Measuring Medical Home for Children and Youth

Methods and Findings from the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health




A Resource Manual

For Child Health Program Leaders, Researchers and Analysts

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Centers for Disease Control and Prevention
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This resource manual was developed through support from the National Center for Health Statistics (NCHS) as part of its ongoing joint efforts with the federal Maternal and Child Health Bureau (MCHB) to improve quality of survey documentation. The contents of the manual reflect nearly a decade of work sponsored by MCHB to define and specify methods to measure Medical Home for all children and children with special health care needs (CSHCN). During 2001-2003, NCHS and MCHB funded the Child and Adolescent Health Measurement Initiative (CAHMI) to conduct analyses and coordinate a national effort to further specify methods for measuring Medical Home using the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs. The project culminated in two reports and a paper that set forth many of the measurement and scoring approaches, criteria and models included in this manual.[1-3]

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INTRODUCTION

Currently, there are two national population-based surveys available that offer the opportunity to document the number and proportion of children in the United States meeting a multi-dimensional definition of Medical Home. These surveys-- National Survey of Children with Special Health Care Needs (NS-CSHCN)[5, 6] and the National Survey of Children's Health (NSCH)[7] --are both sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA/MCHB). The National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC/NCHS) is responsible for survey administration and data collection. A substantial body of prior research contributed to the specific approaches each survey uses to assess whether a child's health care meets Medical Home criteria.[1-3] The purpose of this manual is to:

1. Provide a brief history of the medical home concept for children and youth
2. Document and compare the specific survey items from each year of administration of the NS-CSHCN and NSCH, discussing the implications of question design and placement when assessing the medical home concept
3. Document the analytic methods used to create the various sub-component scores and medical home composite measures from each of these surveys
4. Compare and contrast the medical home results obtained by the different approaches and discuss relative strengths and limitations of each
5. Identify other issues and measurement options for consideration in future work to define approaches to assessing the population-based presence of medical home using parent-reported data from national surveys on children's health

The two national surveys described in this manual assess whether or not children have a medical home ***according to the survey respondent, almost always the child's parent***. Different, though related, methodological issues are posed to compare these parent-reported methods with those that assess "medical home-ness," using responses from ***provider surveys*** or through an ***internal or external evaluation*** of medical practices, such as used in the Medical Home Index measurement system.[4]

I. BRIEF HISTORY OF THE MEDICAL HOME CONCEPT

The American Academy of Pediatrics (AAP) first proposed the medical home concept in a policy statement published in 1992 followed by an updated statement in 2002.[8,9] In the 2002 update, the AAP definition further specified the seven major components of care comprising the medical home. Table 1 presents the seven components and 37 corresponding characteristics of medical home as defined by the AAP, the vast majority of which require or are appropriate to measure using parent-reported data.[9]

According to the AAP, the components of medical home should be delivered and managed by a well-trained physician who is able to establish a partnership of mutual trust and responsibility with the family and child. The AAP statements emphasize that a medical home is "not a building, house, or hospital, but rather an approach to providing continuous and comprehensive primary pediatric care from infancy through young adulthood, with availability 24 hours a day, 7 days a week, from a pediatrician or physician whom families trust."[8,9]

In response to the work of the AAP, increasing children's access to care delivered under the medical home model has been identified as a priority for child health policy at the national and local levels. The U.S. Department of Health and Human Services' *Healthy People 2010* goals and objectives state that "all children with special health care needs will receive regular ongoing comprehensive care within a medical home" and multiple federal programs require that all children have access to an ongoing source of health care.[10,15] By 1997, sentiment in the field for the AAP medical home model gained enough momentum for the federal Maternal and Child Health Bureau to include the concept as one of the 18 national performance measures established for the state Title V programs it administers:

> 3) *The percent of Children with Special Health Care Needs (CSHCN) in the State who have a "medical/health home."* [11]

From 1997 to 2003, this was the wording of the medical home performance measure in the Title V Block Grant Guidance used by the states to submit their Annual Report and Application.

The incorporation of this performance measure into the Title V reporting system preceded the availability of adequate data sources and valid, reliable methods for assessing this model of care. In response to these needs, the Maternal and Child Health Bureau included variables pertaining to the medical home in both the National Survey of Children with Special

Health Care Needs (NS-CSHCN) and the National Survey of Children's Health (NSCH). At the same time, the Bureau supported the development of analytical approaches for summarizing these variables into overall measures of the medical home.[1-3]

After launching the 2001 NS-CSHCN, the Maternal and Child Health Bureau modified the medical home performance measure by explicitly pointing states to the NS-CSHCN as the data source for Title V reporting requirement. Since 2003, the performance measure reads:

> *3) The percent of Children with Special Health Care Needs age 0 – 18 who receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN Survey).*[11]

All 50 states and the District of Columbia are required to report on this performance measure annually in the Title V Block Grant Application and Annual Report.

TABLE 1. Desirable Characteristics of a Medical Home – AAP 2002 Policy Statement

Accessible

1. Care is provided in the child or youth's community.
2. All insurance, including Medicaid, is accepted.
3. Changes in insurance are accommodated.
4. Practice is accessible by public transportation, where available.
5. Families or youth are able to speak directly to the physician when needed.
6. The practice is physically accessible and meets Americans With Disabilities Act10 requirements.

Family-centered

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

Continuous

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

Comprehensive

17. Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.
18. Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.
19. 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.
20. Preventive, primary, and tertiary care needs are addressed.
21. The physician advocates for the child, youth, and family in obtaining comprehensive care and shares responsibility for the care that is provided.
22. The child's or youth's and family's medical, educational, developmental, psychosocial, and other service needs are identified and addressed.
23. Information is made available about private insurance and public resources, including Supplemental Security Income, Medicaid, the State Children's Health Insurance Program, waivers, early intervention programs, and Title V State Programs for Children with Special Health Care Needs.
24. Extra time for an office visit is scheduled for children with special health care needs, when indicated.

Coordinated

25. 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.
26. Care among multiple providers is coordinated through the medical home.
27. 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.
28. The medical home physician shares information among the child or youth, family, and consultant and provides specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals.
29. Families are linked to family support groups, parent-to-parent groups, and other family resources.
30. When a child or youth is referred for a consultation or additional care, the medical home physician assists the child, youth, and family in communicating clinical issues.
31. 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.
32. The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.

Compassionate

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

Culturally effective

35. 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.
36. 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.
37. Written materials are provided in the family's primary language.

Source: American Academy of Pediatrics, Medical Home Initiatives for Children with Special Health Care Needs Project Advisory Committee. Policy statement: the medical home. *Pediatrics.* 2002;110:184-1

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	- 2001 asks if child has a relationship with a single provider, not one or more providers - 2005/06 and 2007 use the same wording as 2003 NSCH question asking about one or more providers	- Question asks parents if there is one or more health providers who function as child's "personal doctor or nurse"
ACCESSIBLE	*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.* *Topics related to the availability and timely access of needed care and services are included under the Comprehensive component of the AAP definition.*	
FAMILY-CENTERED	- 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	- Family-centered care questions focus only on care from child's personal doctor or nurse (PDN) - Family-centered care questions are asked only for sampled children with one or more PDNs
CONTINUOUS	*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.*	
COMPREHENSIVE	- 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 all children in sample	- 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 only for sampled children with PDNs; preventive care visits asked for all children in sample
COORDINATED	- 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	- Questions focus on follow up from personal doctor or nurse after child receives needed specialist care, services, or equipment. - Asked only for children with PDNs
COMPASSIONATE	- Compassionate care is addressed in the context of the family-centered care questions	- Compassionate care is addressed in the context of the family-centered care questions
CULTURALLY EFFECTIVE	- 2005/06 and 2007 have questions on access to language services during health care visits for children from households where primary language in not English - 2001, 2005/06 and 2007ask about health care providers' sensitivity to families' values and customs	- 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/slaits.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/slaits.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

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

TABLE 4 (cont.)

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

TABLE 4 (cont.)

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

III. QUANTIFYING THE MEDICAL HOME CONCEPT

Adequately measuring whether and to what extent children have a medical home involves capturing the relationships within and across various components and characteristics of this complex concept. Such an endeavor presents a unique set of analytic challenges which are further compounded by the opportunities and constraints characteristic of survey data in general, and the NS-CSHCN and NSCH in particular.

3.1 General analytic considerations

Data availability: The type and content of available data elements influence the construction and interpretation of any medical home composite measure that might be computed. Feasibility and methodological constraints often limit the number and type of questions included in a survey. Under ideal circumstances, survey researchers would field a lengthy, comprehensive set of questions which attempt to operationalize the AAP definition in great detail. In practice, survey administration costs, time limits, and respondent burden oblige survey designers to address the most policy relevant concepts or those with the strongest evidence base. In the NS-CSHCN and NSCH, only a subset of the characteristics or topics specified under each component of the AAP medical home definition are addressed. As described in Table 3, neither the NS-CSHCN nor NSCH surveys include questions about the physical and financial accessibility component of AAP medical home definition. The characteristics of compassionate care are measured indirectly through the questions used to address topics within of the Family-centered definitional component.

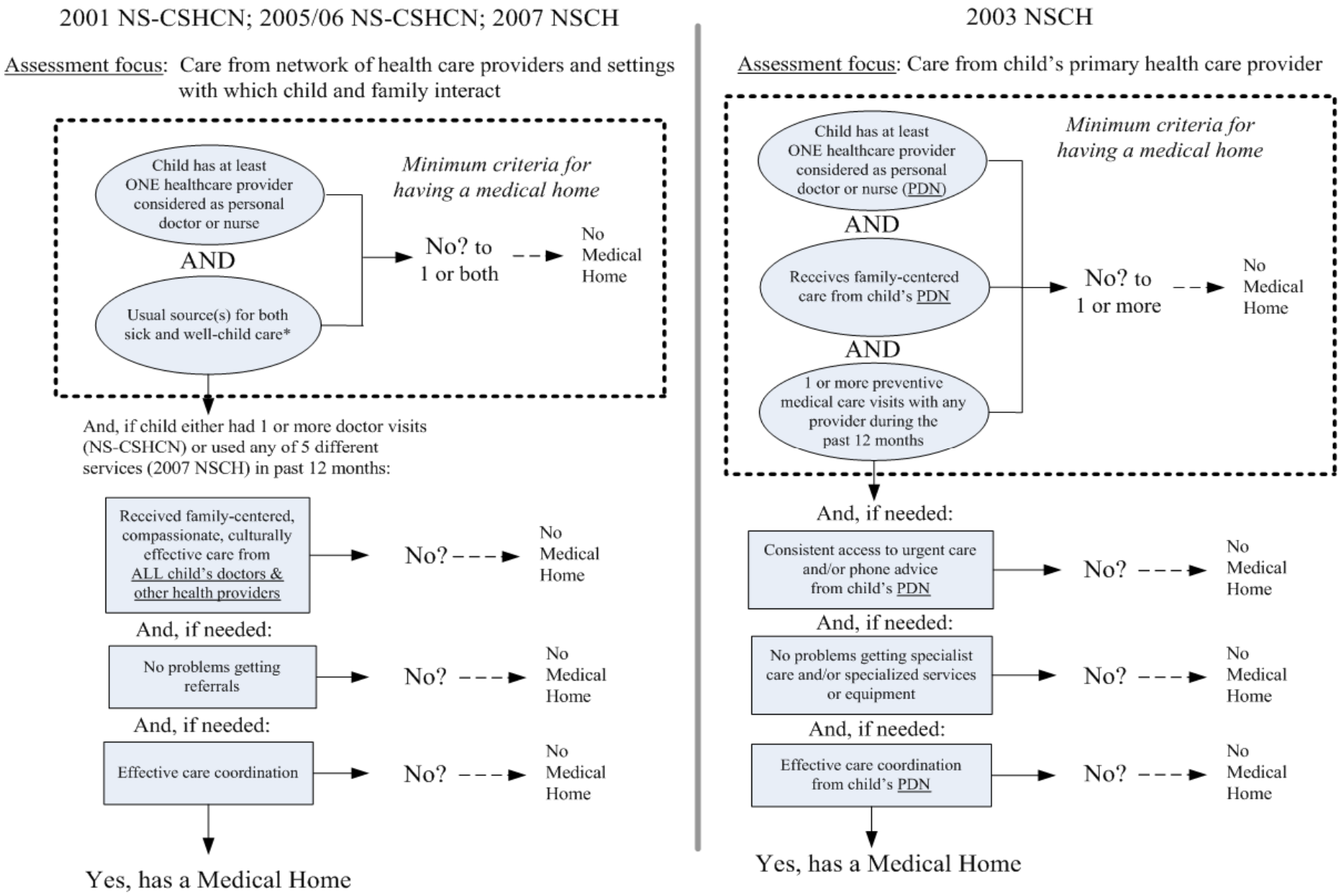
Another common reason for gaps in survey content is a lack of reliable methods for measuring particular concepts. For example, the continuity of care component of the AAP medial home definition is not amendable to assessment using cross-sectional, point in time surveys. Neither survey asks if the child has a care plan in place or whether the child's doctors and other providers maintain a centralized electronic record with all pertinent medical information – both of which are identified by the AAP definition as characteristics of care within the Coordinated Care component. While relevant to the effective delivery of care coordination, reliable methods for eliciting parental report on these topics are not currently available. Additional development work is needed before these and other characteristics of the medical home model are able to be reliably assessed in the context of parent respondent surveys.

Identifying valid denominators: The vast majority of children seldom, if ever, require services beyond basic preventive and acute care. It is a different story for children with special health care needs who experience chronic health conditions for which they require above routine health care and related services. The scope and intensity of health care services required by this group far exceeds that for children in general. At the survey measurement level, the differential need for services within the child population makes it necessary to employ filter questions and skip patterns to identify children who actually need or experience the various types of care so that respondents can legitimately answer the questions asked. For this reason, developing a composite measure of medical home from such data requires methods that distinguish, at both the data collection and analytic levels, children who do and do not need the specific types of care being assessed in order to specify valid denominators for measurement.

Minimum criteria for having a medical home: As described earlier, the NS-CHSCN and the 2007 NSCH assess medical home from the perspective of a network of services and care delivered by multiple providers across a variety of settings, whereas the 2003 NSCH anchors all of its medical home questions to care received from or managed by the child's personal doctor or nurse. These two perspectives on the medical home have been debated in the field, and the evolution of thinking spurred by that debate is reflected in the revisions to questions and approaches used in each subsequent survey. Although both starting point perspectives are reasonable, each translates into conceptual differences regarding the baseline criteria used to develop a composite score for care reflecting the spirit of the medical home model.

The NS-CSHCN and 2007 NSCH baseline medical home criteria call for children to have at least one personal doctor/nurse AND usual sources for health care. In contrast, 2003 NSCH minimum medical home criteria require children to have a personal doctor or nurse who also consistently communicates well AND at least one preventive medical care visit in the past 12 months. Figure 1 illustrates the different criteria for having a medical home used by each survey.

Figure 1: Medical Home Measurement using the National Child Health Surveys



* The 2007 NSCH asks a single question about usual source of care when child is sick or advice is needed about his/her health. The NS-CSHCN separates the concepts of sick care and for well child care into two different questions.

3.2 Overview of the "On Every" Scoring Approach

Given the general analytic considerations discussed above, members of the survey design team for the NS-CSHCN and NSCH considered several approaches for summarizing the data elements in the two surveys into overall composite measures of the medical home concept. Previous research using other surveys identified several options for creating medical home scores from parent-reported data.[3] One of these options, termed the "on every" method, was selected by MCHB for use with the NS-CSHCN and NSCH medical home data.

The "on every" method uses the results from the various sub-component topics assessed within the components of the AAP medical home definition to construct an overall composite measure. Some of the sub-component topics do not apply to all children. For example, not all children need referrals in order to see other doctors or obtain services so it does not make sense to ask the parents of these children whether problems occurred in getting referrals. In such cases, question responses are used to identify children who did not need a specific type of care and thus there is a legitimate reason for their parents not being asked about that topic. To qualify as having a medical home, a child must either receive care that meets the threshold criteria or qualify as not needing such care on EVERY sub-component topic assessed. Constructing the overall composite measure using the "on every" method entails the following steps:

STEP 1: From the set of questions pertaining to a specific sub-component topic, identify the children who needed care and those who are legitimate skips because care was not needed.

STEP 2: Identify responses meeting threshold criteria for care according to the specific scoring parameters for each sub-component topic. Depending upon the number of questions involved, this step may include developing several interim variables to be further aggregated in Step 3.

STEP 3: Use the results from Step 2 to create a summary variable for each sub-component topic by categorizing children into one of 3 mutually exclusive groups:

a) Care meets the threshold criteria for sub-component topic
b) Care does not meet the threshold criteria for sub-component topic
c) Legitimate skip because child did not need the type of care addressed by sub-component topic during the time frame being assessed

STEP 4: Use results from Step 3 to construct the overall composite measure of medical home. To be classified as having a medical home according to the "on every" method, a child must meet the threshold criteria or qualify as not needing care (legitimate skip) on EVERY sub-component topic assessed by the survey.

For example, suppose a child qualifies as needing care covered by three of five different sub-components topics assessed in a particular survey. In order to classify as having a medical home, the child's care must meet the threshold criteria for every one of these three sub-components topics PLUS have responses indicating that he or she did not need the types of care addressed by the remaining two sub-components topics. It is important to note that the medical home concepts measured in the NS-CSHCN and NSCH represent the minimal criteria for having a medical home. In addition, consumer surveys tend to yield optimistic reports of experiences of care on survey items such as those used to assess medical home in the NS-CSHCN and NSCH. These two issue (minimum set asked and positivity bias of surveys) supported the use of an "on every" scoring approach.

***Survey specific considerations*:** The "on every" approach is used to construct the overall medical home composite measures derived from both the NS-CSHCN and the NSCH surveys. The parameters used to develop the sub-component topic scores, however, are specific to each survey because of differences in the structure of the data elements, types of questions, and number of sub-component topics. Sections 3.3 through 3.5 describe the sub-component topic scoring parameters for each of the surveys. These sections also include examples based on six hypothetical cases illustrating how the "on-every" scoring algorithm is applied to different patterns of sub-component topic results from each survey to create the overall medical home composite measures.

3.3 Medical home measurement using NS-CSHCN data elements

The overall medical home measure from the NS-CSHCN is a composite of five different sub-component topics assessing the following:

1. Child has at least one personal doctor or nurse
2. Family-centered care
3. Getting needed referrals
4. Usual source(s) for both sick and well care
5. Effective care coordination

Table 5 organizes the five medical home topics assessed by the NS-CSHCN according to the specific definitional components of the AAP medical home model each is designed to measure. The number of NS-CSHCN survey items used to derive each of the sub-component topic variables varies from one to seven (see Table 2). In the 2001 survey, a total of 17 questions are used to develop the medical home composite measure. Subsequent revisions led to a total of 21 items from the 2005/06 NS-CSHCN used in measuring the medical home concept.

Sub-component topic denominators: Two of the NS-CSHCN sub-component topics are relevant for all children in the sample; the content of the remaining topics pertain only to the children who needed the type of care being addressed. Children with survey responses indicating a specific type of care was not needed are designated as "legitimate skips" because their parents cannot legitimately answer questions about care their children did not receive. The relevant subsets of children (i.e., denominators) for the five sub-component topics assessed in the NS-CSHCN are as follows:

1. Two sub-component topics (*Have at least one personal doctor or nurse; Usual sources for both sick and well care*) include all children in the sample.
2. One sub-component topic (*Family-centered care)* includes only those children with one or more doctor visits during the past 12 months. All other children are considered "legitimate skips" for scoring purposes.
3. Two sub-component topics (*No problems obtaining referrals; Effective care coordination*) pertain only to children who needed these types of services during the past 12 months. Children with survey responses indicating the relevant services were not needed or (as in the case of the care coordination questions for the 2005/06 survey) not used by the child are considered "legitimate skips" for scoring purposes.

Sub-component topic thresholds and legitimate skips: Table 5 summarizes the threshold and legitimate skip criteria for each of the NS-CSHCN sub-component topics. The SAS and SPSS scoring programs provided in Appendices A_1 through B_2 create the five derived variables listed in the second column of the table – one for each of the sub-component topics used to construct a medical home composite measure from the NS-CSHCN data elements.

Table 5: Measuring Medical Home using NS-CSHCN data elements: Sub-component topic variables

Sub-component topics measured within each AAP Medical Home definitional component	**Variable name***	**Threshold criteria**	**Legitimate skip criteria**
RELATIONSHIP WITH SPECIFIC PROVIDER			
1. Has at least one "personal doctor or nurse"	PERSDOC	"Yes" to question about having a personal doctor or nurse	No skips; asked for all sample children
ACCESSIBLE	--	--	--
FAMILY-CENTERED			
2. Receives family-centered care	FAMCENT	Responses of "Usually or Always" to all questions assessing family-centered and culturally effective care	Responses indicating child did not visit a doctor during past 12 months
CONTINUOUS	--	--	--
COMPREHENSIVE			
3. Getting needed referrals	NOREFPRB	"No problem" response to question about obtaining needed referrals	Responses indicating child did not need referrals (2005/06) or did not need specialist care (2001) during past 12 months
4. Usual source(s) for both sick and well care	USUALSW	Responses indicating child has regular sources of care other than hospital emergency room for both sick and well care	No skips; asked for all sample children
COORDINATED			
5. Getting effective care coordination when needed	CARECOOR	Responses indicating getting all desired help with care coordination, and if needed, responses of "Very satisfied" (2005/06) or "Excellent" (2001) to questions about providers' communication with each other and with school/other programs.	Responses indicating no need for professional help with care coordination (2001) In 2005/06, the care coordination questions are only asked for children who used 2 or more services during the past year. Children who used less than 2 services and those whose family members do not report getting or wanting extra help to coordinate child's care are considered legitimate skips.
COMPASSIONATE	*Assessed by questions within the Family-centered Care component*		
CULTURALLY EFFECTIVE	*Responses to questions addressing culturally effective care included in the Family-centered Care sub-component topic scoring*		

-- Not assessed by survey (See Table 2 for details) *2005/06 SAS variable names shown in the table; see Appendices for SPSS variable names

Scoring sub-component topics: As discussed in previous sections, a number of changes and additions were made to the medical home questions used for the 2005/06 NS-CSHCN. Some of these changes resulted in significant revisions in the threshold criteria and valid denominators for the sub-component topics – especially those addressing getting needed referrals and effective care coordination. The scoring parameters for the 2001 and 2005/06 versions of the sub-component topics described earlier in Table 5 are briefly outlined below – including any implications associated with revisions to the medical home questions used in the 2005/06 NS-CSHCN:

1. Child has at least one personal doctor or nurse
    a. Constructed from a single item
    b. *Threshold criteria* = YES responses indicating child has one or more than one personal doctor or nurse
    c. Minor wording changes in 2005/06 resulted in an additional response option for children with 2 or more personal doctors or nurses; no changes to scoring
2. Receives family-centered care
    a. Constructed from five items in 2001; seven items in 2005/06
    b. In 2005/06, two new questions about access to interpreter services, when needed, during child's health care visits were added and incorporated into the family-centered care topic score ; the new questions are only asked for children living in households with primary languages other than English
    c. Wording of the five family-centered care questions remained the same across survey years; no changes
    d. *2001 threshold criteria* = responses indicating child had 1 or more doctor visits during past 12 months AND responses of USUALLY or ALWAYS to all five family-centered care questions
    e. *2005/06 threshold criteria* = responses indicating child had 1 or more doctor visits during past 12 months AND responses of USUALLY or ALWAYS to all five family-centered care questions, AND if needed, responses of USUALLY or ALWAYS to accessing interpreter services during child's health care visits
3. No problems obtaining referrals
    a. Constructed from 2 items
    b. Significant changes in question wording and methods in 2005/06
    c. *2001 threshold criteria* = YES response to child needing care from a specialist doctor during past 12 months AND response of NOT A PROBLEM to obtaining a referral to see a specialist

d. *2005/06 threshold criteria* = YES response to referrals are necessary in order for child to see other doctors or receive services AND response of NOT A PROBLEM to getting the needed referrals

e. IMPORTANT NOTE: In 2001 the valid denominator for "no problems obtaining referrals" sub-component topic are children who needed to see a specialist during the past 12 months (about 50% of CSHCN); in 2005/06 the valid denominator for the sub-component topic changed to children who need to obtain a referral in order to see other doctors or receive services (about 33% of CSHCN).

4. Usual source(s) for both sick and well care

   a. Constructed from four items in 2001; five items in 2005/06

   b. Minor changes in wording and skip patterns in 2005/06 survey to improve question flow; no changes in scoring

   c. *Threshold criteria* = responses across the relevant questions indicating child has regular sources other than hospital emergency room for both sick and well care

5. Receives effective care coordination

   a. Constructed from five items in 2001; six items in 2005/06

   b. Significant changes to question wording and methods in 2005/06

   c. *2001 threshold criteria* = YES responses to needed AND received professional help with care coordination during past 12 months, AND if needed, responses indicating EXCELLENT communication between child's doctors and/or between child's doctors and school or other programs.

   d. *2005/06 threshold criteria* = If child used 2 or more services during past year, affirmative responses indicating (a) family currently receives help coordinating child's care and does not need extra help, OR if extra help was needed, family USUALLY received the help desired; OR (b) no help coordinating care was reported AND no wanted extra help coordinating care was reported; AND (c) if child used any of five different specialized services and communication between doctors was needed, responses of VERY SATISFIED with that communication, AND (d) if needed, responses of VERY SATISFIED with communication between doctors and child's school or other programs.

   e. IMPORTANT NOTE: In 2001, the valid denominator for the care coordination sub-component topic are children whose family members needed professional help with care coordination during the past year (about 12% of CSHCN met the 2001 inclusion criteria)

   f. IMPORTANT NOTE: In 2005/06, valid denominator for the care coordination topic changed to children who used two or more of the services asked about in the NS-CSHCN during past year.

Additional information such as the survey-specific item numbers, exact text of the medical home questions, and details of the interim variables developed to construct each sub-component topic

score is included with the user resources for the NS-CSHCN provided in Appendices A_1 through B_2.

NS-CSHCN medical home composite measure: The SPSS and SAS scoring programs in Appendices A_1 through B_2 use the 'on every' method (see section 3.2) to construct dichotomous composite measures that classify children as either having or not having a medical home. To qualify as having a medical home as measured in the NS-CSHCN, children must:

A) Meet both NS-CSHCN baseline criteria for having a medical home (Fig. 1)

B) AND, either receive care meeting the threshold criteria or qualify as a legitimate skip on each of the three additional sub-components topics.

Figure 2 below presents six hypothetical cases – each illustrating how different combinations of sub-component topic results culminate in the final medical home outcome using the "on every" approach to construct the composite measure. For brevity, the variable names shown in Table 5 are used in Figure 2 to denote each of the five sub-component topics. The details of these derived variables are described in Table 5 and in Appendices A_1 through B_2.

Figure 2: National Survey of CSHCN, 2001 and 2005/06

Scoring algorithm examples for the NS-CSHCN Medical Home composite measure

Derived variable names for the NS-CSHCN sub-component topics (see Table 5)		*Does child meet threshold criteria?* Child #1	Child #2	Child #3	Child #4	Child #5	Child #6
"Baseline criteria for having a medical home"	**PERSDOC**	Yes~	Yes	Yes	No	Yes	Yes
	USUALSW	Yes	Yes	Yes	Yes	Yes	Yes
	FAMCENT	Yes	Yes	X	Yes	Yes	--
	NOREFPRB	Yes	X	X	Yes	No	Yes
	CARECOOR	Yes	X	X	Yes	Yes	Yes
Qualifies as having a Medical Home?		**YES**	**YES**	**YES**	**NO**	**NO**	**--***

X = Legitimate skip – child did not need the type of care addressed by this topic

-- = System missing or "Don't know/Refused" responses to 1 or more questions used to derive the sub-component topic variable

* = Children with missing or "Don't know/Refused" responses for 1 or more sub-component topics variables are NOT included in the valid denominator when calculating the overall medical home composite score

As illustrated in Figure 2, the minimum NS-CSHCN criteria for having a medical home requires children to have a personal doctor/nurse AND usual sources for both sick and preventive care. In addition to meeting these baseline criteria, children also must receive care meeting the threshold criteria OR qualify as a "legitimate skip" on each of three additional sub-components topics measured in the survey (Figure 2, child #1 through child #3). Failing to meet even one of two baseline criterion automatically categorizes a child as not having a medical home, regardless of whether he or she receives care meeting the thresholds for all other sub-component topics (Figure 2, child #4). On the other hand, children meeting the two baseline criterion qualify as having a medical home, even if they did not need any of the other types of care assessed by the three remaining sub-component topics (Figure 2, child #3).

Conversely, if a child meets the baseline criteria for having a medical home and received care that did not meet the threshold for one or more sub-component topics, the result is "no medical home" (Figure 2, child #5). Finally, the NS-CSHCN medical home scoring programs provided in the appendices do not include in the valid denominator for calculating the medical home measure any cases with responses classified as "Don't Know/Refused" or system missing to any subcomponent topic variable (Figure 2, child #6). Nationally, about 5 percent of children in the sample were not included in valid denominators for the medical home composite measures from the 2001 and 2005/06 NS-CSHCN surveys.

Although the revisions to the 2005/06 NS-CSHCN medical home questions resulted in changes to the parameters used to derive several of the sub-component topic variables, the "on every" scoring algorithm for creating the overall medical home composite measure remains the same for both administrations of the NS-CSHCN.

Resources for measuring medical home using NS-CSHCN data: Appendices A_1 through B_2 offer a set of resources to guide SAS and SPSS users in constructing the sub-component topic variables and composite medical home measure using data elements from the 2001 or 2005/06 NS-CSHCN. These resources include:

- Overview tables with derived variable names from SAS and SPSS medical home scoring programs and associated NS-CSHCN data elements

- SAS and SPSS programming code for creating the overall medical home composite measure, each of the various sub-component topic scores and associated interim variables from 2001 or 2005/06 NS-CSHCN
- Summary tables showing aggregate data results for the Medical Home composite measure, sub-component topics and associated interim variables using 2001 or 2005/06 NS-CSHCN data elements
- Tables with the text, response options and associated skip pattern details for each of the survey items from the 2001 or 2005/06 NS-CSHCN used in the SAS and SPSS medical home scoring programs
- Unweighted univariate distributions for the dichotomous medical home composite measure, each of the sub-component topic variables and associated interim variables produced by the SAS or SPSS program code for constructing medical home measures from the 2001 or 2005/06 NS-CSHCN

Another resource includes the NS-CSHCN indicator codebooks available through the Data Resource Center for Child and Adolescent Health website: www.childhealthdata.org

3.4 *Measuring medical home using 2003 NSCH data elements*

The overall medical home measure from the 2003 NSCH is a composite of six different sub-component topics assessing the following:

1. Child has at least one "personal doctor or nurse" (PDN)
2. Preventive care visits during past 12 months
3. Family-centered care from PDN
4. Access to needed urgent care and/or phone advice from PDN
5. Access to needed specialist care and/or specialized services or equipment
6. PDN follow up after child sees specialist and/or gets specialized health services

Table 6 organizes the six medical home topics assessed in the 2003 NSCH according to the specific definitional components of the AAP medical home model each is designed to measure. The number of survey items used to construct the six 2003 NSCH sub-component topic variables ranges from as few as one to as many as nine (see Table 2).

Sub-component denominators: All children in the 2003 NSCH sample are included in the valid denominators for the personal doctor or nurse (PDN) and the preventive care visit sub-component topics. The remaining medical home topics assessed in the 2003 survey apply only to denominators of children with at least one PDN and need for the types of care addressed within a topic. Children without any PDN and those who have a PDN but did not need the specific types of care being assessed are not included in the valid denominators for these sub-component topics. Rather, these cases are designated as "legitimate skips" for scoring purposes because there is no reason to ask parents questions about care children did not need. The valid denominators for the six medical home sub-component scores derived from 2003 NSCH are as follows:

1. Two sub-component topics (*At least one personal doctor or nurse; Preventive care visit during past 12 months)* include all children in the sample in the denominators.
2. One sub-component topic (*Family-centered care from PDN)* includes only children who have at least one PDN in valid denominator. Children who do not have any PDN are considered "legitimate skips" for scoring purposes.
3. Three sub-component scores (*Access to urgent care/phone advice from PDN; Access to needed specialist care/services; Follow up by PDN after child gets specialist care and/or specialized services*) pertain only to children who have PDNs and needed the

specific types of care addressed by each sub-component topic. Children without any PDN and those who have a PDN but did not need the types of care pertaining to these three sub-components topics are considered "legitimate skips" for scoring purposes.

Sub-component thresholds and legitimate skips: Table 6 summarizes the threshold and legitimate skip criteria for each of the 2003 NSCH sub-component topics. The SAS and SPSS scoring programs provided in Appendices C_1 and C_2, create the six derived variables listed in the second column of the table – one for each of the sub-component topics used to construct the 2003 NSCH medical home composite measure.

Table 6: Measuring Medical Home using 2003 NSCH data elements: Sub-component topic variables

Sub-component topics measured within each AAP Medical Home definitional component	**Variable name***	**Threshold criteria**	**Legitimate skip criteria**
RELATIONSHIP WITH SPECIFIC PROVIDER			
1. Has at least one "personal doctor or nurse" (PDN)	S5Q01	"Yes" to question about having a personal doctor or nurse	No skips; asked for all sample children
ACCESSIBLE	--	--	--
FAMILY-CENTERED			
2. Receives family-centered care from PDN	PDNCOM_2	Responses of "Usually or Always" ($\geq$ 75pts) to questions on PDN listening and time spent with child	Responses indicating child does not have a personal doctor or nurse (PDN)
CONTINUOUS	--	--	--
COMPREHENSIVE			
3. Preventive care visit, past 12 months	PC_2	One or more preventive medical care visits with any health care provider during past 12 months	No skips; asked for all sample children
4. Access to needed urgent care and/or phone advice from PDN	CARE_2	Responses of "Usually or Always" ($\geq$ 75pts) for each type of care needed by child	Responses indicating child does not have PDN or has PDN but did not need these types of care during past 12 months
5. Access to needed specialist care and/or specialized services	ACC_2	Responses of "Small Problem or No Problem" ($\geq$ 75pts) accessing each type of care needed by child	Responses indicating child does not have PDN or has PDN but did not need specialized care or services during past 12 months
COORDINATED 6. Follow up by PDN after child gets specialist care and/or specialized services	COOR_2	Responses of "Usually or Always" (score of $\geq$ 75pts) for each type of care for which child needed follow up	Responses indicating child does not have PDN or has PDN but did not need specialized care or services during past 12 months
COMPASSIONATE	*Assessed by questions within the Family-centered Care component*		
CULTURALLY EFFECTIVE	*Included in the Family-centered Care sub-component topic scoring*		

-- Not assessed by survey (See Table 2 for details) *SAS variable names shown in the table; see Appendices for SPSS variable names

Scoring sub-component topics: Somewhat different methods are used to develop the medical home sub-component topic variables derived from the 2003 NSCH and 2007 NSCH and

NS-CSHCN surveys. The scoring methods for the NS-CSHCN and 2007 NSCH excludes cases from the valid denominator when there are responses of "Don't know or Refused" to one or more of the questions used for deriving a sub-component topic variable; the 2003 NSCH method only excludes cases when there are "Don't know or Refused" responses to all questions used for deriving a sub-component topic variable.

The scoring programs for each survey also employ different strategies to identify cases that meet the threshold criteria for a sub-component topic. The 2003 NSCH uses an approach, described in detail elsewhere,[3] previously developed for use with other surveys which typically assessed three or more concepts per sub-component topic. This method assigns points ranging from 0-100 to responses for each relevant question and calculates the average score across all valid responses within a sub-component topic. A score of 75 points or greater is used as the threshold criteria. When applied to surveys that assess a maximum of two concepts per sub-component topic, such as the 2003 NSCH, the "average score" method yields the same results as the approach for the NS-CSHCN and 2007 NSCH which requires a discrete set of responses, such as "Usually or Always," on every relevant question within a sub-component topic in order to meet the threshold criteria.[13]

These different methods used for creating sub-component topic variables are artifacts of on-going efforts to develop robust methodologies for measuring medical home using population-based child health surveys. The differences approaches to medical home measurement taken earlier by the NSCH and NS-CSHCN have been reconciled through the alignment of the 2007 NSCH medical home content and scoring parameters with those used for the 2005/06 NS-CSHCN.

The threshold criteria for the 2003 NSCH sub-component topics used to measure medical home are outlined below

1. Child has at least one personal doctor or nurse
    a. Constructed from a single item
    b. *Threshold criteria* = YES responses indicating child has either one or more than one personal doctor or nurse

2. Preventive care visit during past 12 months
   a. Constructed from a single item
   b. *Threshold criteria* = Responses indicating that child had one or more preventive care visits with any provider during the past 12 months

3. Family-centered care from PDN
   a. Constructed from 2 or 3 items
   b. *Threshold criteria* = responses of USUALLY or ALWAYS ($\geq$ 75 points) to questions asking about communication with child's PDN and adequacy of time PDN spends with child, AND if needed, responses of USUALLY or ALWAYS to question about access to interpreter services during child's health care visits
   c. The question about need for interpreter help during child's health care visits is asked only for children living in households with primary languages other than English

4. Access to needed urgent care and/or phone advice from PDN
   a. Constructed from up to four items
   b. Filter questions are used to identify the children who needed urgent care or phone advice, or both from a PDN during the past 12 months. Only respondents reporting that the child needed one or both of these specific types of care are asked the related questions about how often such care was available when needed.
   c. *Threshold criteria* = If needed during the past 12 months, responses of USUALLY or ALWAYS ($\geq$ 75 points) to question on availability of urgent care from child's PDN, AND if needed during the past 12 months, responses of USUALLY or ALWAYS ($\geq$ 75 points) to question on availability of phone advice from child's PDN

5. Access to needed specialist care and/or specialized services or equipment
   a. Constructed from up to 4 items
   b. Filter questions are used to identify children who have PDNs and needed care from a specialist doctor or needed specialized health services/equipment, or both during the past 12 months. Only respondents reporting that the child needed one or both of these specific types of care are asked whether they experienced any problems accessing the care needed by the child.
   c. *Threshold criteria* = If needed, responses of "NO PROBLEM or SMALL PROBLEM" ($\geq$ 75 points) to getting specialist care for child, AND if needed, responses of "NO PROBLEM or SMALL PROBLEM" ($\geq$ 75 points) to getting specialized health services or equipment needed by child

6. Follow up by PDN after child receives specialist care and/or specialized services
   a. Constructed from up to two items
   b. Filter questions are used to identify children who have PDNs and needed care from a specialist doctor or specialized health services/equipment, or both during the past 12 months. Only respondents reporting that the child needed one or both of these specific types of care are asked how often child's PDN follows up with family after child receives such care.
   c. *Threshold score* = If needed during the past 12 months, responses of USUALLY or ALWAYS (≥ 75 points) when asked how often child's PDN follows up after child visits a specialist, AND if needed during the past 12 months, responses of USUALLY or ALWAYS (≥ 75 points) when asked how often child's PDN follows up after child gets specialized health services

Additional information, including details such as the survey item numbers of questions used for the medical home measures and the interim variables used to construct each sub-component topic variable are found with the SAS and SPSS user resources in Appendices C_1 and C_2.

2003 NSCH medical home composite measure: The scoring programs provided in Appendices C_1 and C_2 use the "on every" method (see section 3.2) to construct a dichotomous composite measure that classifies children as either having or not having a medical home. To be categorized as having a medical home using 2003 NSCH, children must:

A) Meet all three 2003 NSCH baseline criteria for having a medical home (Fig. 1)
B) AND either receive care that meets the threshold criteria for or qualify as a legitimate skip on each of the three additional sub-component topics

Figure 3 on the next page presents six hypothetical cases – each illustrating how a different set of the scoring results culminates in the final medical home outcome using the "on every" approach to construct the composite measure. For brevity, the variable names shown in Table 6 are used in Figure 3 to denote each of the six sub-component topics. The details of the derived variables are further described in Table 6 and in Appendices C_1 and C_2.

Figure 3: National Survey of Children's Health (NSCH), 2003

Scoring algorithm examples for the 2003 NSCH Medical Home composite measure

		Does child meet threshold criteria?					
Derived variable names for the 2003 NSCH sub-component topics (see Table 6)		Child #1	Child #2	Child #3	Child #4	Child #5	Child #6
"Baseline criteria for medical home"	**S5Q01**	Yes	Yes	Yes	Yes	Yes	--
	PDNCOM_2	Yes	Yes	Yes	Yes	Yes	--
	PC_2	Yes	Yes	Yes	No	Yes	Yes
	CARE_2	Yes	X	X	Yes	No	--
	ACC_2	Yes	Yes	X	Yes	Yes	--
	COOR_2	Yes	Yes	X	Yes	Yes	--
Qualifies as having a Medical Home?		**YES**	**YES**	**YES**	**NO**	**NO**	**--***

X = Legitimate skip – child did not need the type of care addressed by this topic

-- = System missing or "Don't know/Refused" responses for all questions used to derive sub-component topic variable

* = Cases with "Don't know/Refused" or systems missing responses to the question asking whether child has at least one personal doctor or nurse are not asked any further questions in the medical home section of the survey. These cases are coded as "missing" and not included in the valid denominator when calculating the overall medical home composite score.

As illustrated in Figure 3, the 2003 NSCH baseline criteria for having a medical home require a child to have at least one personal doctor or nurse from whom he or she receives family-centered care AND at least one preventive medical care visit with any provider during the past year. In addition to meeting the three baseline criteria for medical home, children must also receive care that meets the threshold criteria OR qualify as a "legitimate skip" because care was not needed on each of the three additional sub-component topics measured in the survey (Figure 3, child #1 through child #3) to be classified as having a medical home. As illustrated by example child #4, failing to achieve even one of the three baseline criteria classifies a child as not having a medical home. On the other hand, children who meet all three of the baseline criteria qualify as having a medical home even if they did not need the types of care assessed under the remaining three sub-component topics (Figure 3, child #3).

Children with responses of NO, "Don't Know, Refused" or system missing to the personal doctor/nurse question (S5Q01) are automatically classified as not having a medical home, even if they meet the threshold criteria for having a preventive care visit with any provider

during the past 12 months (Figure 3, child #6). This is because no further questions in the medical home section of the survey are asked for children reported to not have a personal doctor or nurse and those with unknown responses. Subsequently, these cases appear as "system missing" for all questions used to derive the remaining sub-component topic variables other than that for preventive care visits.

Finally, the NSCH medical home scoring programs provided in the appendices treat cases that have either system missing or "Don't Know/Refused" responses to the personal doctor or nurse question – and consequently appear as system missing for the questions used to assess all remaining topics other than preventive care visits – as missing data. These cases are not included in the valid denominator when calculating the composite measure (Figure 3, child #6). Nationally, about 1 percent of sample children were not included in the valid denominator for the 2003 NSCH medical home composite measure.

Resources for measuring medical home using 2003 NSCH data: Appendices C_1 and C_2 offer resources to guide SAS and SPSS users in constructing the sub-component topic variables and the composite measure of medical home using data elements from the 2003 NSCH, including:

- Overview tables with derived variable names from SAS and SPSS medical home scoring programs
- SAS and SPSS programming code for creating the overall medical home composite measure, each of the sub-component topic scores and associated interim variables from 2003 NSCH data elements
- Summary tables with aggregate results for the 2003 NSCH Medical Home composite measure outcome, sub-component scores and associated interim variable
- Tables with text, response options and associated skip pattern details for each of the survey items used in the SAS and SPSS scoring programs
- Unweighted univariate distributions for the dichotomous medical home composite measure, sub-component topic variables and associated interim variables produced by the SAS or SPSS programs. Another useful resource, the 2003 NSCH indicator codebook, is available at: www.childhealthdata.org

3.5 *Medical home measurement using 2007 NSCH data elements*

The overall medical home measure from the 2007 NSCH is a composite of five different sub-component topics assessing the following:

1. Child has at least one personal doctor or nurse
2. Family-centered care
3. Getting needed referral
4. Usual source(s) for care
5. Effective care coordination

Table 7 organizes the five medical home topics assessed by the 2007 NSCH according to the specific definitional components of the AAP medical home model each is intended to measure. A total of 18 questions from the 2007 NSCH are used to develop the medical home composite measure.

Sub-component topic denominators: Two of the 2007 NSCH sub-component topics are relevant for all sampled children; the content of the remaining topics apply only to those children who needed the types of care being asked about. Children with survey responses indicating a specific type of care was not needed are designated as "legitimate skips" for scoring purposes because parents cannot legitimately be asked questions about care that children did not need or receive. The relevant denominators for the five sub-component topics are as follows:

1. Two sub-component topics (*Have at least one personal doctor or nurse; Usual source(s) for care*) include all children in the sample.
2. One sub-component topic (*Family-centered care)* includes only those 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. Children who did not use any of these services during the past 12 months are considered "legitimate skips" for scoring purposes.
3. Two sub-component topics (*No problems obtaining referrals; Effective care coordination*) pertain only to children who qualify as needing these services during the past 12 months. Children with survey responses that do not qualify for needing these services are considered "legitimate skips" for scoring purposes.

Sub-component topic thresholds and legitimate skips: Table 7 summarizes the threshold and legitimate skip criteria for each of the 2007 NSCH medical home sub-component topics. The SPSS scoring program provided in Appendix D_1 create the five derived variables listed in the second column of the table – one for each of the sub-component topics used to construct the medical home composite measure from 2007 NSCH data elements.

Table 7: Measuring Medical Home using 2007 NSCH data elements: Sub-component topic variables

Sub-component topics measured within each AAP Medical Home definitional component	**Variable name***	**Threshold criteria**	**Legitimate skip criteria**
RELATIONSHIP WITH SPECIFIC PROVIDER 1. Has at least one "personal doctor or nurse"	PDN	Responses "Yes, one person" or "Yes, more than one person" to personal doctor or nurse question	No skips; asked for all sample children
ACCESSIBLE	--	--	--
FAMILY-CENTERED 2. Receives family-centered care	FAMCENT	Responses of "Usually or Always" to all family-centered and culturally effective care questions	Responses indicating child did not use any preventive medical care or preventive dental care or mental health or specialist care during past 12 months; interpreter services question asked only for children with a primary household language other than English
CONTINUOUS	--	--	--
COMPREHENSIVE 3. Getting needed referrals	NOREFPRB	"Not a problem" response to question about obtaining needed referrals	Response indicating child did not need a referral in the past 12 months to see any doctors or receive any services
4. Usual source(s) for care	USUAL	Responses indicating child has regular source(s) of health care other than hospital emergency room	No skips; asked for all sample children
COORDINATED 5. Getting effective care coordination when needed	CARECOOR	Responses indicating family currently receives assistance with care coordination or gets needed extra help, and if needed, responses of "Very satisfied" to the questions about doctors' communication with each other or with child's school/other programs.	The care coordination questions are asked only for children who used 2 or more of the following services in the past 12 months: preventive medical care, preventive dental care, mental health care, needed or received care from a specialist doctor. Children who used less than 2 services or do not currently get and did not need extra help to coordinate child's care are considered legitimate skips.
COMPASSIONATE	*Assessed by questions within the Family-centered Care component*		
CULTURALLY EFFECTIVE	*Responses to questions addressing culturally effective care included in the Family-centered Care sub-component scoring*		

-- Not assessed by survey (See Table 2 for details) *2007 SPSS variable names shown in the table

Scoring sub-component topics: The scoring parameters for 2007 NSCH medical home sub-component topics in Table 7 are briefly outlined below:

1. Child has at least one personal doctor or nurse
    a. Constructed from a single item; asked for all children in the sample
    b. *Threshold criteria* = Responses of YES, ONE PERSON or YES, MORE THAN ONE PERSON to question asking if there are one or more persons that the respondent considers as being the child's personal doctor or nurse

2. Receives family-centered care
    a. Constructed from up to seven questions
    b. *Threshold criteria* = responses indicating child used 1 or more of the following services in the past 12 months: preventive medical care, preventive dental care, mental health care, needed or received care from a specialist doctor AND responses of USUALLY or ALWAYS to all five family-centered care questions, AND if primary household language is other than English AND child's family needed interpreter help to speak with child's doctors, responses of USUALLY or ALWAYS to accessing interpreter services during child's health care visits

3. No problems obtaining referrals
    a. Constructed from up to 2 items
    b. *Threshold criteria* = YES response to referrals being needed in past 12 months in order for child to see other doctors or receive services AND response of NOT A PROBLEM to getting the needed referrals

4. Usual source(s) for care
    a. Constructed from two items
    b. *Threshold criteria* = responses indicating that child has regular source(s) for care other than hospital emergency room when sick or advice is needed about his/her health

5. Receives effective care coordination
    a. Constructed from up to six items
    b. *Threshold criteria* = Child used 2 or more of five different health services during the past 12 months (preventive medical care, preventive dental care, mental health care, needed or received care from a specialist doctor) AND affirmative responses indicating (a) family currently receives help coordinating child's care and does

not need extra help, OR if extra help was needed, family USUALLY received the help desired; OR (b) no help coordinating care was reported AND no need for extra help coordinating care was reported; AND (c) if child used any of five different specialized services and communication between doctors was needed, responses of VERY SATISFIED with that communication, AND (d) if needed, responses of VERY SATISFIED with communication between doctors and child's school or other programs.

Additional information such as the survey-specific item numbers, exact text of the medical home questions, and details of the interim variables developed to construct each sub-component topic score is included with the user resources for the 2007 NSCH in Appendices D_1.

2007 NSCH medical home composite measure: The SPSS scoring program in Appendix D_1 uses the 'on every' method (see section 3.2) to construct the dichotomous composite measure classifying children as either having or not having a medical home. To qualify as having a medical home as measured by the 2007 NSCH, children must:

A) Meet both 2007 NSCH baseline criteria for having a medical home (see Fig. 1)

B) AND, either receive care meeting the threshold criteria or qualify as a legitimate skip on each one of the three additional sub-components topics.

Figure 4 presents six hypothetical cases – each illustrating how different combinations of sub-component topic results culminate in the final medical home outcome using the "on every" approach to construct the composite measure. For brevity, the variable names shown in Table 7 are used in Figure 4 to denote each of the five sub-component topics. The details of these derived variables are described in Table 7 and in Appendix D_1.

Figure 4: National Survey of Children's Health (NSCH), 2007

Scoring algorithm examples for the 2007 NSCH Medical Home composite measure

Derived variable names for the 2007 NSCH sub-component topics (see Table 7)		*Does child meet threshold criteria?* Child #1	Child #2	Child #3	Child #4	Child #5	Child #6
"Baseline criteria for having a medical home"	**PDN**	Yes~	Yes	Yes	No	Yes	Yes
	USUAL	Yes	Yes	Yes	Yes	Yes	Yes
	FAMCENT	Yes	Yes	X	Yes	Yes	--
	NOREFPRB	Yes	X	X	Yes	No	Yes
	CARECOOR	Yes	X	X	Yes	Yes	Yes
	Qualifies as having a Medical Home?	**YES**	**YES**	**YES**	**NO**	**NO**	**--***

X = Legitimate skip – child did not need the type of care addressed by this topic

-- = System missing or "Don't know/Refused" responses to 1 or more questions used to derive the sub-component topic variable

* = Children with missing or "Don't know/Refused" responses for 1 or more sub-component topics variables are NOT included in the valid denominator when calculating the overall medical home composite score

As illustrated in Figure 4, the 2007 NSCH minimum criteria for medical home requires children to have at least one personal doctor/nurse AND usual source(s) for care when sick or advice about health is needed. In addition to meeting both of these baseline criteria, children also must receive care meeting the threshold criteria for OR qualify as a "legitimate skip" on each of three additional sub-components topics measured in the survey (Figure 4, child #1 through child #3). Failing to meet either one of the baseline criteria automatically categorizes a child as not having a medical home, regardless of whether he or she receives care meeting the thresholds for all the other sub-component topics (Figure 4, child #4). On the other hand, children meeting the two baseline criteria qualify as having a medical home, even if they did not need any of the other types of care assessed within the three remaining sub-component topics (Figure 4, child #3).

Conversely, if a child meets the baseline criteria for having a medical home and received care that did not meet the threshold for one or more sub-component topics, the result is "no medical home" (Figure 4, child #5). Finally, cases with responses classified as "Don't Know/Refused" or system missing on the subcomponent topic variables are not included in the denominator when calculating the medical home measure (Figure 4, child #6). Nationally, about 4 percent of children in the sample were excluded from valid denominator used for the 2007 NSCH medical home composite measure.

Resources for measuring medical home using 2007 NSCH data elements: Appendix D_1 offers a set of resources to guide SPSS users in constructing the sub-component topic variables and composite medical home measure using 2007 NSCH data elements. These resources include:

- Overview tables with derived variable names from the SPSS medical home scoring programs and associated 2007 NSCH data elements
- SPSS programming code for creating the overall medical home composite measure, each of the various sub-component topic scores and associated interim variables
- Summary tables showing aggregate data results for the Medical Home composite measure, sub-component topic and associated interim variables using 2007 NSCH data elements
- Tables with the text, response options and associated skip pattern details for each of the survey items from the 2007 NSCH used in the SPSS medical home scoring programs
- Unweighted univariate distributions for the dichotomous medical home composite measure, each of the sub-component topic variables and associated interim variables produced by the SPSS programming code for constructing the 2007 NSCH medical home measure
- Other resources for data users are the 2007 NSCH indicator codebooks available through the Data Resource Center for Child and Adolescent Health website: www.childhealthdata.org

IV. MEDICAL HOME FINDINGS FROM THE NS-CSHCN AND NSCH

Although the methods and content addressing medical home differ in important ways, the NS-CSHCN and the NSCH share in common the "on every" scoring approach used to calculate the medical home composite measures derived from these surveys. Table 8 shows the crude results from using the "on every" approach to arrive at the prevalence of children with medical homes based on the various data elements available from the 2001 NS-CSHCN, 2005/06 NS-CSHCN, 2003 NSCH, and 2007 NSCH. National and state-specific results from all years of the NS-CSHCN and the NSCH are also available to query on the Data Resource Center for Child and Adolescent Health website (www.childhealthdata.org).

4.1 Overall prevalence

Despite differences in the methods and specific content involved, the medical home composite measure results across the surveys are remarkably consistent (Table 8). Regardless of health status, roughly one-half of the children in the United States (range: 44.0% to 57.5%) meet the AAP definition for having a medical home as operationalized through the NS-CSHCN and NSCH surveys. Although the overall medical home prevalence tends to be similar, there are substantial variations across the surveys in the proportion of children meeting the inclusion criteria for several medical home sub-components. In some cases, revisions to the questions and methods used to identify valid responders for a sub-component are the principal sources for this variation. For example, in the 2001 NS-CSHCN, nearly 90% of children did not meet the inclusion criteria for the coordinated care sub-component of medical home and subsequently were classified as "legitimate skips" on the basis of not needing such care (Table 8). Due to improvements to the questions used to assess need for care coordination, only 22% of children failed to meet the inclusion criteria for the 2005/06 NS-CSHCN coordinated care sub-component (Table 8).

Factors such as children's health status and differential needs for health care also contribute to variation in sub-component denominator sizes for different groups. In the 2003 NSCH, over 50% of the children identified as having special health care needs required one or more of the specialized health care or services necessary for inclusion in the access to specialty care and services subcomponent topic denominator (Table 8; 11.5% + 42.7%). In contrast, in the same survey only 16% of children without special health care needs required the types of

specialized care or services that are the prerequisite for inclusion in the denominator of this subcomponent topic. Using different content and methods, the 2007 NSCH shows a similar pattern with about one third of CSHCN needing referrals for specialty or services compared to 16 percent of non-CSHCN.

These and other findings from the various administrations of the NS-CSHCN and the NSCH provide useful insights into the influence of question design and underlying population characteristics when assessing the complex and multi-factored medical home concept. Section 4.3 takes a closer look at the contribution of some of these factors to the overall medical home composite scores.

Appendix E provides a list of publications reporting on various analyses using the medical home composite measures or associated sub-components from the NS-CSHCN and NSCH. Several of these articles demonstrate state-specific applications of the medical home data from these surveys.

TABLE 8: Percent of children meeting the criteria for having a medical home overall and within each measured sub-component topic, by survey†

	2001 NS-CSHCN	2005/06 NS-CSHCN	2003 NSCH		2007 NSCH	
Percent with MEDICAL HOME overall:†	% *(95% CI)*	% *(95% CI)*	% *(95% CI)*		% *(95% CI)*	
All children, ages 0-17	--	--	46.1 (45.6 - 46.7)		57.5 (56.5 – 58.6)	
CSHCN, ages 0-17	52.6 (51.7 - 53.6)	47.1 (46.3 – 48.0)	44.2 (42.9 - 45.4)		49.8 (47.5 – 52.0)	
Sub-component topics measured within each AAP Medical Home definitional component:	*CSHCN, ages 0-17 (%)*	*CSHCN, ages 0-17 (%)*	*All children, ages 0-17 (%)*	*CSHCN, Only (%)*	*All children, ages 0-17 (%)*	*CSHCN, Only (%)*
ESTABLISHED RELATIONSHIP WITH SPECIFIC PROVIDER						
Has at least one "personal doctor or nurse"	89.0	93.5	83.3	90.0	92.2	94.7
ACCESSIBLE	--	--	--	--	--	--
FAMILY-CENTERED						
Family-centered care(FCC) from ALL child's doctors and other health care providers						
a) No, does not have FCC care	31.9	32.5	--	--	31.6	34.1
b) Yes, has FCC care	64.2	62.4	--	--	65.1	64.8
c) Legitimate skip	3.9	5.1	--	--	3.3	1.1
Family-centered care (FCC) from child's personal doctor or nurse						
a) No, does not have FCC car	--	--	17.7	16.3	--	--
b) Yes, has FCC care	--	--	65.2	73.4	--	--
c) Legitimate skip	--	--	17.1	10.3	--	--
CONTINUOUS	--	--	--	--	--	--

† All estimated percentages are weighted to represent the U.S. non-institutionalized child population ages 0-17; (95% CI) = 95% confidence interval
-- Not assessed by survey (See Table 2 for details)

TABLE 8: (continued)†

	2001 NS-CSHCN	2005/06 NS-CSHCN	2003 NSCH		2007 NSCH	
Sub-component topics measured within each AAP Medical Home definitional component:	*CSHCN, ages 0-17 (%)*	*CSHCN, ages 0-17 (%)*	*All children, ages 0-17 (%)*	*CSHCN, Only (%)*	*All children, ages 0-17 (%)*	*CSHCN, Only (%)*
COMPREHENSIVE						
Getting needed referrals						
a) Needed, problems getting	10.8	7.0	--	--	2.8	7.0
b) Needed, no problem getting	38.8	26.0	--	--	13.1	25.2
c) Legitimate skip	50.3	67.0	--	--	84.1	67.8
Usual source(s) for both sick and well care	90.5	92.9	--	--	93.1	94.8
Preventive care visit during past 12 months	--	--	77.8	86.5	--	--
Consistent access to urgent care and/or phone advice from personal doctor or nurse						
a) Needed, did not consistently get	--	--	3.6	6.3	--	--
b) Needed, consistently got	--	--	40.1	55.3	--	--
c) Legitimate skip	--	--	56.2	38.4	--	--
Getting needed specialist care, and/or specialized health services or equipment						
a) Needed, problems getting	--	--	3.5	11.5	--	--
b) Needed, no problem getting	--	--	19.2	42.7	--	--
c) Legitimate skip	--	--	77.3	45.9	--	--
COORDINATED						
Getting effective care coordination when needed						
a) Did not get all help wanted	6.7	31.8	--	--	12.9	29.7
b) Got all help wanted	4.5	46.0	--	--	28.3	43.4
c) Legitimate skip(no report of getting or wanting more help with care coordination)	88.8	22.2	--	--	58.8	26.9
Follow up by personal doctor or nurse after child sees specialist care and/or gets specialized health services	--	--	9.4	24.2	--	--
a) Needed, did not consistently get	--	--	12.9	29.4	--	--
b) Needed, consistently got	--	--	77.6	46.4	--	--
c) Legitimate skip						
COMPASSIONATE	*The concept of "compassionate care" is addressed in the context of the family-centered care questions*					
CULTURALLY EFFECTIVE	*For scoring purposes, questions addressing this topic are included in the Family-centered care sub-component*					

†All estimated percentages are weighted to represent the U.S. non-institutionalized child population ages 0-17 -- Not assessed by survey (See Table 2 for details)

4.2 Medical home prevalence by demographic characteristics

Table 9 displays the medical home results again, this time by selected child demographic characteristics. As the results in the table show, the prevalence of having a medical home as measured by the NS-CSHCN and NSCH surveys rarely exceeds 60%, even when subgroups of children are considered. Notable exceptions include non-Hispanic White children and those with household incomes at or exceeding 400 percent of the federal poverty level. In the 2007, nearly70 percent of children from these groups met the NSCH criteria for having a medical home (68.0% and 69.3%, respectively). Children from vulnerable groups are dramatically less likely to have a medical home (Table 9). In the same survey, medical home prevalence is 39% for children whose families have incomes at or below the poverty level, and 46% for those covered by public health insurance. Fewer than half of children who are lower-income, intermittently insured or uninsured children, or non-White or Hispanic had a medical home in 2007. Children with special health care needs, a group with even greater requirements for coordinated and comprehensive care, fared no better and often significantly worse than their non-special needs counterparts.

TABLE 9: Prevalence of Medical Home overall and by demographic characteristics -- U.S. non-institutionalized child population, ages 0-17†

	2001 NS-CSHCN	2005-06 NS-CSHCN	2003 NSCH		2007 NSCH	
	CSHCN, ages 0-17	*CSHCN, ages 0-17*	*All children, ages 0-17*	*CSHCN only*	*All children, ages 0-17*	*CSHCN only*
Number of children in sample (unweighted)	38,866	40,723	102,353	18,578	91,642	18,352
Percent meeting Medical Home criteria† (95% CI)	**52.6** (51.7 - 53.6)	**47.1** (46.3 – 48.0)	**46.1** (45.6 - 46.7)	**44.2** (42.9 - 45.4)	**57.5** (56.5 – 58.6)	**49.8** (47.5 – 52.0)
Medical home prevalence by child characteristics	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Age						
0 – 5 years old	**53.5** (51.3 - 55.7)	**50.4** (48.4 – 52.3)	**55.9** (54.9 - 56.9)	**48.7** (45.7 - 51.6)	**64.0** (62.1 – 65.8)	**55.4** (50.2 – 60.4)
6 – 11 years old	**53.8** (52.4 - 55.3)	**47.4** (46.1 – 48.8)	**42.7** (41.7 - 43.6)	**43.9** (41.8 - 46.0)	**55.2** (53.3 - 57.0)	**47.2** (43.6 - 50.8)
12 – 17 years old	**51.1** (49.6 -52.6)	**45.2** (44.0 – 46.5)	**40.2** (39.3 - 41.0)	**42.2** (40.4 - 44.1)	**53.4** (51.7 - 55.1)	**49.4** (45.9 - 52.9)
Race/ethnicity						
White/non-Hisp	**56.9** (55.9 - 58.0)	**52.8** (51.8 – 53.8)	**52.8** (52.2 - 53.4)	**47.2** (45.8 - 48.6)	**68.0** (66.8 - 69.1)	**57.0** (54.4 - 59.6)
Hispanic	**40.7** (37.5 - 44.0)	**32.2** (29.5 – 35.0)	**30.3** (28.9 - 31.7)	**34.9** (30.5 - 39.6)	**38.5** (35.5 - 41.7)	**31.8** (25.3 - 39.2)
Black/non Hisp	**44.3** (41.5 - 47.2)	**36.6** (34.3 – 38.9)	**39.4** (37.8 - 40.9)	**40.9** (37.2 - 44.8)	**44.2** (41.6 - 46.8)	**39.6** (34.2 - 45.2)
Multi racial/non-Hisp	**49.7** (44.4 - 55.0)	**46.8** (42.3 – 51.3)	**46.0** (43.1 - 48.9)	**38.0** (32.2 - 44.3)	**63.0** (58.0 - 67.8)	**49.9** (41.2 - 58.7)
Other/non-Hisp	**38.3** (31.9 - 45.1)	**40.0** (35.2 – 44.8)	**41.5** (37.7 - 45.3)	**39.2** (30.0 - 49.2)	**48.6** (44.0 - 53.2)	**42.7** (30.7 - 55.7)
Household Income as percentage of Federal poverty level (FPL)						
0- 99% FPL	**37.9** (35.3 - 40.5)	**34.0** (32.0 – 36.0)	**31.2** (29.5 – 32.9)	**34.6** (30.8 – 38.6)	**39.4** (37.3 – 41.5)	**37.1** (33.4 – 41.0)
100% - 199% FPL	**48.7** (46.5 - 50.9)	**41.2** (39.3 – 43.0)	**39.6** (38.2 – 41.0)	**42.2** (38.9 – 45.7)	**49.4** (47.5 – 51.3)	**44.5** (40.8 – 48.3)
200% - 399% FPL	**56.2** (54.5 - 57.9)	**51.1** (49.6 – 52.6)	**50.1** (49.0 – 51.1)	**46.7** (44.3 – 49.2)	**62.5** (61.0 – 63.9)	**55.4** (52.0 – 58.7)
400% FPL or greater	**59.7** (57.8 - 61.5)	**56.3** (54.8 – 57.8)	**56.9†** (55.8 – 58.0)	**49.4** (46.9 – 51.9)	**69.3** (68.0 – 70.6)	**56.4** (53.1 – 59.6)
Income not reported	**50.3** (47.3 - 53.2)	††	††	††	††	††

(CONTINUED)

	2001 NS-CSHCN	2005-06 NS-CSHCN	2003 NSCH		2007 NSCH	
	CSHCN, ages 0-17	*CSHCN, ages 0-17*	*All children, ages 0-17*	*CSHCN only*	*All children, ages 0-17*	*CSHCN only*
Health insurance status, past 12 months						
Insured full year; no gaps	**54.4** (53.4 - 55.4)	**47.9** (47.0 – 48.8)	**49.3** (48.7 - 49.9)	**45.9** (44.5 - 47.2)	**60.9** (59.8 - 62.0)	**52.5** (50.1 - 54.9)
Uninsured for some period of time	**40.0** (36.9 - 43.2)	**26.5** (22.8 – 30.2)	**28.3** (27.0 - 29.7)	**32.3** (28.8 - 36.0)	**38.4** (35.4 - 41.4)	**29.9** (24.5 - 36.0)
Type of health insurance						
Private or employer-based coverage	**58.2** (57.0 - 59.3)	**53.3** (52.2 – 54.3)	**52.6** (52.0 - 53.3)	**47.7** (46.2 - 49.2)	**66.5** (65.3 - 67.8)	**56.6** (53.6 - 59.6)
Publicly insured (Medicaid; SCHIP)	**43.7** (41.6 - 45.9)	**38.9** (37.2 – 40.6)	**38.9** (37.7 - 40.0)	**40.2** (37.8 - 42.7)	**45.4** (43.3 - 47.6)	**42.1** (38.6 - 45.7)
Uninsured at time of survey	**36.4** (32.5 - 40.5)	**26.5** (22.8 – 30.2)	**23.1** (21.6 - 24.6)	**30.2** (25.4 - 35.6)	**35.7** (32.1 - 39.5)	**28.9** (21.8 - 37.4)
Primary household language						
English	n/a	**48.3** (47.4 – 49.3)	**49.3** (48.8 - 49.9)	**45.4** (44.1 - 46.6)	**61.7** (60.7 - 62.8)	**51.8** (49.5 - 54.1)
Other than English	n/a	**22.1** (46.2 – 48.1)	**23.8** (22.2 - 25.5)	**22.7** (17.3 - 29.3)	**28.8** (25.2 - 32.6)	**16.8** (11.2 - 24.5)
Language of the interview						
English	**53.6** (52.7 - 54.6)	n/a	n/a	n/a	n/a	n/a
Other than English	**23.1** (18.5 - 28.4)	n/a	n/a	n/a	n/a	n/a
Qualifying special health care needs criteria						
Managed by Rx meds only	**63.9** (62.5 - 65.4)	**58.9** (57.6 – 60.2)	n/a	**54.3** (52.3 - 56.3)	n/a	**62.5** (58.6 - 66.1)
Elevated services use/need only	**41.1** (38.7 - 43.6)	**35.8** (33.5 – 38.1)	n/a	**31.5** (28.5 - 34.8)	n/a	**39.3** (34.1 - 44.6)
Elevated service need AND Rx meds	**53.6** (51.7 - 55.6)	**45.2** (43.4 – 47.0)	n/a	**45.5** (43.0 - 48.1)	n/a	**50.1** (45.6 - 54.6)
Functional limitations -- alone or with any services or Rx meds use	**41.2** (39.3 - 43.2)	**32.2** (30.4 – 33.9)	n/a	**33.2** (30.7 - 35.9)	n/a	**34.6** (30.2 – 39.2)

† All estimates are weighted to represent the U.S. non-institutionalized child population ages 0-17; (95% CI) = 95% confidence interval

†† When income and/or number of persons in household were not reported, Federal Poverty Level (FPL) of household was estimated using single imputation methods

n/a = information not collected by survey

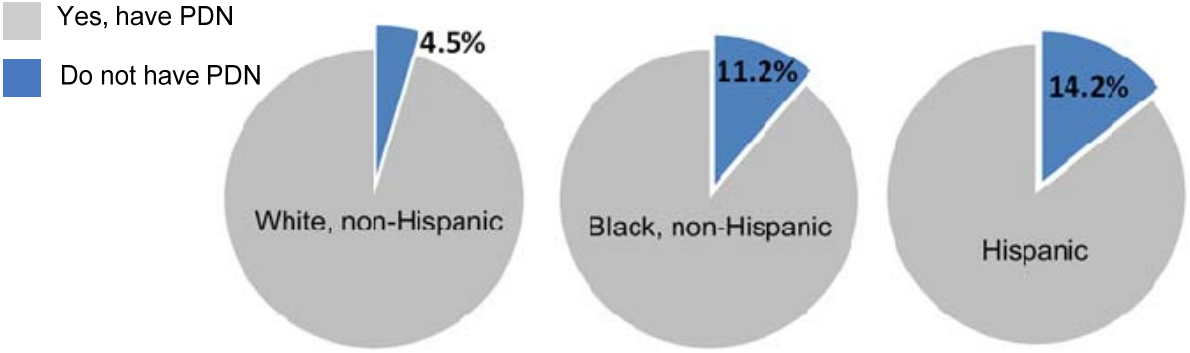
4.3 Influence of survey design on medical home prevalence

Personal doctor or nurse criterion: Prior to the availability of data from the NS-CSHCN and NSCH, States and others often relied upon the proportion of children with a primary care provider, or as it is sometimes termed; "a personal doctor or nurse," as the sole indicator of whether children have a medical home. The advent of more robust assessments, such as those from the NS-CSHCN and NSCH, demonstrated that having a personal doctor or nurse alone is not sufficient for having a medical home as defined by the AAP. At the same time, whether or not children have affirmative responses indicating the presence of a PDN continues to be a significant factor in determing the medical home prevalence estimates generated by these surveys.

Both the NS-CSHCN and NSCH include having a personal doctor or nurse (PDN) as one of several basic or minimum criteria for having a medical home. Children with response of NO to the survey question about having one or more personal doctors or nurses are classified from the outset as not having a medical home, regardless of whether they achieve thresholds scores on all other components of the medical home measure.

In the 2007 NSCH, about 8 percent of children overall were without any PDN. Some groups of children, however, have a disproportionately higher risk. Black, non-Hispanic children are twice as likely and Hispanic children are three times more likely to not have any PDN compared to white, non-Hispanic children (Fig. 5). Similar disparities in meeting the baseline criterion of having at least one PDN strongly contribute to the lower prevalence of medical home among non-white and Hispanic children found in the 2003 NSCH and NS-CSHCN surveys (Table 9).

Figure 5: Children age 0-17 years with at least one personal doctor or nurse (PDN), by race/ethnicity – U.S. non-institutionalized child population, 2007

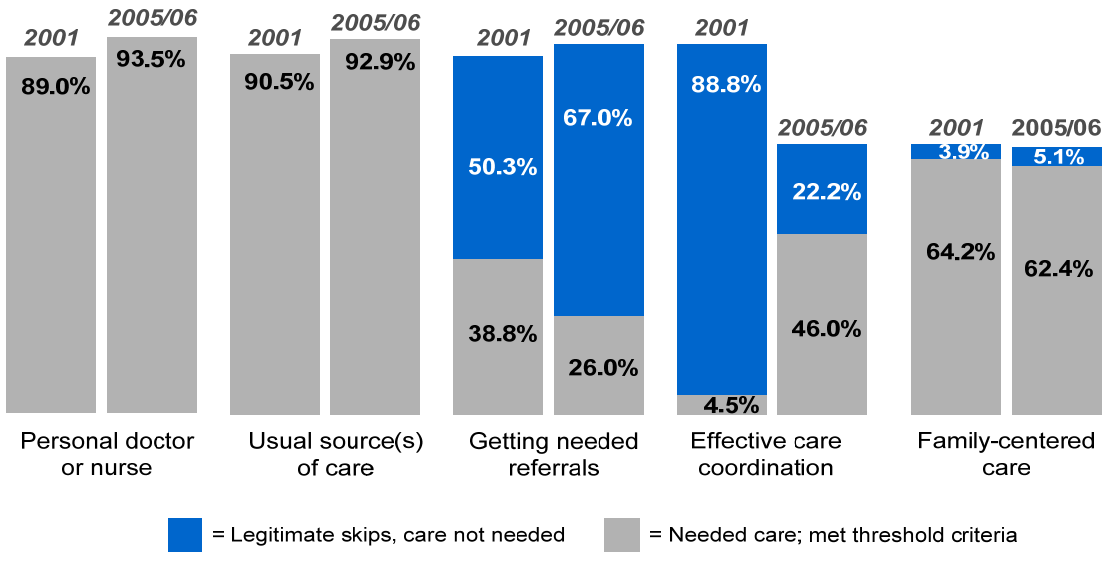


Source: National Survey of Children's Health, 2003

Influence of question changes: In response to issues identified during the first administration of the NS-CSHCN, the Effective Care Coordination and Getting Needed Referrals sub-components of the medical home measure were revised prior to the survey's second administration in 2005/06 (see Sections 2.1 and 3.3). The questions for assessing these sub-components underwent substantial changes in wording, design and content. Included were significant modifications in the criteria used for identifying valid responders and legitimate skips in each of these sub-components. Comparing the medical home results prior to and after these types of revisions provides an opportunity to observe the effect of changes in question design and content on the medical home composite score, and potentially, the estimates of medical home prevalence overall.

Figure 6 compares the 2001 and 2005/06 NS-CSHCN distributions on each of the five medical home sub-component topics for children meeting either the threshold criteria for getting needed care or classified as "legitimate skips" because care was assumed and/or reported to not be needed. The proportion of children either meeting threshold criteria or classified as legitimate skips varies substantially across the five medical home sub-component topics within each and across the two survey administrations. In 2001, Effective Care Coordination was the sub-component topic with the highest combined proportion of threshold achievers and legitimate skips (93.3%) and the Family-Centered Care sub-component topic was the lowest (68.1%).

Figure 6: Proportion of CSHCN receiving care that meets the threshold criteria or classified as "legitimate skips" within each medical home sub-component topic, by NS-CSHCN survey year



In 2005/06, the changes made to the care coordination questions greatly altered the proportions of children either meeting the threshold criteria or classified as legitimate skips within that sub-component topic. As Figure 6 illustrates, Effective Care Coordination went from being the sub-component with the highest combined proportion of threshold achievers and legitimate skips in 2001 to essentially tying with Family-Centered Care sub-component for the lowest proportion in 2005/06 (68.2 % and 67.5%, respectively).

Although changes to the care coordination questions also dramatically changed the individual proportions of children who were classified as needing care coordination and met the threshold criteria or who were classified as not needing care coordination (legitimate skip) in the 2005/06 survey, it is actually the combined proportion of these two categories that has potential to influence the overall medical home score. This is because the overall medical home results are based on the proportion of children who either meet the threshold criteria or qualify as legitimate skips on every one of the five sub-components topics. As such, the proportion of children meeting the overall medical home composite measure cannot exceed the results for the sub-component with the lowest combined proportion of threshold achievers and legitimate skips.

In 2001, the Family-Centered Care sub-component anchored the medical home composite score by having the lowest combined proportion of threshold achievers and legitimate skips. As a result of questions changes in the 2005/06, the Effective Care Coordination sub-component tied with the Family-Centered Care sub-component for the lowest combined proportion of threshold achievers and legitimate skips. Because of this tie, it was the 52 percent of cases that either met the threshold criteria or were legitimates skips across both these of sub-components that formed the new baseline proportion for the overall medical home score, rather than 67.5 percent result for the Family-Centered Care sub-component.

From a question design perspective, it is interesting to note that changes in question content and skip patterns do not always influence a composite measure. The 2005/06 questions for the Getting Needed Referrals sub-component also underwent substantial revision. Although these revisions changed the relative distributions of legitimate skips and threshold achievers within the sub-component, the net effect was only a slight increase over the 2001 results for the combined proportion of these cases (See Fig. 6). As a result, the question changes for this sub-component had minimal, if any, effect on the overall medical home composite score in 2005/06.

V. FUTURE WORK TO REFINE MEASUREMENT OF THE MEDICAL HOME

The NS-CSHCN and NSCH represent major strides toward the development of robust, policy-relevant measures of the AAP's medical home definition for children and youth. Still, work should continue to better understand the utility of various approaches to measuring the medical home concept. The intent of the following discussion is to provide a brief overview of alternative measurement strategies and considerations when using the NS-CSHCN and NSCH approaches in research and policy contexts.

5.1 Other classification approaches

Nominal and ordinal measures: If a single summary measure of the medical home model is the goal of the measurement process, the first issue to be confronted is the level of measurement to use for that single variable. The dichotomous composite measure described in this manual classifies children as either having or not having a medical home. One alternative is to classify children according to the specific defined sub-components of medical home measurement approaches outlined in this manual and derive alternative nominal or ordinal measures based on results. One hypothetical set of nominal categories may include:

1. Evidence of the presence of at least 5 of the 7 components of a medical home
2. Evidence of components 1, 2, 4, and 5
3. Evidence of components (1, 2, and 4) or (1, 2, and 5)
4. Evidence of components (1, 4, and 5) or (2, 4 or 5)
5. Evidence of only 1-2 components of a medical home
6. No evidence of a medical home

These measurement examples are nominal because there is no obvious and consistent ordering of the categories.

Another approach to creating a limited set of categories would be to aim for a more consistent ordering. One hypothetical set of ordinal categories for the medical home concept might potentially classify children as follows:

1. Evidence of the presence of at least 5 of the 7 components of a medical home
2. Evidence of any 4 components
3. Evidence of any 3 components

4. Evidence of any 2 components
5. Evidence of only 1 component
6. No evidence of a medical home

***"Across all" approach*:** The "across all" approach, originally developed using data from other child health surveys[3], is another alternative to the "on every" scoring method described in Section 3.2. Like the "on every" method, the "across all" approach uses the scoring parameters described in early sections of the manual to develop each of the separate sub-component scores. The difference is that the "across all" approach does not require the creation of categorical variables that classify children according to whether they achieve or fail to achieve the threshold scores in each of the sub-components for which they meet the inclusion criteria. Instead, point values are standardized using a 0-100 scale in which 75 points or above is the equivalent of consistently getting needed care. The standardized values are used to compute an average score for each sub-component in which the child meets the inclusion criteria. To create the overall composite measure, the sub-component point averages are first summed and then divided by the number of sub-components for which the child met the inclusion criteria. Children with an overall mean score of 75 points or above across all needed sub-components are classified as having a medical home. Children with an overall mean of less than 75 points are classified as not having a medical home. This is a less stringent threshold for having a medical home than that used by the "on every" method. Under the "across all" approach, some children will be classified as having a medical home even though they do not actually achieve a score of 75 points or above on every specific aspect of the medical home for which they are valid responders. In contrast, the more exacting criteria of the "on every" method requires that children achieve a threshold score on every sub-component for which they meet the inclusion criteria of needing care.

Continuous measures of "medical home-ness:" Another potential way to quantify the medical home concept is to create a continuous measure. One way to approach this would be to calculate an average of the points achieved for each child by using the "across all" sub-components grand mean or the sub-component point averages directly, without defining threshold values. Rather than describing the proportion of children meeting a specific threshold for having medical home, a continuous measure of this type would lead to reporting an average medical home score using a 0-100 scale. Such a measure would provide information about the

degree of medical home-ness by indicating how close or far children are from having the full complement of medical home characteristics outlined in the AAP definition. More information on constructing such a score can be found in Bethell, Read, et al.[3]

Continuous medical home scores could be reported across all components combined or separately for each medical home sub-component. Such an approach might lead, for example, to statements such as, "The average score for all measured components of the medical home concept among survey respondents was 68 points using a 0-100 scale;" or "The average score for care coordination among survey respondents was 80 points out of 100, while the average score for compassionate care was 62 points out of 100." As with other approaches, methods for developing a continuous measure of medical home need to include strategies that accommodate children who do not need every aspect of care measured.

Potential applications: The use of dichotomous, nominal, or ordinal categories influences the type of further statistical analyses to be carried out, as well as the type of statistics that can be reported. As with any evaluation activity, it is important to choose methods and metrics appropriate for the purposes and goals of the research questions and reporting requirements.

Defining a dichotomous medical home variable as done using the "on every" method described in this manual or the "across all" approach outlined above leads to reporting of a single proportion reflecting the prevalence of children classified as having a medical home. For surveillance reporting, a dichotomous outcome is very useful as a high level "signal" of the current status in the population. For other reporting purposes, nominal categories can be valuable for understanding of the relative prevalence of particular combinations of the components and sub-components of the medical home. Such information would call attention to gaps and point to potential initiatives for improving health care for children. The use of ordinal measures of medical home provide a more straightforward view of the overall impact of increasing numbers of elements of a medical home, or what even might be considered a "dose response" for degree of medical home-ness.

Continuous scores are similar to ordinal measures in that both provide a view of the overall impact of moving closer to having a medical home and the wider range of possible values may provide a better estimate of incremental enhancements to the health care delivery system for

children. Continuous measures offer other analytic options not possible with categorical data. To be most effective, however, it is necessary to standardize the point values in some meaningful way in order to help distinguish the policy and performance relevant differences between scores of 50 points and 70 points.

5.2 Differential weighting of scoring components

In the analytic approaches discussed thus far, all data elements corresponding to characteristics of the medical home concept are given equal weight in the scoring process. Implicitly though, available data elements are weighted more heavily than the characteristics that are not measured at all. In addition, a strong differential exists in terms of the level of children's need for the different types of care represented in the medical home model. As shown in Table 7 and discussed in depth throughout the scoring sections, only a minority of children can be expected to meet the inclusion criteria for every subcomponent of medical home measured through the surveys addressed in this manual. Fewer needs for care translate into meeting the inclusion criteria for fewer sub-component scores. At the individual child-level, the fewer sub-component scores available means each score will make a correspondingly larger contribution to the overall medical home composite result for that child. Conversely, the more sub-components scores available for a child, the less weight any specific score will carry when calculating the overall medical home composite for that individual. Given these scenarios, it is reasonable to contemplate in a research application whether the sub-components of medical home measured through the NS-CSHCN and NSCH surveys should all be given equal weight or whether some aspects are of lesser or greater importance and should be weighted accordingly.

Further theoretical and empirical work is needed to examine the implications of differentially weighting schemes for certain components of the medical home concept as well as differentially weighting specific sub-component characteristics within each component.. Researchers interested in developing such methods will need to carefully examine the resulting overall prevalence estimates and justify the conceptual grounds for the differential weighting scheme applied. More work is required to arrive at sound theoretical approaches and policy relevant rationale for appropriate differential weighting of components for purposes of creating overall composite measures of medical home.

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