDN; access to needed specialist care and services; and receipt of preventive care during past year - Access questions asked <u>only</u> for sampled children with PDNs; preventive care visits asked for <u>all</u> children in sample
COORDINATED	<ul style="list-style-type: none"> - Questions about receipt of needed help and satisfaction with communication among all child's doctors, other providers, schools, and other programs - Substantial changes made in 2005/06 to 2001 question content and skip patterns - 2007 uses same questions as 2005/06 	<ul style="list-style-type: none"> - Questions focus on follow up from personal doctor or nurse after child receives needed specialist care, services, or equipment. - Asked <u>only</u> for children with PDNs
COMPASSIONATE	<ul style="list-style-type: none"> - Compassionate care is addressed in the context of the family-centered care questions 	<ul style="list-style-type: none"> - Compassionate care is addressed in the context of the family-centered care questions
CULTURALLY EFFECTIVE	<ul style="list-style-type: none"> - 2005/06 and 2007 have questions on access to language services during health care visits for children from households where primary language is not English - 2001, 2005/06 and 2007ask about health care providers' sensitivity to families' values and customs 	<ul style="list-style-type: none"> - Questions ask about access to language services during health care visits - Asked only for children living in households where the primary language is not English

2.3 Differences in Methods and Content Used to Assess Medical Home

Table 4 provides the abbreviated wording and corresponding survey instrument numbering for the questions from each survey used to assess specific topics within each definitional component of medical home. This information allows readers to compare and contrast the content used to assess medical home in each of the surveys. Highlights include the presence or absence of specific questions, variation in the number of questions used to address topics within each component of medical home, nuances in question wording across the NS-CSHCN survey years, and the presence or absence of skip patterns for identifying qualifying (“legitimate”) responders. Of particular importance are differences across the surveys in terms of the assessment focus and the recall timeframes specified for respondents. These factors, in turn, influence the content and wording of questions used to assess the medical home concept. These differences and related measurement considerations are discussed in more detail below.

Differences in focus of assessment: As shown in Table 4, both surveys focus closely on health care providers’ contributions to the medical home model. Both the NS-CSHCN and 2007 NSCH take a broad approach by anchoring the medical home assessment to what might be termed the “network of health care providers and settings” with which the child and family interact. In contrast, medical home assessment in the 2003 NSCH focuses solely on care from the child’s primary health care provider(s) described in the survey questions as the child’s “personal doctor or nurse.” The question content, wording, and skip patterns used in each survey reflect these different starting points for evaluating the medical home model.

Differences in wording and content: The focus of assessment directly influences the wording and content of questions used to assess medical home. As seen in Table 4, the family-centered care questions used in the NS-CSHCN and 2007 NSCH ask parents to consider communication and partnership among “child’s doctors and other health providers” when responding. In contrast, the 2003 NSCH asks about family-centered care only in terms of the “child’s personal doctor or nurse.” The effect of the different anchoring approaches persists across the surveys, determining to a large extent the selection and content of the questions used to assess topics within each of the medical home definitional components, and ultimately, the concept of “medical home-ness” overall. As a result, the 2001 and 2005/06 NS-CSHCN and 2003 NSCH share very few questions in common, despite the fact that both surveys address the same five definitional components of AAP medical home model. On the other hand, the medical home questions in the 2007 NSCH are the same ones used by the 2005/06 NS-CSHCN. Starting

in 2007, the medical home prevalence measures from the NSCH and NS-CSHCN are based on the same content and methodology to yield comparable estimates across years for both surveys.

Differences in recall timeframes: Recall timeframes have particular relevance for the medical home model because the concept of duration is inherent throughout many of the AAP definitional components. For instance, the concepts of care coordination and that of building partnerships with families imply ongoing connectedness among children, their families, health providers, and the health care delivery system. Capturing the duration of these relationships using a cross-sectional survey is a challenge that can be addressed at least partially through question design. The survey development team for both the NS-CSHCN and NSCH chose to anchor the medical home assessment to the past 12 months, using question stems stating “During the past 12 months did (child) need ...” or “During the past 12 months, how often ...” in order to prompt a response that incorporates the respondents’ experiences over time. These question stems are not used consistently across the two surveys. Referring again to the family-centered care items in Table 4, notice that NS-CSHCN and 2007 NSCH questions begin with “During the past 12 months....” The 2003 NSCH questions assessing the similar concepts ask “how often” and do not include a specific timeframe. On the other hand, some of the coordinated care questions in both surveys ask respondents to reflect on their children’s care over the past year; others do not specify a timeframe.

Additional considerations when using survey-reported data: Within any given survey, design considerations such as those mentioned above and others contribute to decisions about the wording of question stems, the type of response categories used, whether to use the same response categories for similar questions, and the use of skip pattern criteria to identify qualifying (“legitimate”) responders for certain questions. Each of these decisions ultimately influence the interpretation and application of the data collected. It is essential that researchers seek out and understand the methodological considerations contributing to the selection and design of specific questions in these surveys. Such understanding will help ensure these data are analyzed and interpreted in a valid, effective manner for the purposes of surveillance and monitoring, hypothesis testing, or policy development.

The survey year specific methodology reports for the NS-CSHCN and NSCH are available for download from <http://www.cdc.gov/nchs/slait.htm> . These reports offer a wealth of detail regarding the study design, question testing and use history, sampling, and administration

of these surveys. The reports also include information about the construction of the sampling weights, survey strata and primary sampling unit variables, and edits made to confidential data elements released in the public use files.

2.4 Full Text Copies of the Medical Home Questions

The full text of the medical home questions used in each survey, including response categories and complete skip pattern directions, are found in Appendices A_1 through D_1. To obtain copies of the Computer Assisted Telephone Interview (CATI) formatted survey instruments, go to <http://www.cdc.gov/nchs/slait.htm> and follow the survey-specific links. Survey items and response options from the NS-CSHCN and the NSCH can also be obtained from the Child and Adolescent Health Measurement Initiative's Data Resource Center for Child and Adolescent Health website (www.childhealthdata.org) by searching the interactive "Guide to Topics and Questions Asked" located under the LEARN ABOUT THE SURVEY area for each survey.

TABLE 4: Survey item numbers and brief description of questions used to assess the AAP definitional components of Medical Home, by survey

<i>Medical Home components</i>	2001 NS-CSHCN	2005/06 NS-CSHCN	2003 NSCH	2007 NSCH
Established relationship with a specific provider	C4Q02A: Child has <u>one</u> health care provider considered to be personal doctor or nurse	C4Q02A: Child has <u>one or more</u> health care providers considered to be personal doctor or nurse	S5Q01: Child has <u>one or more</u> health care providers considered to be personal doctor or nurse (PDN)	K4Q04: Child has <u>one or more</u> health care providers considered to be personal doctor or nurse (PDN)
ACCESSIBLE	<i>(Not about asked in way defined via AAP definition of medical home)</i>	<i>(Not about asked in way defined via AAP definition of medical home)</i>	<i>(Not about asked in way defined via AAP definition of medical home)</i>	<i>(Not about asked in way defined via AAP definition of medical home)</i>
FAMILY-CENTERED	<p><i>During past 12 months, how often did all child's doctors and other health providers:</i></p> <p>C6Q02: Spend enough time with child?</p> <p>C6Q03: Listen carefully to parent?</p> <p>C6Q05: Provide needed information?</p> <p>C6Q06: Help parents feel like partner in child's care?</p>	<p><i>During past 12 months, how often did all child's doctors and other health providers:</i></p> <p>C6Q02: Spend enough time with child?</p> <p>C6Q03: Listen carefully to parent?</p> <p>C6Q05: Provide needed information?</p> <p>C6Q06: Help parents feel like partner in child's care?</p>	<p><i>How often does child's PDN:</i></p> <p>S5Q04: Spend enough time with child?</p> <p>S5Q02: Explain things in ways that child and parents understand?</p>	<p><i>During past 12 months, how often did all child's doctors and other health providers:</i></p> <p>K5Q40: Spend enough time with child?</p> <p>K5Q41: Listen carefully to parent?</p> <p>K5Q43: Provide needed information?</p> <p>K5Q44: Help parents feel like partner in child's care?</p>
CONTINUOUS	<i>(Not asked about in survey)</i>	<i>(Not asked about in survey)</i>	<i>(Not asked about in survey)</i>	<i>(Not asked about in survey)</i>
COMPREHENSIVE	<p>A) <u>Referrals for specialist care</u> <i>During past 12 months:</i></p> <p>C4Q05X02: Needed care from a specialty doctor?</p> <p>C4Q07: Any problem getting referrals to any specialist child needed to see?</p>	<p>A) <u>Referrals for specialist care</u> <i>During past 12 months:</i></p> <p>C5Q11: Needed a referral to see any doctors or receive any services?</p> <p>C4Q07: IF yes, any problems getting the referral that was needed?</p>	<p>A) <u>Access to urgent care or advice</u> <i>During past 12 months:</i></p> <p>S5Q06: Needed to call child's PDN for help or advice?</p> <p>S5Q06A: IF yes, got help from child's PDN?</p> <p>S5Q07: Needed care right away from child's PDN?</p> <p>S5Q07A: IF yes, got care right away from child's PDN?</p>	<p>A) <u>Referrals for specialist care</u> <i>During past 12 months:</i></p> <p>K5Q10: Needed a referral to see any doctors or receive any services?</p> <p>K5Q11: IF yes, any problems getting the referral that was needed?</p>

TABLE 4 (cont.)

<i>Medical Home components</i>	2001 NS-CSHCN	2005/06 NS-CSHCN	2003 NSCH	2007 NSCH
COMPREHENSIVE (cont.)	<p>B) Usual sources for care</p> <p>C4Q0A: Is there a place child usually goes when he/she is sick?</p> <p>C4Q0B: IF yes: What kind of place is it?</p> <p>C4Q01: Is this the same place that child goes for routine preventive care?</p> <p>C4Q02: IF no, where does child go for routine preventive care?</p>	<p>B) Usual sources for care</p> <p>C4Q0A: Is there a place child usually goes when he/she is sick?</p> <p>C4Q0B: IF yes: What kind of place is it?</p> <p>C4Q0D: Is there a place child usually goes for routine preventive care?</p> <p>C4Q01: IF yes, Is this the same place that child goes for routine preventive care?</p> <p>C4Q02: IF no, What kind of place does child go for routine preventive care?</p>	<p>B) Access to specialty care</p> <p><i>During past 12 months:</i></p> <p>S5Q09: Needed specialist doctor care recommended by child's PDN?</p> <p>S5Q09A: IF yes, problems getting needed specialist care?</p> <p>S5Q10: Needed special services or equipment not available from PDN?</p> <p>S5Q10A: IF yes, problems getting needed special health services or equipment?</p> <p>C) Preventive care visit</p> <p>S2Q03: Number of preventive care visits during past 12 months with any health provider</p>	<p>B) Usual sources for care</p> <p>K4Q01: Is there a place child usually goes when he/she is sick?</p> <p>K4Q02: IF yes: What kind of place is it? Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?</p>
COORDINATED	<p>A) Professional care coordination</p> <p><i>During past 12 months:</i></p> <p>C4Q06X0A: Child's family needed professional care coordination?</p> <p>C4Q06X0AA: IF yes, received all professional care coordination needed?</p> <p>C5Q02: How often does a professional help coordinate child's care?</p> <p>B) Provider communication</p> <p>C5Q05: How well do all child's doctors and other providers communicate with each other?</p> <p>C5Q06: How well do all child's doctors and other providers communicate with school and other programs?</p>	<p>A) Help with care coordination</p> <p><i>During past 12 months:</i></p> <p>C5Q12: Does anyone help family to arrange or coordinate child's care?</p> <p>C5Q17: Did family need extra help arranging or coordinating child's health care?</p> <p>C5Q09: IF yes, how often got as much help as needed arranging or coordinating child's health care?</p> <p>B) Provider communication</p> <p>C5Q10: How satisfied with communication between child's doctors and other providers?</p> <p>C5Q05: Needed doctors or other providers to communicate with child's school or other programs?</p> <p>C5Q06: IF yes, how satisfied with that communication?</p>	<p>A) Follow up after specialty care</p> <p><i>During past 12 months:</i></p> <p>S5Q09C: How often did PDN follow up with parents after child visited a specialist?</p> <p>S5Q10C: How often did PDN follow up with parents after child received special health services or equipment?</p>	<p>A) Help with care coordination</p> <p><i>During past 12 months:</i></p> <p>K5Q20: Does anyone help family to arrange or coordinate child's care?</p> <p>K5Q21: Did family need extra help arranging or coordinating child's health care?</p> <p>K5Q22: IF yes, how often got as much help as needed arranging or coordinating child's health care?</p> <p>B) Provider communication</p> <p>K5Q30: How satisfied with communication between child's doctors and other providers?</p> <p>K5Q31: Needed doctors or other providers to communicate with child's school or other programs?</p> <p>K5Q32: IF yes, how satisfied with that communication?</p>

TABLE 4 (cont.)

<i>Medical Home components</i>	2001 NS-CSHCN	2005/06 NS-CSHCN	2003 NSCH	2007 NSCH
COMPASSIONATE	<i>(This concept is addressed by the Family-centered Care component questions)</i>	<i>(Addressed in the Family-centered Care component questions)</i>	<i>(Addressed in the Family-centered Care component questions)</i>	<i>(Addressed in the Family-centered Care component questions)</i>
CULTURALLY EFFECTIVE	<p>A) <u>Respect for diversity</u> <i>During past 12 months, how often were child's doctors and other health providers:</i></p> <p>C6Q04: Sensitive to family's values and customs?</p>	<p>A) <u>Respect for diversity</u> <i>During past 12 months, how often were child's doctors and other health providers:</i></p> <p>C6Q04: Sensitive to family's values and customs?</p> <p>B) <u>Language services</u> <i>During past 12 months:</i></p> <p>S5Q13: Needed an interpreter to help speak with child's doctors or nurses?</p> <p>S5Q13A: IF yes, how often able to get someone other than a family member to help speak with child's doctors or nurses?</p>	<p>B) <u>Language services</u> <i>During past 12 months:</i></p> <p>S5Q13: Needed an interpreter to help speak with child's doctors or nurses?</p> <p>S5Q13A: IF yes, how often able to get someone other than a family member to help speak with child's doctors or nurses?</p>	<p>A) <u>Respect for diversity</u> <i>During past 12 months, how often were child's doctors and other health providers:</i></p> <p>K5Q42: Sensitive to family's values and customs?</p> <p>B) <u>Language services</u> <i>During past 12 months:</i></p> <p>K5Q45: Needed an interpreter to help speak with child's doctors or nurses?</p> <p>K5Q46: IF yes, how often able to get someone other than a family member to help speak with child's doctors or nurses?</p>