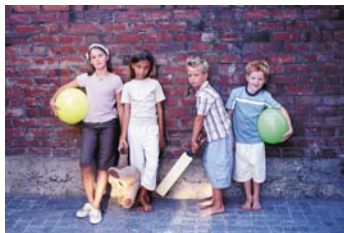

Measuring Medical Home for Children and Youth

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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*A Resource Manual
for Child Health Program Leaders,
Researchers and Analysts*

Prepared by

CAHMI – The Child and Adolescent Health Measurement Initiative
Oregon Health & Science University
for

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
National Center for Health Statistics

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Table of Contents

	Page
Acknowledgements	ii
Introduction	1
I. Brief History of the Medical Home Concept	2
II. Assessment of the Medical Home Concept	
2.1 Overview of the Surveys	5
<i>2001 NS-CSHCN</i>	
<i>2003 NSCH</i>	
<i>2005/2006 NS-CSHCN</i>	
<i>2007 NSCH</i>	
2.2 Overview of Methods and Content Used to Assess Medical Home	8
2.3 Differences in Methods and Content Used to Assess Medical Home	11
<i>Differences in focus of assessment</i>	
<i>Differences in wording and content</i>	
<i>Differences in recall timeframes</i>	
<i>Additional considerations when using survey-reported data</i>	
2.4 Full Text Copies of the Medical Home Questions from Each Survey	13
III. Quantifying the Medical Home Concept	
3.1 General Analytic Considerations	17
<i>Data availability</i>	
<i>Identifying valid denominators</i>	
<i>Minimum criteria for having a medical home</i>	
3.2 Overview of “On Every” Scoring Approach	20
<i>Survey specific considerations</i>	
3.3 Medical Home Measurement with the NS-CSHCN	22
<i>Sub-component topic denominators</i>	
<i>Sub-component topic thresholds and legitimate skips</i>	
<i>Scoring sub-component topics</i>	
<i>NS-CSHCN medical home composite measure</i>	
<i>Resources for measuring medical home using NS-CSHCN data</i>	

Table of Contents

	Page
3.4 Medical Home Measurement with the 2003 NSCH	29
<i>Sub-component topic denominators</i>	
<i>Sub-component topic thresholds and legitimate skips</i>	
<i>Scoring sub-component topics</i>	
<i>2003 NSCH medical home composite measure</i>	
<i>Resources for measuring medical home using 2003 NSCH data</i>	
3.5 Medical Home Measurement with the 2007 NSCH	36
<i>Sub-component topic denominators</i>	
<i>Sub-component topic thresholds and legitimate skips</i>	
<i>Scoring sub-component topics</i>	
<i>2007 NSCH medical home composite measure</i>	
<i>Resources for measuring medical home using 2007 NSCH data</i>	
IV. Medical Home Findings from the NS-CSHCN and NSCH	
4.1 Overall prevalence of medical home	42
4.2 Medical home prevalence by child demographic characteristics	46
4.3 Influence of survey design on medical home prevalence	49
<i>Personal doctor or nurse criterion</i>	
<i>Question changes</i>	
V. Future Work to Refine the Measurement of the Medical Home	
5.1 Other classification approaches	52
<i>Nominal and ordinal measures</i>	
<i>“Across all” approach</i>	
<i>Continuous measures of “medical home-ness”</i>	
<i>Potential applications</i>	
5.2 Differential weighting of scoring components	55
References	56

Appendices

Programming Code and Resources for Medical Home Measurement	Page
<i>2001 National Survey of Children with Special Health Care Needs</i>	
Appendix A_1: SAS User Resources	51
Appendix A_2: SPSS User Resources	81
<i>2005/2006 National Survey of Children with Special Health Care Needs</i>	
Appendix B_1: SAS User Resources	113
Appendix B_2: SPSS User Resources	141
<i>2003 National Survey of Children's Health</i>	
Appendix C_1: SAS User Resources	173
Appendix C_2: SPSS User Resources	209
<i>2007 National Survey of Children's Health</i>	
Appendix D_1: SPSS User Resources	209
Other Resources	
Appendix E: List of Selected Publications Using Medical Home Data from the NS_CSHCN and NSCH.	253

Tables and Figures

	Page
List of Tables	
Table 1: Desirable Characteristics of a Medical Home – AAP 2002 Policy Statement	4
Table 2: Overview of Medical Home measurement in two national child health surveys	8
Table 3: Across surveys comparison of methods and content for assessing medical home	10
Table 4: Survey item numbers and brief description of questions used to assess the AAP definitional components of Medical Home, by survey	14
Table 5: Measuring Medical Home using NS-CSHCN data elements: Sub-component topic variables	23
Table 6: Measuring Medical Home using 2003 NSCH data elements: Sub-component topic variables	30
Table 7: Measuring Medical Home using 2007 NSCH data elements: Sub-component topic variables	37
Table 8: Percent of children meeting the performance threshold criteria for medical home overall and within each measured sub-component topic, by survey	44
Table 9: Prevalence of Medical Home overall and by socio-demographic characteristics	47
List of Figures	
Figure 1: Medical Home measurement in national child health surveys	19
Figure 2: Scoring algorithm examples for NS-CSHCN Medical Home composite measure	26
Figure 3: Scoring algorithm examples for 2003 NSCH Medical Home composite measure	34
Figure 4: Scoring algorithm examples for 2007 NSCH Medical Home composite measure	40
Figure 5: 2003 NSCH: Percent of children ages 0-17 with at least one personal doctor or nurse, by child’s race/ethnicity	49
Figure 6: Comparison of NS-CSHCN medical home sub-component scoring results by year of survey	50

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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.

II. ASSESSMENT OF THE MEDICAL HOME CONCEPT

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

2.1 Overview of the Surveys

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

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

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

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

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

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

2.2 Overview of Methods and Content Used to Assess Medical Home

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

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

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

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

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

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

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

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

2.3 Differences in Methods and Content Used to Assess Medical Home

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

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

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

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

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

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

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

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

2.4 Full Text Copies of the Medical Home Questions

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

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

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

TABLE 4 (cont.)

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

TABLE 4 (cont.)

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

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 medical home definition is not amenable 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.

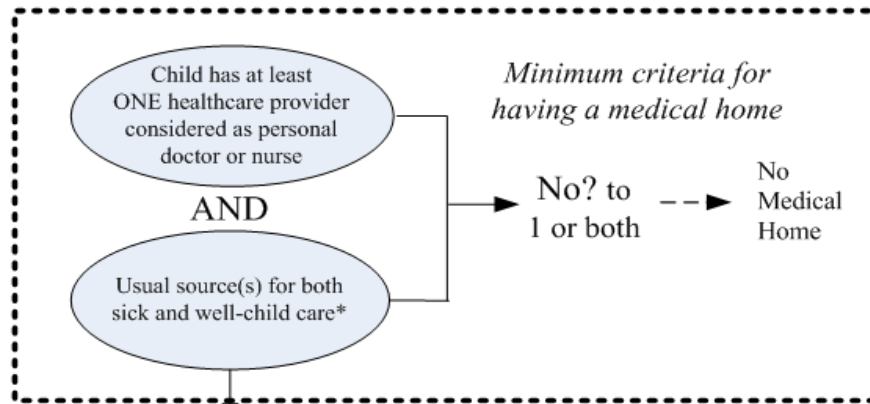
Minimum criteria for having a medical home: As described earlier, the NS-CHSCN and the 2007 NSCH assess medical home from the perspective of a network of services and care delivered by multiple providers across a variety of settings, whereas the 2003 NSCH anchors all of its medical home questions to 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.

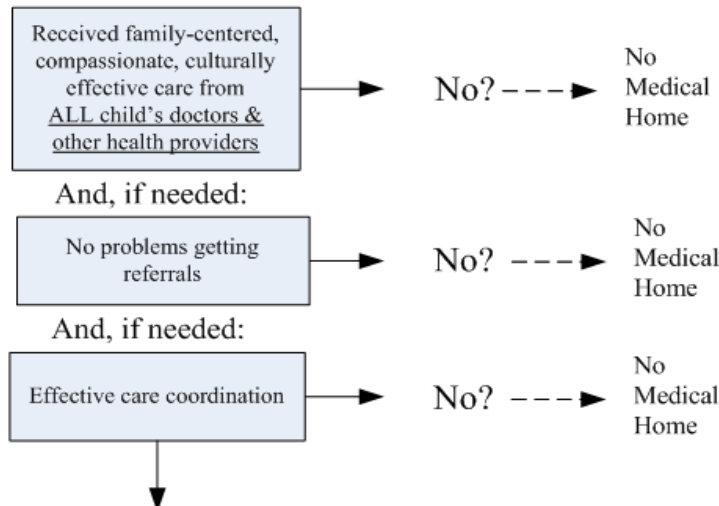
Figure 1: Medical Home Measurement using the National Child Health Surveys

2001 NS-CSHCN; 2005/06 NS-CSHCN; 2007 NSCH

Assessment focus: Care from network of health care providers and settings with which child and family interact



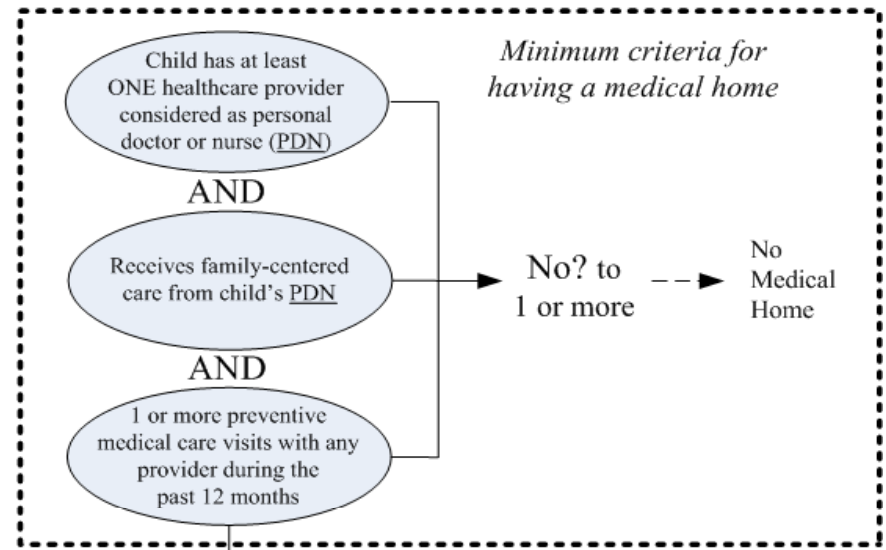
And, if child either had 1 or more doctor visits (NS-CSHCN) or used any of 5 different services (2007 NSCH) in past 12 months:



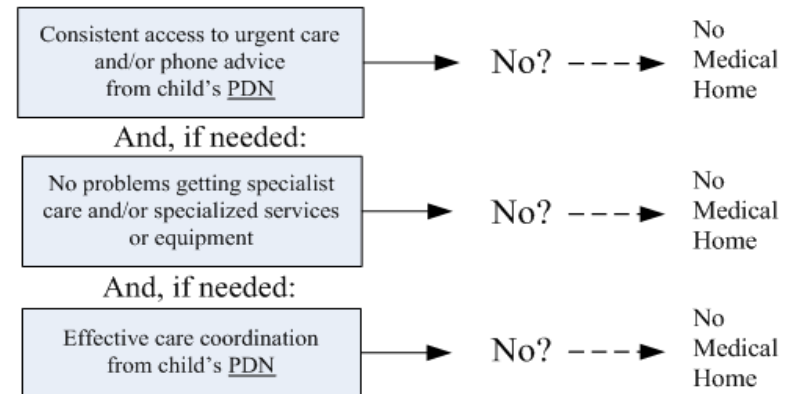
Yes, has a Medical Home

2003 NSCH

Assessment focus: Care from child's primary health care provider



And, if needed:



Yes, has a Medical Home

* 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

<i>Sub-component topics measured within each AAP Medical Home definitional component</i>	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		<i>Assessed by questions within the Family-centered Care component</i>	
CULTURALLY EFFECTIVE		<i>Responses to questions addressing culturally effective care included in the Family-centered Care sub-component topic scoring</i>	

-- 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

		<i>Does child meet threshold criteria?</i>					
<i>Derived variable names for the NS-CSHCN sub-component topics (see Table 5)</i>		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

<i>Sub-component topics measured within each AAP Medical Home definitional component</i>	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” (≥ 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” (≥ 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” (≥ 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 ≥ 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	<i>Assessed by questions within the Family-centered Care component</i>		
CULTURALLY EFFECTIVE	<i>Included in the Family-centered Care sub-component topic scoring</i>		
-- 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 (≥ 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 (≥ 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 (≥ 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" (≥ 75 points) to getting specialist care for child, AND if needed, responses of "NO PROBLEM or SMALL PROBLEM" (≥ 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

<i>Derived variable names for the 2003 NSCH sub-component topics (see Table 6)</i>		<i>Does child meet threshold criteria?</i>					
		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

<i>Sub-component topics measured within each AAP Medical Home definitional component</i>	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		<i>Assessed by questions within the Family-centered Care component</i>	
CULTURALLY EFFECTIVE		<i>Responses to questions addressing culturally effective care included in the Family-centered Care sub-component scoring</i>	

-- 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

<i>Derived variable names for the 2007 NSCH sub-component topics (see Table 7)</i>		<i>Does child meet threshold criteria?</i>					
		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)	
<i>All children, ages 0-17</i>	--	--	46.1 (45.6 - 46.7)		57.5 (56.5 - 58.6)	
<i>CSHCN, ages 0-17</i>	52.6 (51.7 - 53.6)	47.1 (46.3 - 48.0)	44.2 (42.9 - 45.4)		49.8 (47.5 - 52.0)	
<i>Sub-component topics measured within each AAP Medical Home definitional component:</i>	<i>CSHCN, ages 0-17 (%)</i>	<i>CSHCN, ages 0-17 (%)</i>	<i>All children, ages 0-17 (%)</i>	<i>CSHCN, Only (%)</i>	<i>All children, ages 0-17 (%)</i>	<i>CSHCN, Only (%)</i>
ESTABLISHED RELATIONSHIP WITH SPECIFIC PROVIDER						
<u>Has at least one “personal doctor or nurse”</u>	89.0	93.5	83.3	90.0	92.2	94.7
ACCESSIBLE	--	--	--	--	--	--
FAMILY-CENTERED						
<u>Family-centered care(FCC) from ALL child’s doctors and other health care providers</u>						
<i>a) No, does not have FCC care</i>	31.9	32.5	--	--	31.6	34.1
<i>b) Yes, has FCC care</i>	64.2	62.4	--	--	65.1	64.8
<i>c) Legitimate skip</i>	3.9	5.1	--	--	3.3	1.1
<u>Family-centered care (FCC) from child’s personal doctor or nurse</u>						
<i>a) No, does not have FCC car</i>	--	--	17.7	16.3	--	--
<i>b) Yes, has FCC care</i>	--	--	65.2	73.4	--	--
<i>c) Legitimate skip</i>	--	--	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	
<i>Sub-component topics measured within each AAP Medical Home definitional component:</i>	<i>CSHCN, ages 0-17 (%)</i>	<i>CSHCN, ages 0-17 (%)</i>	<i>All children, ages 0-17 (%)</i>	<i>CSHCN, Only (%)</i>	<i>All children, ages 0-17 (%)</i>	<i>CSHCN, Only (%)</i>
COMPREHENSIVE						
<u>Getting needed referrals</u>						
<i>a) Needed, problems getting</i>	10.8	7.0	--	--	2.8	7.0
<i>b) Needed, no problem getting</i>	38.8	26.0	--	--	13.1	25.2
<i>c) Legitimate skip</i>	50.3	67.0	--	--	84.1	67.8
<u>Usual source(s) for both sick and well care</u>	90.5	92.9	--	--	93.1	94.8
<u>Preventive care visit during past 12 months</u>	--	--	77.8	86.5	--	--
<u>Consistent access to urgent care and/or phone advice from personal doctor or nurse</u>						
<i>a) Needed, did not consistently get</i>	--	--	3.6	6.3	--	--
<i>b) Needed, consistently got</i>	--	--	40.1	55.3	--	--
<i>c) Legitimate skip</i>	--	--	56.2	38.4	--	--
<u>Getting needed specialist care, and/or specialized health services or equipment</u>						
<i>a) Needed, problems getting</i>	--	--	3.5	11.5	--	--
<i>b) Needed, no problem getting</i>	--	--	19.2	42.7	--	--
<i>c) Legitimate skip</i>	--	--	77.3	45.9	--	--
COORDINATED						
<u>Getting effective care coordination when needed</u>						
<i>a) Did not get all help wanted</i>	6.7	31.8	--	--	12.9	29.7
<i>b) Got all help wanted</i>	4.5	46.0	--	--	28.3	43.4
<i>c) Legitimate skip(no report of getting or wanting more help with care coordination)</i>	88.8	22.2	--	--	58.8	26.9
<u>Follow up by personal doctor or nurse after child sees specialist care and/or gets specialized health services</u>						
<i>a) Needed, did not consistently get</i>	--	--	9.4	24.2	--	--
<i>b) Needed, consistently got</i>	--	--	12.9	29.4	--	--
<i>c) Legitimate skip</i>	--	--	77.6	46.4	--	--
COMPASSIONATE	<i>The concept of "compassionate care" is addressed in the context of the family-centered care questions</i>					
CULTURALLY EFFECTIVE	<i>For scoring purposes, questions addressing this topic are included in the Family-centered care sub-component</i>					

†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, nearly 70 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	
	<i>CSHCN, ages 0-17</i>	<i>CSHCN, ages 0-17</i>	<i>All children, ages 0-17</i>	<i>CSHCN only</i>	<i>All children, ages 0-17</i>	<i>CSHCN only</i>
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)
<i>Medical home prevalence by child characteristics</i>	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
<u>Age</u>						
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)
<u>Race/ethnicity</u>						
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)
<u>Household Income as percentage of Federal poverty level (FPL)</u>						
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	
	<i>CSHCN, ages 0-17</i>	<i>CSHCN, ages 0-17</i>	<i>All children, ages 0-17</i>	<i>CSHCN only</i>	<i>All children, ages 0-17</i>	<i>CSHCN only</i>
<u>Health insurance status, past 12 months</u>						
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)
<u>Type of health insurance</u>						
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)
<u>Primary household language</u>						
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)
<u>Language of the interview</u>						
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
<u>Qualifying special health care needs criteria</u>						
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

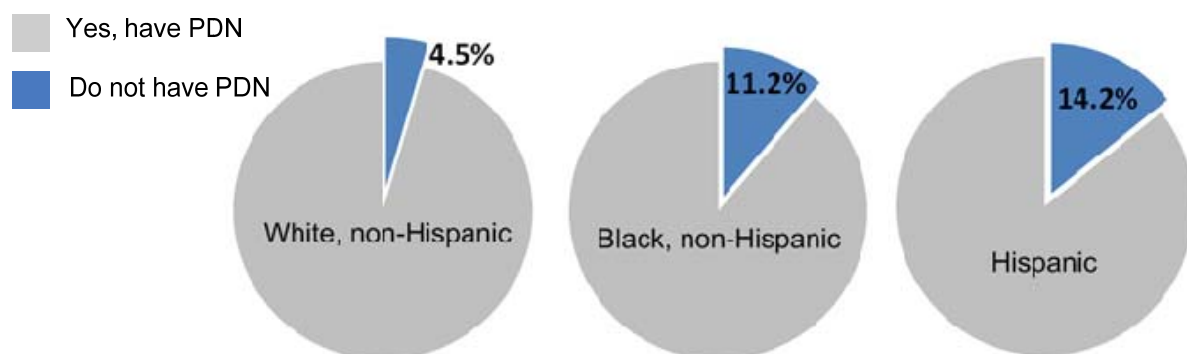
4.3 Influence of survey design on medical home prevalence

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 determining 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

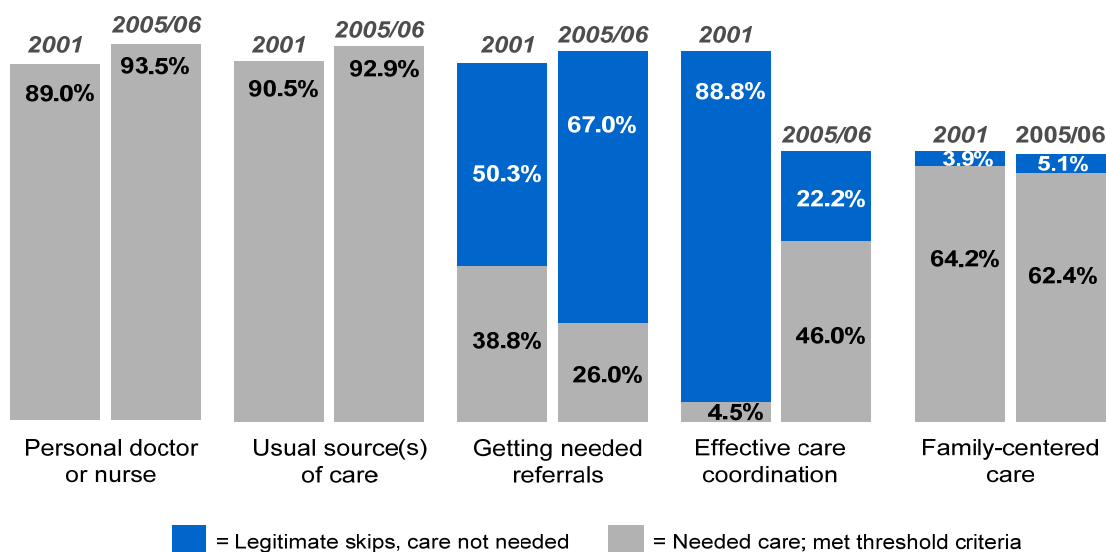


Source: National Survey of Children's Health, 2003

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 surveys³, 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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**2001 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

APPENDIX A_1: SAS User Resources

Programming Code and Other Resources
for Medical Home Measurement

National Survey of Children with Special Health Care Needs (NS-CSHCN)

Weighted estimates* for Medical Home composite measure, the five sub-component scores and associated interim variables

	2001 NS-CSHCN	2005/06 NS-CSHCN	
	% CSHCN ages 0-17*	% CSHCN ages 0-17*	NOTES*
Meet overall criteria for having a Medical Home:	52.6	47.1	
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER			
1) <u>Child has a “personal doctor or nurse”</u>	89.0	93.5	1) Revised question wording used in 2005/06
ACCESSIBLE	--	--	--
FAMILY CENTERED			
2) <u>Child’s doctors and other health providers do each of the following:</u>	64.2	62.4	
a. <u>Usually or always</u> spend enough time with child and parent	80.0	74.7	f. New question on interpreter services added in 2005/06; only asked for households where primary language is not English
b. <u>Usually or always</u> listen carefully to child and parent	84.5	84.3	
c. <u>Usually or always</u> sensitive to family’s values and customs	82.2	84.4	
d. <u>Usually or always</u> provide needed information	77.4	78.9	
e. <u>Usually or always</u> make family feel like a partner in child’s care	82.2	83.2	
AND			
f. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	--	0.8	
CONTINUOUS	--	--	
COMPREHENSIVE			
3) <u>IF needed, no problems obtaining referrals</u>	38.8	26.0	3) Significant changes were made in 2005/06 to the question wording, placement, and skip patterns use to assess problems obtaining needed referrals
a. Needed referral during past 12 months	49.6	33.0	
4) <u>Have usual source(s) for both sick and well care</u>	90.5	92.9	
a. Child has a usual source for sick care	90.6	94.3	
b. Child has a usual source for preventive care	98.8	97.1	
COORDINATED			
5) <u>IF needed, gets effective care coordination</u>	4.5	46.0	5) Significant changes were made in 2005/06 in the content, wording, placement, and skip patterns of the questions used to assess effective care coordination
a. <u>Needed and received</u> professional help with care coordination	9.5	--	
b. <i>IF needed</i> care coordination, <u>excellent</u> communication btw doctors	5.1	--	
c. <i>IF needed</i> care coordination, doctor communication with school or other programs the child attends is <u>excellent</u>	3.0	--	
d. <u>Needed and usually got</u> extra help with care coordination	--	30.4	
e. <i>IF needed</i> , <u>very satisfied</u> with communication btw doctors	--	41.8	
f. <i>IF needed</i> , <u>very satisfied</u> with how doctors communicate with school or other programs the child attends	--	14.1	
COMPASSIONATE			Assessed under the Family Centered Care component†
CULTURALLY EFFECTIVE			Assessed under the Family Centered Care component†

* All estimated percentages are weighted to represent the U.S. non-institutionalized population of CSHCN ages 0-17 years

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.

-- Not assessed by the survey.

**2001 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*SAS Medical Home
scoring program*

Measuring Medical Home using Data Elements from the
2001 National Survey of Children with Special Health Care Needs(NS-CSHCN)

SAS scoring program variable names for the five sub-component scores and
associated interim variables used to derive the Medical Home composite measure

2001 NS-CSHCN		
	SAS Variable names	Survey items or interim variables used to construct
Meet overall criteria for having a Medical Home:	MH_COMP	[PDN; FAMCENT; NOREFPRB; USUAL; CARECOOR]
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER		
1) <u>Child has a “personal doctor or nurse”</u>	PDN	[C4Q02a]
ACCESSIBLE		
--		
FAMILY CENTERED		
2) <u>Child’s doctors and other health providers do each of the following:</u>	FAMCENT	[TIME; LISTEN; SENSITV;INFO; PARTNER]
a. <u>Usually or always</u> spend enough time with child and parent	TIME	C6q02
b. <u>Usually or always</u> listen carefully to child and parent	LISTEN	C6q03
c. <u>Usually or always</u> sensitive to family’s values and customs	SENSITV	C6q04
d. <u>Usually or always</u> provide needed information	INFO	C6q05
e. <u>Usually or always</u> make family feel like a partner in child’s care	PARTNER	C6q06
CONTINUOUS		
--		
COMPREHENSIVE		
3) <u>IF needed, no problems needed obtaining referrals</u>	NOREFPRB	[C4Q07; C4Q05_02]
4) <u>Usual source(s) for both sick and well care</u>	USUAL	[SICK; WELL]
a. Child has a usual source for sick care	SICK	C4q0a; C4q0b
b. Child has a usual source for preventive care	WELL	C4q01; C4q02, C4q0b
COORDINATED		
5) <u>Gets effective care coordination when needed</u>	CARECOOR	[COORRCV; DOCCOMM; OTHCOMM]
a. <u>Needed and usually got</u> extra help w/ care coordination	COORRCV	C4q06_0a; C4q6x0aa
b. <u>IF needed, very satisfied</u> with communication btw doctors	DOCCOMM	C4q06_0a; C5q02; C5q05
c. <u>IF needed, very satisfied</u> with how doctors communicate with school or other programs the child attends	OTHCOMM	C4q06_0a; C5q02; C5q06
COMPASSIONATE		
		<i>Assessed under the Family Centered Care component†</i>
CULTURALLY EFFECTIVE		
		<i>Assessed under the Family Centered Care component†</i>

-- Not assessed by the survey.

MEDICAL HOME	
Composite measure	Children with special health care needs (CSHCN) receiving ongoing, coordinated and comprehensive care within a medical home
Survey Items Used	C4Q02a, C6Q02 – C6Q06, C4Q07, C4Q05_02, C4Q0a, C4Q0b, C4Q01, C4Q02, C4Q06_0a, C4Q6X0aa, C5Q02, C5Q05, C5Q06
Numerator	Children with special health care needs (CSHCN) meeting scoring criteria for having a Medical Home
Denominator	Children with special health care needs (CSHCN) ages 0–17 years
Description	Percent of CSHCN ages 0–17 who have a primary care provider (e.g. personal doctor or nurse) AND usual sources for both sick and preventive care AND consistently get family-centered care from their doctors and other health care providers AND, if needed, receive effective care coordination AND, if needed, no problems getting referrals
Notes for Data-Users	
<p>The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of “medical home”. According to this definition, children ideally should have access to “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home.”</p> <p>The presence of medical home for CSHCN is one of the six performance measures or outcomes that states submit as part of the Title V Block Grant reporting requirements. The final medical home composite score used to measure this outcome is derived from the five sub-components constructed below.</p>	
SAS Code and Annotation	
Formats	
<p>**** The following program sets the formats for the medical home sub-components, associated interim variables, and the overall medical home composite measure created by the SAS scoring program</p> <pre> proc format library = library name; value pdn /*PDN sub-component*/ 0 = "Do not have a personal dr or nurse" 1 = "Yes, have a personal dr or nurse"; value family /*interim variable*/ 0 = "Sometimes/Never" 1 = "Usually/Always" 99 = "DK/Ref/Missing to item or number of dr visits"; value famcent /*FCC sub-component*/ 0 = "Does NOT have fcc" 1 = "Yes, has fcc" 3 = "Legitimate skip"; value c4q07f /*interim variable*/ 0 = "Big or small problem" 1 = "No problems" 4 = "Ch did NOT need to see a specialist" </pre>	

```

5 = "No need to get referrals"
999 = "DK/Ref/Missing";
value norefprb /*Getting referrals sub-component*/
0 = "Needed referrals, problems getting"
1 = "Needed referrals, no problems"
3 = "Legitimate skip";
value yn /*interim variable*/
0 = "No"
1 = "Yes";
value usual /*Usual source care care sub-component*/
0 = "Does not have usual sources of care"
1 = "DOES have usual sources for sick and well care";
value coorrcv /*interim variable*/
0 = "Needed, did not get all prof care coor"
1 = "Needed & got all prof care coor"
3 = "Did not need prof care coor"
99 = "DK/Ref/Missing to one or both"
999 = "DK/Ref/Missing";
value comm /*interim variables for care coor communication*/
1 = "Excellent/Very Good"
2 = "Good/Fair/Poor"
3 = "Legitimate skip"
6 = "Communication not needed"
999 = "DK/Ref";
value carecoor /*Effect care coor sub-component*/
1 = "Has effective care coor"
0 = "Does not have effective care coor"
3 = "Legitimate skip -- not needed or needed/never helped";
value medhome /*Composite meas*/
1 = "Care MEETS medical home criteria"
2 = "Care DOES NOT meet medical home criteria";
RUN;

```

Scoring program

```

*****Personal doctor or nurse (PDN) Component*****

/**PERSONAL DOCTOR OR NURSE (PDN)COMPONENT**/

/**"Personal Doctor or Nurse" sub-component of MEDICAL HOME compnsite measure***/
pdn = c4q02a;
if c4q02a in (6,7) then pdn = .;
label pdn = "Personal doctor or nurse sub-component of MEDICAL HOME composite measure";

***** Family Centered Care Component *****

/**FAMILY CENTERED CARE sub-component of MEDICAL HOME composite measure**/

/*** STEP 1: The following code sets up the interim variables used to derive the overall score for the
"Effective Care Coordination" sub-component of the MEDICAL HOME composite measure**/
time = .;
if c6q02 in (1,2) then time = 0;
if c6q02 in (3,4) then time = 1;
if c6q01r = 996 or c6q01r = 997 then time = .;
label time = "How often drs spent enough time";

```

```

listen = .;
if c6q03 in (1,2) then listen = 0;
if c6q03 in (3,4) then listen = 1;
if c6q01r = 996 or c6q01r = 997 then listen = .;
label listen = "How often drs listened carefully";
sensitiv = .;
if c6q04 in (1,2) then sensitv = 0;
if c6q04 in (3,4) then sensitv = 1;
if c6q01r = 996 or c6q01r = 997 then sensitv = .;
label sensitv = "How often drs sensitive to families values/customs";
info = .;
if c6q05 in (1,2) then info = 0;
if c6q05 in (3,4) then info = 1;
if c6q01r = 996 or c6q01r = 997 then info = .;
label info = "How often got enough info from dr re: medical problems";
partner = .;
if c6q06 in (1,2) then partner = 0;
if c6q06 in (3,4) then partner = 1;
if c6q01r = 996 or c6q01r = 997 then partner = .;
label partner = "How drs helped parents feel like partners";

/**STEP 2: Construct "Family Centered Care" sub-component of MEDICAL HOME composite measure**/
famcent = .;
if time eq 0 or listen eq 0 or sensitv eq 0 or info eq 0 or partner eq 0 then famcent = 0;
if time eq 1 and listen eq 1 and sensitv eq 1 and info eq 1 and partner eq 1 then famcent = 1;
if time = . or listen = . or sensitv = . or info = . or partner = . then famcent = .;
if time eq . or listen eq . or sensitv eq . or info eq . or partner eq . then famcent = .;
if c6q01r = 0 then famcent = 3;
label famcent = "Family Centered Care sub-component of MEDICAL HOME composite measure";

*****Comprehensive Care Component *****

/**GETTING NEEDED REFERRALS sub-component of MEDICAL HOME composite measure**/

/**STEP 1: The following code sets up the interim variable used to derive the overall score for the "No
Problems Getting Needed Referrals" sub-component of the MEDICAL HOME composite measure**/
r_c4q07 = .;
if c4q07 = 3 then r_c4q07 = 1;
if c4q07 = 4 then r_c4q07 = 4;
if c4q07 = 5 then r_c4q07 = 5;
if c4q07 in (1,2) then r_c4q07 = 0;
if c4q07 in (6,7) then r_c4q07 = .;
label r_c4q07 = "Problems getting referral to specialist";

/**STEP 2: Construct "No Problems Getting Needed Referrals" sub-component of MEDICAL HOME
composite measure**/
norefprb = .;
if c4q05_02 = 1 and r_c4q07 = 0 then norefprb = 0;
if c4q05_02 = 1 and r_c4q07 = 1 then norefprb = 1;
if c4q05_02 = 0 or r_c4q07 = 4 or r_c4q07 = 5 then norefprb = 3;
if c4q05_02 = 6 or c4q05_02 = 7 then norefprb = .;
label norefprb = "Getting needed referrals sub-component of MEDICAL HOME composite measure";

```

```

/**USUAL SOURCES for SICK and WELL CARE sub-component of MEDICAL HOME composite measure**/

/**STEP 1: The following code sets up the interim variables used to derive the overall score for the "Usual
Sources for Sick and Well Care" sub-component of the MEDICAL HOME composite measure***/
sick = .;
if (c4q0a = 1 or c4q0a = 3) and (c4q0b = 1 or c4q0b = 3 or c4q0b = 4 or c4q0b = 5 or c4q0b = 6 or c4q0b =
8) then sick = 1;
if (c4q0a = 2) or (c4q0b = 2 or c4q0b = 7) then sick = 0;
label sick = "Child has usual place for sick care";

well = .;
if (c4q01 = 1) or (c4q02 = 2 or c4q02 = 4 or c4q02 = 5 or c4q02 = 6 or c4q02 = 7 or c4q02 = 9) then well = 1;
if c4q02 = 1 or c4q02 = 3 or c4q02 = 8 or c4q02 = 10 then well = 0;
if c4q02 = 96 or c4q02 = 97 then well = .;
if c4q01 = 6 or c4q01 = 7 then well = .;
if c4q01 = 1 and (c4q0b = 2 or c4q0b = 7) then well = 0;
label well = "Child has usual place for well care";

/**STEP 2: Construct "Usual Sources for Sick and Well Care" sub-component of MEDICAL HOME
composite measure***/
usual = .;
usual = .;
if sick = 1 and well = 1 then usual = 1;
if sick = 0 or well = 0 then usual = 0;
if well = . or sick = . then usual = .;
label usual = "Usual sources for sick and well care sub-component of MEDICAL HOME composite measure";

*****Coordinated Care Component *****

/**EFFECTIVE CARE COORDINATION sub-component of MEDICAL HOME composite measure**/

/**STEP 1: The following code sets up the interim variables used to derive the overall score for the
"Effective Care Coordination" sub-component of the MEDICAL HOME composite measure***/
coorrcv = 99;
if c4q6x0aa = 1 then coorrcv = 1;
if c4q6x0aa = 0 then coorrcv = 0;
if c4q06_0a = 0 then coorrcv = 3;
label coorrcv = "Received NEEDED professional care coordination";

r_c5q05 = .;
if c5q05 eq 6 then r_c5q05 = 6;
if c5q05 eq 96 then r_c5q05 = 999;
if c5q05 in (.M,.L,.A) then r_c5q05 = 999;
if c5q05 in (1,2) then r_c5q05 = 1;
if c5q05 in (3,4,5) then r_c5q05 = 2;

doccomm = 999;
if r_c5q05 = 1 then doccomm = 1;
if r_c5q05 = 2 then doccomm = 2;
if r_c5q05 = 6 then doccomm = 3;
if c4q06_0a = 0 then doccomm = 3;
if c5q02 = 1 then doccomm = 3;
label doccomm = "Level of communication btw child's doctors";

```

```

r_c5q06 = 999;
if c5q06 eq 6 then r_c5q06 = 6;
if c5q06 eq 96 then r_c5q06 = 999;
if c5q06 in (.M, .L, .A) then r_c5q06 = 999;
if c5q06 in (1,2) then r_c5q06 = 1;
if c5q06 in (3,4,5) then r_c5q06 = 2;
label r_c5q06 = "Recoded level of dr communication with other services";

othcom_1 = 999;
if r_c5q06 = 1 then othcom_1 = 1;
if r_c5q06 = 2 then othcom_1 = 2;

othcom_2 = 999;
if c4q06_0a = 0 then othcom_2 = 3;
if c4q06_0a = 1 and othcom_1 = 1 then othcom_2 = 1;
if c4q06_0a = 1 and othcom_1 = 2 then othcom_2 = 2;
if c4q06_0a = 1 and c5q02 = 1 then othcom_2 = 3;
if c4q06_0a = 1 and c5q02 >= 6 then othcom_2 = 999;

othcomm = 999;
if r_c5q06 = 1 and othcom_2 = 1 then othcomm = 1;
if r_c5q06 = 1 and othcom_2 = 3 then othcomm = 3;
if r_c5q06 = 2 and othcom_2 = 2 then othcomm = 2;
if r_c5q06 = 2 and othcom_2 = 3 then othcomm = 3;
if r_c5q06 = 6 and othcom_2 = 3 then othcomm = 3;
if r_c5q06 = 6 and othcom_2 = 999 then othcomm = 3;
if r_c5q06 = 999 and othcom_2 = 3 then othcomm = 3;
label othcomm = "Level of dr communication with other services";

/**STEP 2: Construct the "EFFECTIVE CARE COORDINATION" sub-component of the MEDICAL HOME
composite measure**/
carecoor = 3;
if coorrvc = 1 and (doccomm = 1 or doccomm = 3) and (othcomm = 1 or othcomm = 3) then carecoor = 1;
if coorrvc = 0 or doccomm = 2 or othcomm = 2 then carecoor = 0;
if coorrvc = 99 or doccomm = 999 or othcomm = 999 then carecoor = .;
label carecoor = "Effective care coordination sub-component of the MEDICAL HOME composite measure";

***** MEDICAL HOME COMPOSITE MEASURE*****

/**The following code uses the five sub-components created above to derive the MEDICAL HOME
composite measure using the ON EVERY scoring approach**/

mh_comp = .;
if (pdn = 1 and usual = 1) and (carecoor = 1 or carecoor = 3) and (norefprb = 1 or norefprb = 3) and (famcent
= 1 or famcent = 3) then mh_comp = 1;
if (pdn = 0) or (usual = 0) or (carecoor = 0) or (norefprb = 0) or (famcent = 0) then mh_comp = 0;
if pdn = . or usual = . or famcent = . or norefprb = . or carecoor = . then mh_comp = .;
if mh_comp = 0 then mh_comp = 2;
label mh_comp = "% of CSHCN receiving coordinated, ongoing, comprehensive care within a medical home";
RUN;

```

PROC FREQ DATA=*dataset name*;

FORMAT time family.
 listen family.
 sensitv family.
 info family.
 partner family.
 pdn PDN.
 famcent famcent.
 r_c4q07 c4q07f.
 norefprb norefprb.
 sick well yn.
 usual usual.
 coorrcv coorrcv.
 r_c5q05 r_c5q06 othcom_1 othcom_2 othcomm doccomm comm.
 carecoor carecoor.
 mh_comp medhome;

TABLES pdn time listen sensitv info partner famcent r_c4q07 norefprb sick well usual coorrcv r_c5q05
 doccomm r_c5q06 othcom_1 othcom_2 othcomm carecoor mh_comp;

RUN;

**2001 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*Unweighted frequency distributions for the
Medical Home sub-components, related interim variables
and composite measure generated by the
SAS scoring program*

Personal Doctor or Nurse (PDN) Component

**PDN sub-component score (PDN)

Personal doctor or nurse sub-component of MEDICAL HOME composite measure

pdn	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Do not have a personal dr or nurse	3927	10.14	3927	10.14
Yes, have a personal dr or nurse	34784	89.86	38711	100.00

Frequency Missing = 155

Family-Centered Care Component

**Interim variables for Family-Centered Care sub-component

How often drs spent enough time

time	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/Never	5391	14.65	5391	14.65
Usually/Always	31408	85.35	36799	100.00

Frequency Missing = 2067

How often drs listened carefully

listen	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/Never	4015	10.89	4015	10.89
Usually/Always	32857	89.11	36872	100.00

Frequency Missing = 1994

How often drs sensitive to families values/customs

sensitiv	Frequency	Cumulative Percent	Cumulative Frequency	Percent
Sometimes/Never	4258	11.69	4258	11.69
Usually/Always	32167	88.31	36425	100.00

Frequency Missing = 2441

How often got enough info from dr re: medical problems

info	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/Never	6497	17.69	6497	17.69
Usually/Always	30237	82.31	36734	100.00

Frequency Missing = 2132

How drs helped parents feel like partners

partner	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/Never	4633	12.58	4633	12.58
Usually/Always	32204	87.42	36837	100.00

Frequency Missing = 2029

****Family-Centered Care sub-component score (FAMCENT)**

Family Centered Care sub-component of MEDICAL HOME composite measure

famcent	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Does NOT have fcc	11031	29.48	11031	29.48
Yes, has fcc	24987	66.77	36018	96.25
Legitimate skip	1404	3.75	37422	100.00

Frequency Missing = 1444

Comprehensive Care Component

**Interim variables for No Problems Getting Needed Referrals sub-component

Problems getting referral to specialist

r_c4q07	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Big or small problem	5676	14.64	5676	14.64
No problems	29787	76.83	35463	91.47
Ch did NOT need to see a specialist	2210	5.70	37673	97.17
No need to get referrals	1098	2.83	38771	100.00

Frequency Missing = 95

** No Problems Getting Needed Referrals sub-component score (NOREFPRB)

Getting needed referrals sub-component of MEDICAL HOME composite measure

norefprb	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Needed referrals, problems getting	4026	10.40	4026	10.40
Needed referrals, no problems	16016	41.37	20042	51.77
Legitimate skip	18670	48.23	38712	100.00

Frequency Missing = 154

**Interim variables Usual Sources for Sick and Well Care sub-component

Child has usual place for sick care

sick	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	3661	9.45	3661	9.45
Yes	35083	90.55	38744	100.00

Frequency Missing = 122

Child has usual place for well care

well	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	369	0.95	369	0.95
Yes	38368	99.05	38737	100.00

Frequency Missing = 129

****Usual Sources for Sick and Well Care sub-component score (USUAL)**

Usual sources for sick and well care sub-component
of MEDICAL HOME composite measure

usual	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Does not have usual sources of care	3664	9.49	3664	9.49
DOES have usual sources care for sick and well	34964	90.51	38628	100.00

Frequency Missing = 238

Coordinated Care Component

****Interim variables Effective Care Coordination sub-component**

Received NEEDED professional care coordination

coorrcv	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Needed, did not get all prof care coor	779	2.00	779	2.00
Needed & got all prof care coor	3748	9.64	4527	11.65
Did not need prof care coor	34160	87.89	38687	99.54
DK/Ref/Missing to one or both	179	0.46	38866	100.00

r_c5q05

r_c5q05	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Excellent/Very Good	1970	5.07	1970	5.07
Good/Fair/Poor	1740	4.48	3710	9.55
Communication not needed	66	0.17	3776	9.72
DK/Ref	35090	90.28	38866	100.00

Level of communication btw child's doctors

doccomm	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Excellent/Very Good	1970	5.07	1970	5.07
Good/Fair/Poor	1740	4.48	3710	9.55
Legitimate skip	34919	89.84	38629	99.39
DK/Ref	237	0.61	38866	100.00

Recoded level of dr communication with other services

r_c5q06	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Excellent/Very Good	15706	40.41	15706	40.41
Good/Fair/Poor	13763	35.41	29469	75.82
Communication not needed	8427	21.68	37896	97.50
DK/Ref	970	2.50	38866	100.00

othcom_1

othcom_1	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Excellent/Very Good	15706	40.41	15706	40.41
Good/Fair/Poor	13763	35.41	29469	75.82
DK/Ref	9397	24.18	38866	100.00

othcom_2

othcom_2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Excellent/Very Good	1203	3.10	1203	3.10
Good/Fair/Poor	1993	5.13	3196	8.22
Legitimate skip	34852	89.67	38048	97.90
DK/Ref	818	2.10	38866	100.00

Level of dr communication with other services

othcomm	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Excellent/Very Good	1203	3.10	1203	3.10
Good/Fair/Poor	1993	5.13	3196	8.22
Legitimate skip	35409	91.11	38605	99.33
DK/Ref	261	0.67	38866	100.00

****Effective Care Coordination sub-component score (CARECOOR)**

Effective care coordination sub-component
of the MEDICAL HOME composite measure

carecoor	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Does not have effective care coor	2665	6.92	2665	6.92
Has effective care coor	1691	4.39	4356	11.31
Legitimate skip/ not needed or needed/never helped	34160	88.69	38516	100.00

Frequency Missing = 350

Medical Home Composite Measure

**Medical Home Composite Measure score (MH_COMP)

% of CSHCN receiving coordinated, ongoing, comprehensive care within a medical home

mh_comp	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Care MEETS medical home criteria	20019	54.53	20019	54.53
Care DOES NOT meet medical home criteria	16691	45.47	36710	100.00

Frequency Missing = 2156

**2001 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*Full text and response options for questions
used to assess Medical Home*

2001 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<u>SECTION 4: ACCESS TO CARE: UTILIZATION AND UNMET NEEDS</u>	
<p>C4q0a Is there a place that (S.C.) USUALLY goes when (he/she) is sick or you need advice about (his/her) health?</p> <p><i>If Yes to C4q0a:</i></p> <p>C4q0b Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?</p>	<p>(1) YES (2) THERE IS NO PLACE [SKIP TO C4Q02] (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW [SKIP TO C4Q02] (7) REFUSED [SKIP TO C4Q02]</p> <p>(01) DOCTOR'S OFFICE [SKIP TO C4Q01] (02) HOSPITAL EMERGENCY ROOM [SKIP TO C4Q01] (03) HOSPITAL OUTPATIENT DEPARTMENT [SKIP TO C4Q01] (04) CLINIC OR HEALTH CENTER [SKIP TO C4Q01] (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) [SKIP TO C4Q01] (06) SOME OTHER PLACE [SKIP TO C4Q01] (07) DOES NOT GO TO ONE PLACE MOST OFTEN [SKIP TO C4Q02] (96) DON'T KNOW [SKIP TO C4Q02] (97) REFUSED [SKIP TO C4Q02]</p>
<p>C4q01 Is the [place selected in C4q0b] that (S.C.) goes to when (he/she) is sick the same place (S.C.) usually goes for routine preventive care?</p>	<p>(1) YES [SKIP TO C4Q02A] (2) NO [SKIP TO C4Q02] (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A]</p>
<p>C4q02 What kind of place does (S.C.) go to most often when (he/she) needs routine preventive care?</p>	<p>(01) DOES NOT GET PREVENTIVE CARE ANYWHERE (02) DOCTOR'S OFFICE (03) HOSPITAL EMERGENCY ROOM (04) HOSPITAL OUTPATIENT DEPARTMENT (05) CLINIC OR HEALTH CENTER (06) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (07) SOME OTHER PLACE [SKIP TO C4Q02_1] (08) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED</p>
<p>C4q02a A personal doctor or nurse is the health provider who knows (S.C.) best. Do you have ONE person that you think of as (S.C.)'s personal doctor or nurse?</p>	<p>(1) YES [SKIP TO C4Q03] (2) NO [SKIP TO C4Q03] (6) DON'T KNOW [SKIP TO C4Q03] (7) REFUSED [SKIP TO C4Q03]</p>

2001 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
C4q05_02 During the past 12 months, was there any time when (“S” CHILD) needed care from a specialty doctor?	(1) YES (2) NO (6) DON’T KNOW (7) REFUSED [SKIP TO C4Q05_03] [SKIP TO C4Q05_03] [SKIP TO C4Q05_03]
C4q06_0a During the past 12 months, was there any time when you or other family members needed professional care coordination among different health care providers and services that the child uses? <i>If Yes to C4q06_0a:</i> C4q06x0aa Did you or your family receive all the professional care coordination that was needed?	(1) YES (2) NO (6) DON’T KNOW (7) REFUSED [SKIP TO C4Q06_01] [SKIP TO C4Q06_01] [[SKIP TO C4Q06_01] (1) YES (2) NO (6) DON’T KNOW (7) REFUSED
C4q07 In the past 12 months, how much of a problem, if any, was it to get a referral to a specialist that your child needed to see?	(1) Big problem (2) Small problem (3) Not a problem (4) Child did not go to see a specialist in the past 12 months (5) DID NOT NEED REFERRALS (6) DON’T KNOW (7) REFUSED
<u>SECTION 5: CARE COORDINATION</u>	
C5q02 Earlier you told me that you or other family members needed professional assistance coordinating (“S” CHILD)’s care. How often does a professional help you coordinate (“S” CHILD)’s care among (his/her) different providers and services?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED [SKIP TO C5q06] [SKIP TO C5q06] [SKIP TO C5q06]
C5q05 How well do you think (“S” CHILD)’s doctors and other health care providers communicate with each other about (“S” CHILD)’s care?	(01) Excellent (02) Very Good (03) Good (04) Fair or (05) Poor (06) COMMUNICATION NOT NEEDED (96) DON’T KNOW (97) REFUSED

2001 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
C5q06 How well do you think (“S” CHILD) ’s doctors and other health care providers communicate with (his/her) school, early intervention program, child care providers, or vocational rehabilitation program?	(01) Excellent (02) Very Good (03) Good (04) Fair or (05) Poor (06) COMMUNICATION NOT NEEDED (96) DON’T KNOW (97) REFUSED
<u>SECTION 6: SATISFACTION WITH CARE</u>	
C6q02 During the past 12 months, how often did (S.C.)’s doctors and other health care providers spend enough time with (him/her)?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED
C6q03 During the past 12 months, how often did (S.C.)’s doctors and other health care providers listen carefully to you?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED
C6q04 When (S.C.) is seen by doctors or other health care providers, how often are they sensitive to your family’s values and customs?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED
C6q05 During the past 12 months, how often did you get the specific information you needed from (S.C.)’s doctors and other health care providers?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED
C6q06 During the past 12 months, how often did (S.C.)’s doctors or other health care providers help you feel like a partner in (his/her) care?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED

**2001 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

APPENDIX A_2: SPSS User Resources

Programming Code and Other Resources
for Medical Home Measurement

National Survey of Children with Special Health Care Needs (NS-CSHCN)

Weighted estimates* for Medical Home composite measure, the five sub-component scores and associated interim variables

	2001 NS-CSHCN	2005/06 NS-CSHCN	
	% CSHCN ages 0-17*	% CSHCN ages 0-17*	NOTES*
Meet overall criteria for having a Medical Home:	52.6	47.1	
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER			
1) <u>Child has a “personal doctor or nurse”</u>	89.0	93.5	1) Revised question wording used in 2005/06
ACCESSIBLE	--	--	--
FAMILY CENTERED			
2) <u>Child’s doctors and other health providers do each of the following:</u>	64.2	62.4	
a. <u>Usually or always</u> spend enough time with child and parent	80.0	74.7	f. New question on interpreter services added in 2005/06; only asked for households where primary language is not English
b. <u>Usually or always</u> listen carefully to child and parent	84.5	84.3	
c. <u>Usually or always</u> sensitive to family’s values and customs	82.2	84.4	
d. <u>Usually or always</u> provide needed information	77.4	78.9	
e. <u>Usually or always</u> make family feel like a partner in child’s care	82.2	83.2	
AND			
f. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	--	0.8	
CONTINUOUS	--	--	
COMPREHENSIVE			
3) <u>IF needed, no problems obtaining referrals</u>	38.8	26.0	3) Significant changes were made in 2005/06 to the question wording, placement, and skip patterns use to assess problems obtaining needed referrals
a. Needed referral during past 12 months	49.6	33.0	
4) <u>Have usual source(s) for both sick and well care</u>	90.5	92.9	
a. Child has a usual source for sick care	90.6	94.3	
b. Child has a usual source for preventive care	98.8	97.1	
COORDINATED			
5) <u>IF needed, gets effective care coordination</u>	4.5	46.0	5) Significant changes were made in 2005/06 in the content, wording, placement, and skip patterns of the questions used to assess effective care coordination
a. <u>Needed and received</u> professional help with care coordination	9.5	--	
b. <i>IF needed</i> care coordination, <u>excellent</u> communication btw doctors	5.1	--	
c. <i>IF needed</i> care coordination, doctor communication with school or other programs the child attends is <u>excellent</u>	3.0	--	
d. <u>Needed and usually got</u> extra help with care coordination	--	30.4	
e. <i>IF needed</i> , <u>very satisfied</u> with communication btw doctors	--	41.8	
f. <i>IF needed</i> , <u>very satisfied</u> with how doctors communicate with school or other programs the child attends	--	14.1	
COMPASSIONATE	Assessed under the Family Centered Care component†		
CULTURALLY EFFECTIVE	Assessed under the Family Centered Care component†		

* All estimated percentages are weighted to represent the U.S. non-institutionalized population of CSHCN ages 0-17 years

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.

-- Not assessed by the survey.

**2001 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*SPSS Medical Home
scoring program*

Measuring Medical Home using Data Elements from the 2001 National Survey of Children with Special Health Care Needs(NS-CSHCN)

SPSS scoring program variable names for the five sub-component scores and
associated interim variables used to derive the Medical Home composite measure

2001 NS-CSHCN		
	SPSS Variable names	Survey items or interim variables used to construct
Meet overall criteria for having a Medical Home:	MH_COMP	[PDN; FAMCENT; NOREFPRB; USUAL; CARECOOR]
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER		
1) <u>Child has a “personal doctor or nurse”</u>	PDN	[C4Q02a]
ACCESSIBLE		
--		
FAMILY CENTERED		
2) <u>Child’s doctors and other health providers do each of the following:</u>	FAMCENT	[TIME; LISTEN; SENSITIV;INFO; PARTNER]
a. <u>Usually or always</u> spend enough time with child and parent	TIME	C6q02
b. <u>Usually or always</u> listen carefully to child and parent	LISTEN	C6q03
c. <u>Usually or always</u> sensitive to family’s values and customs	SENSITIV	C6q04
d. <u>Usually or always</u> provide needed information	INFO	C6q05
e. <u>Usually or always</u> make family feel like a partner in child’s care	PARTNER	C6q06
CONTINUOUS		
--		
COMPREHENSIVE		
3) <u>IF needed, no problems needed obtaining referrals</u>	NOREFPRB	[C4Q07; C4Q05_02]
4) <u>Usual source(s) for both sick and well care</u>	USUAL	[SICK; WELL]
a. Child has a usual source for sick care	SICK	C4q0a; C4q0b
b. Child has a usual source for preventive care	WELL	C4q01; C4q02, C4q0b
COORDINATED		
5) <u>Gets effective care coordination when needed</u>	CARECOOR	[COORRCV; DOCCOMM; OTHCOMM]
a. <u>Needed and usually got</u> extra help w/ care coordination	COORRCV	C4q06_0a; C4q6x0aa
b. <u>IF needed, very satisfied</u> with communication btw doctors	DOCCOMM	C4q06_0a; C5q02; C5q05
c. <u>IF needed, very satisfied</u> with how doctors communicate with school or other programs the child attends	OTHCOMM	C4q06_0a; C5q02; C5q06
COMPASSIONATE		
<i>Assessed under the Family Centered Care component†</i>		
CULTURALLY EFFECTIVE		
<i>Assessed under the Family Centered Care component†</i>		

-- Not assessed by the survey.

MEDICAL HOME Composite measure	Children with special health care needs (CSHCN) receiving ongoing, coordinated and comprehensive care within a medical home
Survey Items Used	C4Q02a, C6Q02 – C6Q06, C4Q07, C4Q05_02, C4Q0a, C4Q0b, C4Q01, C4Q02, C4Q06_0a, C4Q6X0aa, C5Q02, C5Q05, C5Q06
Numerator	Children with special health care needs (CSHCN) meeting scoring criteria for having a Medical Home
Denominator	Children with special health care needs (CSHCN) ages 0–17 years
Description	Percent of CSHCN ages 0–17 who have a primary care provider (e.g. personal doctor or nurse) AND usual sources for both sick and preventive care AND consistently get family-centered care from their doctors and other health care providers AND, if needed, receive effective care coordination AND, if needed, no problems getting referrals
Notes for Data-Users	
<p>The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of “medical home”. According to this definition, children ideally should have access to “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home.”</p> <p>The presence of medical home for CSHCN is one of the six performance measures or outcomes that states submit as part of the Title V Block Grant reporting requirements. The final medical home composite score used to measure this outcome is derived from the five sub-components constructed below.</p>	
SPSS Code and Annotation	
<pre>*****Personal doctor or nurse (PDN) Component ***** ***PERSONAL DOCTOR or NURSE sub-component of MEDICAL HOME composite measure COMPUTE pdn = c4q02a. EXECUTE. VARIABLE LABEL pdn 'Personal doctor or nurse sub-component of MEDICAL HOME composite measure'. VALUE LABEL pdn 0 'Do not have a personal dr or nurse' 1 'Yes, have a personal dr or nurse'. ***** Family Centered Care Component ***** *** FAMILY-CENTERED CARE sub-component of MEDICAL HOME composite measure ***** Step 1: The following syntax sets up the interim variables used to derive the overall score for "Family-Centered Care" sub-component of MEDICAL HOME composite measure</pre>	

MISSING VALUES c6q01r ().
EXECUTE.

*COMPUTE time = 99.
IF (c6q02 = 1 or c6q02 = 2) time = 0.
IF (c6q02 = 3 or c6q02 = 4) time = 1.
IF (c6q01r = 996 or c6q01r = 997) time = 99.
EXECUTE.

VARIABLE LABEL time 'How often drs spent enough time'.
VALUE LABELS time
0 'Sometimes or never'
1 'Usually or always'
99 'DK/REF to item or # of dr visits'.

*COMPUTE listen = 99.
IF (c6q03 = 1 or c6q03 = 2) listen = 0.
IF (c6q03 = 3 or c6q03 = 4) listen = 1.
IF (c6q01r = 996 or c6q01r = 997) listen = 99.
EXECUTE.

VARIABLE LABEL listen 'How often drs listened carefully'.
VALUE LABELS listen
0 'Sometimes or never'
1 'Usually or always'
99 'DK/REF to item or # of dr visits'.

*COMPUTE sensitiv = 99.
IF (c6q04 = 1 or c6q04 = 2) sensitiv = 0.
IF (c6q04 = 3 or c6q04 = 4) sensitiv = 1.
IF (c6q01r = 996 or c6q01r = 997) sensitiv = 99.
EXECUTE.

VARIABLE LABEL sensitiv 'How often drs sensitive to families values/customs'.
VALUE LABELS sensitiv
0 'Sometimes or never'
1 'Usually or always'
99 'DK/REF to item or # of dr visits'.

*COMPUTE info = 99.
IF (c6q05 = 1 or c6q05 = 2) info = 0.
IF (c6q05 = 3 or c6q05 = 4) info = 1.
IF (c6q01r = 996 or c6q01r = 997) info = 99.
EXECUTE.

VARIABLE LABEL info 'How often got enough info from dr re: medical problems'.
VALUE LABELS info
0 'Sometimes or never'
1 'Usually or always'
99 'DK/REF to item or # of dr visits'.

*COMPUTE partner = 99.
IF (c6q06 = 1 or c6q06 = 2) partner = 0.
IF (c6q06 = 3 or c6q06 = 4) partner = 1.
IF (c6q01r = 996 or c6q01r = 997) partner = 99.
EXECUTE.

VARIABLE LABEL partner 'How often drs helped parents feel like partners'.
VALUE LABELS partner

0 'Sometimes or never'
 1 'Usually or always'
 99 'DK/REF to item or # of dr visits'.

***** Step 2: Construct "Family-Centered Care" sub-component of MEDICAL HOME composite measure

```
COMPUTE famcent = 99.
IF (time = 0) or (listen = 0) or (sensitiv = 0) or (info = 0) or (partner = 0) famcent = 0.
IF (time =1) and (listen =1) and (sensitiv =1) and (info =1) and (partner =1) famcent = 1.
IF ((SYSMIS (time)) or (SYSMIS (listen)) or (SYSMIS (sensitiv)) or (SYSMIS (info)) or (SYSMIS (partner)))
famcent = 99.
IF (c6q01r = 0) famcent = 3.
EXECUTE.
```

```
VARIABLE LABEL famcent 'Family centered care sub-component of MEDICAL HOME composite
measure'.
VALUE LABEL famcent
0 'Does NOT have fcc'
1 'Yes, has fcc'
3 'Legitimate skip'
99 'DK/Ref to any item and/or # of dr visits'.
RECODE
  famcent (1=1) (0=0) (3=3) (99=SYSMIS).
EXECUTE.
```

*****Comprehensive Care Component*****

*** GETTING NEEDED REFERRALS sub-component of MEDICAL HOME composite measure

***** Step 1: The following syntax sets up the interim variable used to derive the overall score for "No Problems Getting Needed Referrals" sub-component of MEDICAL HOME composite measure

```
MISSING VALUES c4q07 c4q05_02 ().
EXECUTE.

RECODE
  c4q07
  (3=1) (4=4) (5=5) (1 thru 2=0) (6 thru 7=999) INTO r_c4q07 .
EXECUTE .
VAR LABEL r_c4q07 'Problems getting referral to specialist'.
VALUE LABEL r_c4q07
0 'Big or small problem'
1 'No problems'
4 'Ch did NOT need to see a specialist'
5 'No need to get referrals'
999 'DK/Ref/Missing'.
```

***** Step 2: Construct "No Problems Getting Needed Referrals " sub-component of MEDICAL HOME composite measure

```
COMPUTE norefprb = 999.
IF (c4q05_02 = 1) and (r_c4q07 = 0) norefprb = 0.
IF (c4q05_02 = 1) and (r_c4q07 = 1) norefprb = 1.
IF (c4q05_02 = 0) or (r_c4q07 = 4) or (r_c4q07 = 5) norefprb = 3.
```

```
IF (c4q05_02 = 6 or c4q05_02 = 7) norefprb = 999.
EXECUTE.
```

```
VARIABLE LABELS norefprb 'Getting needed referrals sub-component of MEDICAL HOME composite measure'.
```

```
VALUE LABELS norefprb
```

```
0 'Needed referrals, problems getting'
```

```
1 'Needed referrals, no problems'
```

```
3 'Legitimate skip'
```

```
999 'DK/Ref/Missing'.
```

```
RECODE norefprb
```

```
(999=SYSMIS).
```

```
***USUAL SOURCES FOR SICK AND WELL CARE sub-component of MEDICAL HOME composite measure
```

```
***** Step 1: The following syntax sets up the interim variables used to derive the overall score for "Usual Sources for Sick and Well Care" sub-component of MEDICAL HOME composite measure
```

```
COMPUTE sick = 99.
```

```
IF ((c4q0a = 1) or (c4q0a = 3)) and ((c4q0b = 1 or c4q0b = 3 or c4q0b = 4 or c4q0b = 5 or c4q0b = 6 or c4q0b = 8)) sick = 1.
```

```
IF (c4q0a = 2) or ((c4q0b = 2 or c4q0b = 7)) sick = 0.
```

```
EXECUTE.
```

```
RECODE
```

```
sick (1=1) (0=0) (ELSE=SYSMIS).
```

```
VARIABLE LABEL sick 'Ch. has usual place for sick care'.
```

```
VALUE LABEL sick
```

```
0 'No'
```

```
1 'Yes'.
```

```
COMPUTE well = 99.
```

```
IF (c4q01 = 1) or ((c4q02 = 2 or c4q02 = 4 or c4q02 = 5 or c4q02 = 6 or c4q02 = 7 or c4q02 = 9)) well = 1.
```

```
IF (c4q02 = 1 or c4q02 = 3 or c4q02 = 8 or c4q02 = 10) well = 0.
```

```
IF (c4q02 = 96 or c4q02 = 97) well = 4.
```

```
IF (c4q01 = 6 or c4q01 = 7) well = 4.
```

```
IF ((c4q01 = 1) and (c4q0b = 2 or c4q0b = 7)) well = 0.
```

```
EXECUTE.
```

```
MISSING VALUES well (4).
```

```
RECODE
```

```
well (1=1) (0=0) (ELSE=SYSMIS) .
```

```
EXECUTE .
```

```
VARIABLE LABEL well 'Ch. has usual place for well care'.
```

```
VALUE LABEL well
```

```
0 'No'
```

```
1 'Yes'.
```

```
***** Step 2: Construct "Usual Sources for Sick and Well Care " sub-component of MEDICAL HOME composite measure
```

```
COMPUTE usual = 99.
```

```
IF (sick = 1) and (well = 1) usual = 1.
```

```
IF (sick = 0) or (well = 0) usual = 0.
```

```
IF (SYSMIS (well)) or (SYSMIS (sick)) usual = 4.
```

```
EXECUTE.
```

```
MISSING VALUES usual (4).
```

```

RECODE
usual (1=1) (0=0) (ELSE=SYSMIS) .
EXECUTE .
VARIABLE LABEL usual 'Usual sources for sick and well care sub-component of MEDICAL HOME
composite measure'.
VALUE LABEL usual
0 'Ch. does not have usual source of care'
1 'Ch. has usual source of care'.

*****Coordinated Care Component*****

***EFFECTIVE CARE COORDINATION sub-component of MEDICAL HOME composite measure

***** Step 1: The following syntax sets up the interim variables used to derive the overall score
for "Effective Care Coordination" sub-component of MEDICAL HOME composite measure
COMPUTE coorrcv = 99.
IF (c4q6x0aa = 1) coorrcv = 1.
IF (c4q6x0aa = 0) coorrcv = 0.
IF (c4q06_0a = 0) coorrcv = 3.
EXECUTE.
VARIABLE LABEL coorrcv 'Received NEEDED professional care coordination'.
VALUE LABEL coorrcv
0 'Needed, did not get all prof care coor'
1 'Needed & got all prof care coor'
3 'Did not need prof care coor'
99 'DK/Ref/Missing to one or both'.

RECODE
c5q05
(6=6) (96=999) (SYSMIS=999) (1 thru 2=1) (3 thru 5=2) INTO r_c5q05 .
EXECUTE .

COMPUTE doccomm = 999.
IF (r_c5q05 = 1) doccomm = 1.
IF (r_c5q05 = 2) doccomm = 2.
IF (r_c5q05 = 6) doccomm = 3.
IF (c4q06_0a = 0) doccomm = 3.
IF (c5q02 = 1) doccomm = 3.
EXECUTE.
VAR LABEL doccomm "Level of communication btw child's doctors".
VALUE LABEL doccomm
1 'Excellent/very good'
2 'Good/Fair/Poor'
3 'Legitimate skip'
999 'DK/Ref/Missing'.

RECODE
c5q06
(6=6) (96=999) (97=999) (SYSMIS=999) (1 thru 2=1) (3 thru 5=2) INTO r_c5q06 .
EXECUTE .
VAR LABEL r_c5q06 'Recoded level of dr communication with other services'.
VALUE LABEL r_c5q06
1 'Excellent/Very Good'
2 'Good/Fair/Poor'
6 'Communication not needed'
999 'DK/Ref'.

COMPUTE othcom_1 = 999.

```

```

IF (r_c5q06 = 1) othcom_1 = 1.
IF (r_c5q06 = 2) othcom_1 = 2.
EXECUTE.
VALUE LABEL othcom_1
1 'Excellent/Very Good'
2 'Good/Fair/Poor'
999 'Communication not needed or DK/Ref'.

MISSING VALUES c5q02 ().
EXECUTE.

COMPUTE othcom_2 = 999.
IF (c4q06_0a = 0) othcom_2 = 3.
IF (c4q06_0a = 1) and (othcom_1 = 1) othcom_2 = 1.
IF (c4q06_0a = 1) and (othcom_1 = 2) othcom_2 = 2.
IF (c4q06_0a = 1) and (c5q02 = 1) othcom_2 = 3.
IF (c4q06_0a = 1) and (c5q02 >= 6) othcom_2 = 999.
EXECUTE.
VALUE LABEL othcom_2
1 'Ex/VG'
2 'G/F/P'
3 'Prof care coor NOT needed or needed/NEVER helped'
999 'DK/Ref'.

COMPUTE othcomm = 999.
IF (r_c5q06 = 1) and (othcom_2 = 1) othcomm = 1.
IF (r_c5q06 = 1) and (othcom_2 = 3) othcomm = 3.
IF (r_c5q06 = 2) and (othcom_2 = 2) othcomm = 2.
IF (r_c5q06 = 2) and (othcom_2 = 3) othcomm = 3.
IF (r_c5q06 = 6) and (othcom_2 = 3) othcomm = 3.
IF (r_c5q06 = 6) and (othcom_2 = 999) othcomm = 3.
IF (r_c5q06 = 999) and (othcom_2 = 3) othcomm = 3.
EXECUTE.
VAR LABEL othcomm 'Level of dr communication with other services'.
VALUE LABEL othcomm
1 'Ex/VG'
2 'G/F/P'
3 'Legitimate skip'
999 'DK/Ref'.

***** Step 2: Construct "EFFECTIVE CARE COORDINATION " sub-component of MEDICAL HOME
composite measure

COMPUTE carecoor = 3.
IF (coorrcv = 1) and ((doccomm = 1) or (doccomm = 3)) and ((othcomm = 1) or
(othcomm = 3)) carecoor = 1.
IF (coorrcv = 0) or (doccomm = 2) or (othcomm = 2) carecoor = 0.
IF (coorrcv = 99) or (doccomm = 999) or (othcomm = 999) carecoor = 999.
EXECUTE.
VAR LABEL carecoor 'Effective care coordination sub-component of MEDICAL HOME composite
measure'.
VALUE LABEL carecoor
1 'Yes'
0 'No'
3 'Legitimate skip -- not needed or needed & never get help'
999 'DK/Ref/Missing'.
RECODE
carecoor
(999=SYSMIS) .

```

***** MEDICAL HOME COMPOSITE MEASURE*****

***The following code uses the five sub-components created above to derive the MEDICAL HOME composite measure using the ON EVERY scoring approach

COMPUTE mh_comp= 99.

IF ((pdn = 1) and (usual = 1)) and ((carecoor = 1) or (carecoor = 3)) and ((norefprb = 1) or (norefprb = 3)) and ((famcent = 1) or (famcent = 3)) mh_comp = 1.

IF (pdn = 0) or (usual = 0) or (carecoor = 0) or (norefprb = 0) or (famcent = 0) mh_comp = 0.

IF (SYSMIS (pdn)) or (SYSMIS (usual)) or (SYSMIS (famcent)) or (SYSMIS (norefprb)) or (SYSMIS (carecoor)) mh_comp = 99.

EXECUTE.

MISSING VALUES mh_comp (99).

VARIABLE LABEL mh_comp '% of CSHCN receiving coordinated, ongoing, comprehensive care within a medical home'.

VALUE LABEL mh_comp

0 'Care DOES NOT meet medical home criteria'

1 'Care MEETS medical home criteria'.

**2001 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*Unweighted frequency distributions for the
Medical Home sub-components, related interim variables
and composite measure generated by the
SPSS scoring program*

Personal Doctor or Nurse (PDN) Component

**PDN sub-component score (PDN)

pdn Personal doctor or nurse sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Do not have a personal dr or nurse	3927	10.1	10.1	10.1
	1 Yes, have a personal dr or nurse	34784	89.5	89.9	100.0
	Total	38711	99.6	100.0	
Missing	System	155	.4		
Total		38866	100.0		

Family-Centered Care Component

**Interim variables for Family-Centered Care sub-component

time How often drs spent enough time

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes or never	5391	13.9	14.5	14.5
	1 Usually or always	31408	80.8	84.2	98.7
	99 DK/REF to item or # of dr visits	503	1.3	1.3	100.0
	Total	37302	96.0	100.0	
Missing	System	1564	4.0		
Total		38866	100.0		

listen How often drs listened carefully

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes or never	4015	10.3	10.7	10.7
	1 Usually or always	32857	84.5	87.9	98.7
	99 DK/REF to item or # of dr visits	503	1.3	1.3	100.0
	Total	37375	96.2	100.0	
Missing	System	1491	3.8		
Total		38866	100.0		

sensitiv How often drs sensitive to families values/customs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes or never	4258	11.0	11.5	11.5
	1 Usually or always	32167	82.8	87.1	98.6
	99 DK/REF to item or # of dr visits	503	1.3	1.4	100.0
	Total	36928	95.0	100.0	
Missing	System	1938	5.0		
Total		38866	100.0		

info How often got enough info from dr re: medical problems

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes or never	6497	16.7	17.4	17.4
	1 Usually or always	30237	77.8	81.2	98.6
	99 DK/REF to item or # of dr visits	503	1.3	1.4	100.0
	Total	37237	95.8	100.0	
Missing	System	1629	4.2		
Total		38866	100.0		

partner How often drs helped parents feel like partners

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes or never	4633	11.9	12.4	12.4
	1 Usually or always	32204	82.9	86.2	98.7
	99 DK/REF to item or # of dr visits	503	1.3	1.3	100.0
	Total	37340	96.1	100.0	
Missing	System	1526	3.9		
Total		38866	100.0		

Family-Centered Care sub-component score (FAMCENT**)

famcent Family centered care sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Does NOT have fcc	11031	28.4	29.5	29.5
	1 Yes, has fcc	24987	64.3	66.8	96.2
	3 Legitimate skip	1404	3.6	3.8	100.0
	Total	37422	96.3	100.0	
Missing	System	1444	3.7		
Total		38866	100.0		

Comprehensive Care Component

**Interim variables for No Problems Getting Needed Referrals sub-component

r_c4q07 Problems getting referral to specialist

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Big or small problem	5676	14.6	14.6	14.6
	1 No problems	29787	76.6	76.6	91.2
	4 Ch did NOT need to see a specialist	2210	5.7	5.7	96.9
	5 No need to get referrals	1098	2.8	2.8	99.8
	999 DK/Ref/Missing	95	.2	.2	100.0
Total		38866	100.0	100.0	

** No Problems Getting Needed Referrals sub-component score (**NOREFPRB**)

norefprb Getting needed referrals sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Needed referrals, problems getting	4026	10.4	10.4	10.4
	1 Needed referrals, no problems	16016	41.2	41.4	51.8
	3 Legitimate skip	18670	48.0	48.2	100.0
	Total	38712	99.6	100.0	
Missing	System	154	.4		
Total		38866	100.0		

****Interim variables Usual Sources for Sick and Well Care sub-component**

sick Ch. has usual place for sick care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No	3661	9.4	9.4	9.4
	1 Yes	35083	90.3	90.6	100.0
	Total	38744	99.7	100.0	
Missing	System	122	.3		
Total		38866	100.0		

well Ch. has usual place for well care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No	369	.9	1.0	1.0
	1 Yes	38368	98.7	99.0	100.0
	Total	38737	99.7	100.0	
Missing	System	129	.3		
Total		38866	100.0		

****Usual Sources for Sick and Well Care sub-component score (USUAL)**

usual Usual sources for sick and well care sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Ch. does not have usual source of care	3664	9.4	9.5	9.5
	1 Ch. has usual source of care	34964	90.0	90.5	100.0
	Total	38628	99.4	100.0	
Missing	System	238	.6		
Total		38866	100.0		

Coordinated Care Component

**Interim variables Effective Care Coordination sub-component

coorrcv Received NEEDED professional care coordination

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Needed, did not get all prof care coor	779	2.0	2.0	2.0
	1 Needed & got all prof care coor	3748	9.6	9.6	11.6
	3 Did not need prof care coor	34160	87.9	87.9	99.5
	99 DK/Ref/Missing to one or both	179	.5	.5	100.0
Total		38866	100.0	100.0	

r_c5q05

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	1970	5.1	5.1	5.1
	2	1740	4.5	4.5	9.5
	6	66	.2	.2	9.7
	999	35090	90.3	90.3	100.0
Total		38866	100.0	100.0	

doccomm Level of communication btw child's doctors

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Excellent/very good	1970	5.1	5.1	5.1
	2 Good/Fair/Poor	1740	4.5	4.5	9.5
	3 Legitimate skip	34919	89.8	89.8	99.4
	999 DK/Ref/Missing	237	.6	.6	100.0
Total		38866	100.0	100.0	

r_c5q06 Recoded level of dr communication with other services

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Excellent/Very Good	15706	40.4	40.4	40.4
	2 Good/Fair/Poor	13763	35.4	35.4	75.8
	6 Communication not needed	8427	21.7	21.7	97.5
	999 DK/Ref	970	2.5	2.5	100.0
	Total	38866	100.0	100.0	

othcom_1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Excellent/Very Good	15706	40.4	40.4	40.4
	2 Good/Fair/Poor	13763	35.4	35.4	75.8
	999 Communication not needed or DK/Ref	9397	24.2	24.2	100.0
	Total	38866	100.0	100.0	

othcom_2

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Ex/VG	1203	3.1	3.1	3.1
	2 G/F/P	1993	5.1	5.1	8.2
	3 Prof care coor NOT needed or needed/NEVER helped	34852	89.7	89.7	97.9
	999 DK/Ref	818	2.1	2.1	100.0
	Total	38866	100.0	100.0	

othcomm Level of dr communication with other services

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Ex/VG	1203	3.1	3.1	3.1
	2 G/F/P	1993	5.1	5.1	8.2
	3 Legitimate skip	35409	91.1	91.1	99.3
	999 DK/Ref	261	.7	.7	100.0
	Total	38866	100.0	100.0	

****Effective Care Coordination sub-component score (CARECOOR)**

carecoor Effective care coordination sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No	2665	6.9	6.9	6.9
	1 Yes	1691	4.4	4.4	11.3
	3 Legitimate skip -- not needed or needed & never get help	34160	87.9	88.7	100.0
	Total	38516	99.1	100.0	
Missing	System	350	.9		
Total		38866	100.0		

Medical Home Composite Measure

****Medical Home Composite Measure score (MH_COMP)**

mh_comp % of CSHCN receiving coordinated, ongoing, comprehensive care within a medical home

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Care DOES NOT meet medical home criteria	16691	42.9	45.5	45.5
	1 Care MEETS medical home criteria	20019	51.5	54.5	100.0
	Total	36710	94.5	100.0	
Missing	99	2156	5.5		
Total		38866	100.0		

**2001 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*Full text and response options for questions
used to assess Medical Home*

2001 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<u>SECTION 4: ACCESS TO CARE: UTILIZATION AND UNMET NEEDS</u>	
<p>C4q0a Is there a place that (S.C.) USUALLY goes when (he/she) is sick or you need advice about (his/her) health?</p> <p><i>If Yes to C4q0a:</i></p> <p>C4q0b Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?</p>	<p>(1) YES (2) THERE IS NO PLACE [SKIP TO C4Q02] (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW [SKIP TO C4Q02] (7) REFUSED [SKIP TO C4Q02]</p> <p>(01) DOCTOR'S OFFICE [SKIP TO C4Q01] (02) HOSPITAL EMERGENCY ROOM [SKIP TO C4Q01] (03) HOSPITAL OUTPATIENT DEPARTMENT [SKIP TO C4Q01] (04) CLINIC OR HEALTH CENTER [SKIP TO C4Q01] (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) [SKIP TO C4Q01] (06) SOME OTHER PLACE [SKIP TO C4Q01] (07) DOES NOT GO TO ONE PLACE MOST OFTEN [SKIP TO C4Q02] (96) DON'T KNOW [SKIP TO C4Q02] (97) REFUSED [SKIP TO C4Q02]</p>
<p>C4q01 Is the [place selected in C4q0b] that (S.C.) goes to when (he/she) is sick the same place (S.C.) usually goes for routine preventive care?</p>	<p>(1) YES [SKIP TO C4Q02A] (2) NO [SKIP TO C4Q02] (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A]</p>
<p>C4q02 What kind of place does (S.C.) go to most often when (he/she) needs routine preventive care?</p>	<p>(01) DOES NOT GET PREVENTIVE CARE ANYWHERE (02) DOCTOR'S OFFICE (03) HOSPITAL EMERGENCY ROOM (04) HOSPITAL OUTPATIENT DEPARTMENT (05) CLINIC OR HEALTH CENTER (06) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (07) SOME OTHER PLACE [SKIP TO C4Q02_1] (08) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED</p>
<p>C4q02a A personal doctor or nurse is the health provider who knows (S.C.) best. Do you have ONE person that you think of as (S.C.)'s personal doctor or nurse?</p>	<p>(1) YES (2) NO [SKIP TO C4Q03] (6) DON'T KNOW [SKIP TO C4Q03] (7) REFUSED [SKIP TO C4Q03]</p>

2001 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
C4q05_02 During the past 12 months, was there any time when (“S” CHILD) needed care from a specialty doctor?	(1) YES (2) NO (6) DON’T KNOW (7) REFUSED [SKIP TO C4Q05_03] [SKIP TO C4Q05_03] [SKIP TO C4Q05_03]
C4q06_0a During the past 12 months, was there any time when you or other family members needed professional care coordination among different health care providers and services that the child uses? <i>If Yes to C4q06_0a:</i> C4q06x0aa Did you or your family receive all the professional care coordination that was needed?	(1) YES (2) NO (6) DON’T KNOW (7) REFUSED [SKIP TO C4Q06_01] [SKIP TO C4Q06_01] [[SKIP TO C4Q06_01] (1) YES (2) NO (6) DON’T KNOW (7) REFUSED
C4q07 In the past 12 months, how much of a problem, if any, was it to get a referral to a specialist that your child needed to see?	(1) Big problem (2) Small problem (3) Not a problem (4) Child did not go to see a specialist in the past 12 months (5) DID NOT NEED REFERRALS (6) DON’T KNOW (7) REFUSED
<u>SECTION 5: CARE COORDINATION</u>	
C5q02 Earlier you told me that you or other family members needed professional assistance coordinating (“S” CHILD)’s care. How often does a professional help you coordinate (“S” CHILD)’s care among (his/her) different providers and services?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED [SKIP TO C5q06] [SKIP TO C5q06] [SKIP TO C5q06]
C5q05 How well do you think (“S” CHILD)’s doctors and other health care providers communicate with each other about (“S” CHILD)’s care?	(01) Excellent (02) Very Good (03) Good (04) Fair or (05) Poor (06) COMMUNICATION NOT NEEDED (96) DON’T KNOW (97) REFUSED

2001 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
C5q06 How well do you think (“S” CHILD) ’s doctors and other health care providers communicate with (his/her) school, early intervention program, child care providers, or vocational rehabilitation program?	(01) Excellent (02) Very Good (03) Good (04) Fair or (05) Poor (06) COMMUNICATION NOT NEEDED (96) DON’T KNOW (97) REFUSED
<u>SECTION 6: SATISFACTION WITH CARE</u>	
C6q02 During the past 12 months, how often did (S.C.)’s doctors and other health care providers spend enough time with (him/her)?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED
C6q03 During the past 12 months, how often did (S.C.)’s doctors and other health care providers listen carefully to you?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED
C6q04 When (S.C.) is seen by doctors or other health care providers, how often are they sensitive to your family’s values and customs?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED
C6q05 During the past 12 months, how often did you get the specific information you needed from (S.C.)’s doctors and other health care providers?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED
C6q06 During the past 12 months, how often did (S.C.)’s doctors or other health care providers help you feel like a partner in (his/her) care?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED

**2005/2006 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

APPENDIX B_1: SAS User Resources

Programming Code and Other Resources
for Medical Home Measurement

National Survey of Children with Special Health Care Needs (NS-CSHCN)

Weighted estimates* for Medical Home composite measure, the five sub-component scores and associated interim variables

	2001 NS-CSHCN	2005/06 NS-CSHCN	
	% CSHCN ages 0-17*	% CSHCN ages 0-17*	NOTES*
Meet overall criteria for having a Medical Home:	52.6	47.1	
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER			
1) <u>Child has a “personal doctor or nurse”</u>	89.0	93.5	1) Revised question wording used in 2005/06
ACCESSIBLE	--	--	--
FAMILY CENTERED			
2) <u>Child’s doctors and other health providers do each of the following:</u>	64.2	62.4	
a. <u>Usually or always</u> spend enough time with child and parent	80.0	74.7	f. New question on interpreter services added in 2005/06; only asked for households where primary language is not English
b. <u>Usually or always</u> listen carefully to child and parent	84.5	84.3	
c. <u>Usually or always</u> sensitive to family’s values and customs	82.2	84.4	
d. <u>Usually or always</u> provide needed information	77.4	78.9	
e. <u>Usually or always</u> make family feel like a partner in child’s care	82.2	83.2	
AND			
f. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	--	0.8	
CONTINUOUS	--	--	
COMPREHENSIVE			
3) <u>IF needed, no problems obtaining referrals</u>	38.8	26.0	3) Significant changes were made in 2005/06 to the question wording, placement, and skip patterns use to assess problems obtaining needed referrals
a. Needed referral during past 12 months	49.6	33.0	
4) <u>Have usual source(s) for both sick and well care</u>	90.5	92.9	
a. Child has a usual source for sick care	90.6	94.3	
b. Child has a usual source for preventive care	98.8	97.1	
COORDINATED			
5) <u>IF needed, gets effective care coordination</u>	4.5	46.0	5) Significant changes were made in 2005/06 in the content, wording, placement, and skip patterns of the questions used to assess effective care coordination
a. <u>Needed and received</u> professional help with care coordination	9.5	--	
b. <i>IF needed</i> care coordination, <u>excellent</u> communication btw doctors	5.1	--	
c. <i>IF needed</i> care coordination, doctor communication with school or other programs the child attends is <u>excellent</u>	3.0	--	
d. <u>Needed and usually got</u> extra help with care coordination	--	30.4	
e. <i>IF needed</i> , <u>very satisfied</u> with communication btw doctors	--	41.8	
f. <i>IF needed</i> , <u>very satisfied</u> with how doctors communicate with school or other programs the child attends	--	14.1	
COMPASSIONATE			Assessed under the Family Centered Care component†
CULTURALLY EFFECTIVE			Assessed under the Family Centered Care component†

* All estimated percentages are weighted to represent the U.S. non-institutionalized population of CSHCN ages 0-17 years

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.

-- Not assessed by the survey.

**2005/2006 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*SAS Medical Home
scoring program*

**Measuring Medical Home using Data Elements from the
2005/06 National Survey of Children with Special Health Care Needs
(NS-CSHCN)**

SAS scoring program variable names for the five sub-component scores and
associated interim variables used to derive the Medical Home composite measure

2005/06 NS-CSHCN		
	SAS	Survey items or interim variables
	Variable names	used to construct:
Meet overall criteria for having a Medical Home:	MH_COMP	[PERSDOC; FAMCENT; NOREFPRB; USUALSW; CARECOOR]
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER		
1) <u>Child has at least one “personal doctor or nurse”</u>	PERSDOC	C4Q02a
ACCESSIBLE		
--		
FAMILY CENTERED		
2) <u>Child’s doctors and other health providers do each of the following:</u>	FAMCENT	[TIME; LISTEN; SENSITIV; INFO; PARTNER2, INTERPRET]
a. <u>Usually or always</u> spend enough time with child and parent	TIME	C6q02
b. <u>Usually or always</u> listen carefully to child and parent	LISTEN	C6q03
c. <u>Usually or always</u> sensitive to family’s values and customs	SENSITIV	C6q04
d. <u>Usually or always</u> provide needed information	INFO	C6q05
e. <u>Usually or always</u> make family feel like a partner in child’s care	PARTNER2	C6q06
f. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	INTERPRET	S5q13; S5q13a
CONTINUOUS		
--		
COMPREHENSIVE		
3) <u>IF needed, no problems obtaining referrals</u>	NOREFPRB	C5q11; C4q07
4) <u>Usual source(s) for both sick and well care</u>	USUALSW	[USUALS; USUALW]
a. Child has a usual source for sick care	USUALS	C4q0a; C4q0b
b. Child has a usual source for preventive care	USUALW	C4q0d; C4q01; C4q02
COORDINATED		
5) <u>Gets effective care coordination when needed</u>	CARECOOR	[COORRCV; DOCCOMM; OTHCOMM]
a. <u>Needed and usually got</u> extra help with care coordination	COORRCV	C5q12, C5q17; C5q09
b. <i>IF needed</i> , <u>very satisfied</u> with communication btw doctors	DOCCOMM	C5q10
c. <i>IF needed</i> , <u>very satisfied</u> with how doctors communicate with school or other programs the child attends	OTHCOMM	C5q05; C5q06
COMPASSIONATE		
<i>Assessed under the Family Centered Care component†</i>		
CULTURALLY EFFECTIVE		
<i>Assessed under the Family Centered Care component†</i>		

2005/06 NS-CSHCN MEDICAL HOME Composite measure	
Survey Items Used	C4Q02a, C6Q02 – C6Q06, S5Q13, S5Q13a, C5Q11, C4Q07, C4Q0a, C4Q0b, C4Q0d, C4Q01, C4Q02, C5Q12, C5Q17, C5Q09, C5Q10, C5Q05, C5Q06
Numerator	Children with special health care needs (CSHCN) meeting scoring criteria for having a Medical Home
Denominator	Children with special health care needs (CSHCN) ages 0–17 years
Description	Percent of CSHCN ages 0–17 who have a primary care provider (e.g. personal doctor or nurse) AND usual sources for both sick and preventive care AND consistently get family-centered care from their doctors and other health care providers AND, if needed, receive effective care coordination AND, if needed, no problems getting referrals
Notes for Data-Users	
<p>The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of “medical home. ‘ According to this definition, children ideally should have access to “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home.”</p> <p>The presence of medical home for CSHCN is one of the six performance measures or outcomes that states submit as part of the Title V Block Grant reporting requirements. The final medical home composite score used to measure this outcome is derived from the five sub-components constructed below.</p>	
SAS Code and Annotation	
Formats	
<p>**** The following program sets the formats for the medical home sub-components, associated interim variables, and the overall medical home composite measure created by the SAS scoring program</p> <pre> proc format library = library name; value persdoc /*PDN sub-component*/ 2 = "Do not have personal dr or nurse" 1 = "Yes, have a personal dr or nurse"; value howoften /*interim variable*/ 2 = "Sometimes/Never" 1 = "Usually/Always"; value fcc /*FCC sub-component*/ 2 = "Does NOT have fcc" 1 = "Yes, has fcc" ; value referral /*Getting referrals sub-component*/ 2 = "Needed referrals, problems getting" 1 = "Needed referrals, no problems"; value yn /*interim variable*/ 0 = "No" 2 = "No" 1 = "Yes" ; </pre>	


```

value usualsw /*Usual source care care sub-component*/
2 = "Does not have usual sources of care"
1 = "DOES have usual sources for sick and well care";
value cccom /*interim variables for care coor communication*/
1 = "Very satisfied"
2 = "Less than very satisfied";
value effcarecoor /*Effect care coor sub-component*/
1 = "Has effective care coor"
2 = "Does not have effective care coor";
value medhome /*Composite meas*/
1 = "Care MEETS medical home criteria"
2 = "Care DOES NOT meet medical home criteria";
RUN;

```

Scoring program

```

*****Personal doctor or nurse (PDN) Component*****

/*Personal Doctor or Nurse Component*/
/**Personal Doctor or Nurse" sub-component of MEDICAL HOME composite measure**/
persdoc=.;
if c4q02a in (1,2) then persdoc = 1;
else if c4q02a = 3 then persdoc = 2;
else if c4q02a in (6,7,.M) then persdoc = .M;
label persdoc = "Personal Doctor or Nurse sub-component of MEDICAL HOME
composite measure";

***** Family Centered Care Component *****

/**FAMILY CENTERED COMPONENT**/
/**Family Centered Care" sub-component of MEDICAL HOME composite measure**/
/**Step 1: Set up the interim variables used to derive the Family Centered Care
sub-component of the MEDICAL HOME composite measure**/
time=.;
if c6q02 in (6,7) then time = .M;
else if c6q02 = .L then time = .L;
else if c6q02 = 1 or c6q02 = 2 then time = 2;
else if c6q02 = 3 or c6q02 = 4 then time = 1;
label time = 'FCC: Doctors usually or always spend enough time';

listen=.;
if c6q03 in (6,7) then listen = .M;
else if c6q03 = .L then listen = .L;
else if c6q03 = 1 or c6q03 = 2 then listen = 2;
else if c6q03 = 3 or c6q03 = 4 then listen = 1;
label listen = 'FCC: Doctors usually or always listen carefully';

sensitiv=.;
if c6q04 in (6,7) then sensitiv = .M;
else if c6q04 = .L then sensitiv = .L;
else if c6q04 = 1 or c6q04 = 2 then sensitiv = 2;
else if c6q04 = 3 or c6q04 = 4 then sensitiv = 1;
label sensitiv = 'FCC: Doctors are usually or always sensitive to values and
customs';

```

```

info=.;
if c6q05 in (6,7) then info = .M;
else if c6q05 = .L then info = .L;
else if c6q05 = 1 or c6q05 = 2 then info = 2;
else if c6q05 = 3 or c6q05 = 4 then info = 1;
label info = 'FCC: Doctors usually or always provide needed information';

partner2=.;
if c6q06 in (6,7) then partner2 = .M;
else if c6q06 = .L then partner2 = .L;
else if c6q06 = 1 or c6q06 = 2 then partner2 = 2;
else if c6q06 = 3 or c6q06 = 4 then partner2 = 1;
label partner2 = 'FCC: Doctors usually or always make the family feel like a
partner';

interpret=.;
if s5q13a in (6,7) then interpret = .M;
else if s5q13a = .L then interpret = .L;
else if s5q13a = 1 or s5q13a = 2 then interpret = 2;
else if s5q13a = 3 or s5q13a = 4 then interpret = 1;
label interpret = 'FCC: An interpreter is usually or always available when
needed';

/**Step 2: Construct the Family Centered Care sub-component of MEDICAL HOME
composite measure**/
famcent = .;
if time = .M or listen = .M or sensitiv = .M or info = .M or partner2 = .M or
interpret = .M then famcent = .M;
else if time = .L then famcent = .L;
else if time in (1,.L) and listen in (1,.L) and sensitiv in (1,.L) and info in
(1,.L) and partner2 in (1,.L) and interpret in (1,.L) then famcent = 1;
else if time = 2 or listen = 2 or sensitiv = 2 or info = 2 or partner2 = 2 or
interpret = 2 then famcent = 2;
label famcent = 'Family-Centered Care sub-component of MEDICAL HOME composite
measure';

*****Comprehensive Care Component*****

/**COMPREHENSIVE CARE COMPONENT**/
/**No Problems Getting Needed Referrals sub-component of MEDICAL HOME composite
measure**/
norefprb = .;
if c5q11 = 0 then norefprb = .L;
else if c5q11 in (6,7) then norefprb = .M;
else if c4q07 in (1,2) then norefprb = 2;
else if c4q07 = 3 then norefprb = 1;
else if c4q07 in (6,7) then norefprb = .M;
label norefprb = 'Getting Needed Referrals sub-component of MEDICAL HOME
composite measure';

```

```

/**Usual Sources for Sick and Well Care sub-component of MEDICAL HOME composite
measure**/
/**Step 1: Set up the interim variables used to derive the Usual Sources for
Sick and Well Care sub-component of the MEDICAL HOME composite measure**/
usuals = .;
if c4q0a in (1,3) and c4q0br in (1,3,4,5,6,8,10) then usuals = 1;
else if c4q0a = 2 or c4q0br in (2,7,9) then usuals = 2;
else if c4q0a in (6,7) or c4q0br in (.M,96,97) then usuals = .M;
label usuals = 'Has a usual source for sick care';

usualw = .;
if c4q0d in (1,3) and (usuals = .M and c4q01 = 1) then usualw = .M;
else if c4q0d in (1,3) and c4q01 in (6,7) then usualw = .M;
else if c4q0d in (1,3) and ((usuals = 1 and c4q01 = 1) or (c4q02r in
(1,3,4,5,6,8))) then usualw = 1;
else if c4q0d in (1,3) and (usuals = 2 and c4q01 = 1) then usualw = 2;
else if c4q0d = 2 or c4q02r in (2,7,9) then usualw = 2;
else if c4q0d in (6,7) or c4q02r in (96,97) then usualw = .M;
label usualw

/**Step 2: Construct the Usual Sources for Sick and Well Care sub-component of
MEDICAL HOME composite measure**/
usualsw = .;
if usuals = .M or usualw = .M then usualsw = .M;
else if usuals in (1,.L) and usualw in (1,.L) then usualsw = 1;
else if usuals = 2 or usualw = 2 then usualsw = 2;
label usualsw = 'Usual Sources for Sick and Well sub-component of MEDICAL HOME
composite measure';

*****Coordinated Care Component*****

/**COORDINATED CARE COMPONENT**/
/**Gets Effective Care Coordination sub-component of MEDICAL HOME composite
measure**/
/**Step 1: Set up the interim variables used to derive the Gets Effective Care
Coordination sub-component of the MEDICAL HOME composite measure**/
if (c4q05x02a = 1 or c4q05x02c = 1) or (c4q05x05a = 1 or c4q05x05c = 1) or
(c4q05x06a = 1 or c4q05x06c = 1) or (c4q05x07a = 1 or c4q05x07c = 1) or
(c4q05x08a = 1 or c4q05x08c = 1) then doccommneed = 1;
else if (c4q05_x02 = 0 or c4q05x02c = 0) and (c4q05_x05 = 0 or c4q05x05c = 0)
and (c4q05_x06 = 0 or c4q05x06c = 0) and (c4q05_x07 = 0 or c4q05_x07 = .L or
c4q05x07c = 0) and (c4q05_x08 = 0 or c4q05x08c = 0) then doccommneed = 0;
else doccommneed = .M;
label doccommneed = 'Doctor communication needed if specialist, MH, PT/OT/ST,
sub abuse, or home hlth care used';

doccomm = .;
if doccommneed = 0 then doccomm = .L;
else if doccommneed = .M then doccomm = .M;
else if c5q10 = 1 then doccomm = 1;
else if c5q10 in (2,3,4) then doccomm = 2;
else if c5q10 = 5 then doccomm = .L;
else if c5q10 in (6,7,.M) then doccomm = .M;
else if c5q10 = .L then doccomm = .L;
label doccomm = 'Family is very satisfied with doctors communication with each
other';

```

```

othcomm = .;
if c5q05 = 2 then othcomm = .L;
else if c5q05 in (6,7) then othcomm = .M;
else if c5q06 = 1 then othcomm = 1;
else if c5q06 in (2,3,4) then othcomm = 2;
else if c5q06 in (6,7,.M) then othcomm = .M;
else if c5q06 = .L then othcomm = .L;
label othcomm = 'Family is very satisfied with doctors communication with other
programs';

coorrcv = .;
if c5q12 = .L then coorrcv = .L;
else if c5q12 = .M then coorrcv = .M;
else if c5q12 = 0 and c5q17 = 0 then coorrcv = .L;
else if c5q12 in (6,7) and c5q17 = 0 then coorrcv = .M;
else if c5q17 in (6,7) then coorrcv = .M;
else if c5q09 in (6,7) then coorrcv = .M;
else if c5q12 = 1 and c5q17 = 0 then coorrcv = 1;
else if c5q09 = 3 then coorrcv = 1;
else if c5q09 in (1,2) then coorrcv = 2;
label coorrcv = 'Family usually or always gets sufficient help coordinating care
if needed';

/**Step 2: Construct the Gets Effective Care Coordination sub-component of
MEDICAL HOME composite measure**/
carecor = .;
if coorrcv = .M or doccomm = .M or othcomm = .M then carecor = .M;
else if coorrcv = .L and doccomm = .L and othcomm = .L then carecor = .L;
else if coorrcv in (1,.L) and doccomm in (1,.L) and othcomm in (1,.L) then
carecor= 1;
else if coorrcv = 2 or doccomm = 2 or othcomm = 2 then carecor = 2;
label carecor = 'Effective Care Coord sub-component of MEDICAL HOME composite
measure';

***** MEDICAL HOME COMPOSITE MEASURE*****

/**** MEDICAL HOME COMPOSITE MEASURE****/
/**The following code uses the 5 sub-components created above to derive the
MEDICAL HOME composite measure using the ON EVERY scoring approach**/

mh_comp= .;
if persdoc = .M or usualsw = .M or famcent = .M or norefprb = .M or carecor =
.M then mh_comp= .M;
else if persdoc = .L and usualsw = .L and famcent = .L and norefprb = .L and
carecor = .L then mh_comp= .L;
else if persdoc in (1,.L) and usualsw in (1,.L) and norefprb in (1,.L) and
famcent in (1,.L) and carecor in (1,.L) then mh_comp= 1;
else if persdoc = 2 or usualsw = 2 or norefprb = 2 or famcent = 2 or carecor =
2 then mh_comp= 2;
label mh_comp= '% CSHCN receiving coordinated, ongoing, comprehensive care
within a medical home';
RUN;

```

```
PROC FREQ DATA=dataset name;  
FORMAT   time howoften.  
         listen howoften.  
         sensitiv howoften.  
         info howoften.  
         partner2 howoften.  
         interpret howoften.  
         persdoc persdoc.  
         famcent fcc.  
         norefprb referral.  
         usuals usualw doccommneed coorrcv yn.  
         usualsw usualsw.  
         othcomm doccomm cccom.  
         carecoor effcarecoor.  
         mh_comp medhome. ;  
  
TABLES persdoc time listen sensitiv info partner2 interpret famcent norefprb  
       usuals usualw usualsw coorrcv doccomm othcomm carecoor mh_comp ;  
RUN;
```

**2005/2006 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*Unweighted frequency distributions for the
Medical Home sub-components, related interim variables and
composite measure generated by the
SAS scoring program*

Personal Doctor or Nurse (PDN) Component

**PDN sub-component score (PERSDOC)

Personal Doctor or Nurse sub-component of MEDICAL HOME composite measure

	Frequency	Percent	Cumulative Frequency	Cumulative Percent
persdoc				
Yes, have a personal dr or nurse	38358	94.34	38358	94.34
Do not have personal dr or nurse	2300	5.66	40658	100.00

Frequency Missing = 65

Family-Centered Care Component

**Interim variables for Family-Centered Care sub-component

FCC: Doctors usually or always spend enough time

	Frequency	Percent	Cumulative Frequency	Cumulative Percent
time				
Usually/Always	31287	80.71	31287	80.71
Sometimes/Never	7478	19.29	38765	100.00

Frequency Missing = 1958

FCC: Doctors usually or always listen carefully

	Frequency	Percent	Cumulative Frequency	Cumulative Percent
listen				
Usually/Always	34819	89.72	34819	89.72
Sometimes/Never	3990	10.28	38809	100.00

Frequency Missing = 1914

FCC: Doctors are usually or always sensitive to values and customs

sensitiv	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Usually/Always	34746	90.12	34746	90.12
Sometimes/Never	3809	9.88	38555	100.00

Frequency Missing = 2168

FCC: Doctors usually or always provide needed information

info	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Usually/Always	32367	83.48	32367	83.48
Sometimes/Never	6406	16.52	38773	100.00

Frequency Missing = 1950

FCC: Doctors usually or always make the family feel like a partner

partner2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Usually/Always	34380	88.55	34380	88.55
Sometimes/Never	4445	11.45	38825	100.00

Frequency Missing = 1898

FCC: An interpreter is usually or always available when needed

interpret	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Usually/Always	248	59.05	248	59.05
Sometimes/Never	172	40.95	420	100.00

Frequency Missing = 40303

****Family-Centered Care sub-component score (FAMCENT)**

Family-Centered Care sub-component of MEDICAL HOME composite measure

famcent	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Yes, has fcc	25910	67.75	25910	67.75
Does NOT have fcc	12332	32.25	38242	100.00

Frequency Missing = 2481

Comprehensive Care Component

**** No Problems Getting Needed Referrals sub-component score (NOREFPRB)**

Getting Needed Referrals sub-component of MEDICAL HOME composite measure

norefprb	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Needed referrals, no problems	10675	79.91	10675	79.91
Needed referrals, problems getting	2683	20.09	13358	100.00

Frequency Missing = 27365

****Interim variables Usual Sources for Sick and Well Care sub-component**

Has a usual source for sick care

usuals	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Yes	38506	94.81	38506	94.81
No	2108	5.19	40614	100.00

Frequency Missing = 109

Has a usual source for preventive care

usualw	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Yes	39508	97.25	39508	97.25
No	1118	2.75	40626	100.00

Frequency Missing = 97

****Usual Sources for Sick and Well Care sub-component score (USUALSW)**

Usual Sources for Sick and Well sub-component
of MEDICAL HOME composite measure

usualsw	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DOES have usual sources for sick and well care	37830	93.29	37830	93.29
Does not have usual sources of care	2721	6.71	40551	100.00

Frequency Missing = 172

Coordinated Care Component

****Interim variables Effective Care Coordination sub-component**

Family usually or always gets sufficient
help coordinating care if needed

coorrcv	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Yes	12252	68.82	12252	68.82
No	5551	31.18	17803	100.00

Frequency Missing = 22920

Family is very satisfied with doctors communication with each other

docomm	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Very satisfied	17070	63.92	17070	63.92
Less than very satisfied	9636	36.08	26706	100.00

Frequency Missing = 14017

Family is very satisfied with doctors communication with other programs

othcomm	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Very satisfied	5690	51.37	5690	51.37
Less than very satisfied	5387	48.63	11077	100.00

Frequency Missing = 29646

****Effective Care Coordination sub-component score (CARECOOR)**

Effective Care Coor sub-component of MEDICAL HOME composite measure

carecoor	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Has effective care coor	18395	59.39	18395	59.39
Does not have effective care coor	12576	40.61	30971	100.00

Frequency Missing = 9752

Medical Home Composite Measure

**Medical Home Composite Measure score (MH_COMP)

% CSHCN receiving coordinated, ongoing, comprehensive care within a medical home

mh_comp	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Care MEETS medical home criteria	18977	48.80	18977	48.80
Care DOES NOT meet medical home criteria	19909	51.20	38886	100.00

Frequency Missing = 1837

**2005/2006 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*Full text and response options for questions
used to assess Medical Home*

2005/06 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<u>SECTION 4: ACCESS TO CARE -- UTILIZATION AND UNMET NEEDS</u>	
<p>C4q0a Is there a place that (S.C.) USUALLY goes when (he/she) is sick or you need advice about (his/her) health?</p> <p><i>If Yes to C4q0a:</i> C4q0b Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?</p>	<p>(1) YES (2) THERE IS NO PLACE [SKIP TO C4Q0D] (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW [SKIP TO C4Q0D] (7) REFUSED [SKIP TO C4Q0D]</p> <p>(01) DOCTOR'S OFFICE [SKIP TO C4Q0D] (02) HOSPITAL EMERGENCY ROOM [SKIP TO C4Q0D] (03) HOSPITAL OUTPATIENT DEPARTMENT [SKIP TO C4Q0D] (04) CLINIC OR HEALTH CENTER [SKIP TO C4Q0D] (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) [SKIP TO C4Q0D] (06) FRIEND/RELATIVE [SKIP TO C4Q0D] (07) MEXICO/OTHER LOCATIONS OUT OF US [SKIP TO C4Q0D] (08) SOME OTHER PLACE [SKIP TO C4Q0C] (09) DOES NOT GO TO ONE PLACE MOST OFTEN [SKIP TO C4Q0D] (96) DON'T KNOW [SKIP TO C4Q0D] (97) REFUSED [SKIP TO C4Q0D]</p>
<p>C4q0d Is there a place that (S.C.) USUALLY goes when (he/she) needs routine preventive care, such as a physical examination or well-child check-up?</p> <p><i>If Yes to C4q0d:</i> C4q01 Is the [place selected in C4q0b] that (S.C.) goes to when (he/she) is sick the same place (S.C.) usually goes for routine preventive care?</p>	<p>(1) YES (2) THERE IS NO PLACE [SKIP TO C4Q02A] (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A]</p> <p>(1) YES [SKIP TO C4Q02A] (2) NO (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A]</p>
<p>C4q02 What kind of place does (S.C.) go to most often when (he/she) needs routine preventive care?</p>	<p>(01) DOCTOR'S OFFICE (02) HOSPITAL EMERGENCY ROOM (03) HOSPITAL OUTPATIENT DEPARTMENT (04) CLINIC OR HEALTH CENTER (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (06) FRIEND/RELATIVE (07) MEXICO/OTHER LOCATIONS OUT OF US (08) SOME OTHER PLACE [SKIP TO C4Q02_1] (09) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED</p>

2005/06 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<p>C4q02a A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as (S.C.)'s personal doctor or nurse?</p>	<p>(1) YES, ONE PERSON (2) YES, MORE THAN ONE PERSON (3) NO (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C4Q03] [SKIP TO C4Q03] [SKIP TO C4Q03]</p>
SECTION 5: CARE COORDINATION	
<p>C5q11 During the past 12 months, did (S.C.) need a referral to see any doctors or receive any services?</p> <p><i>If Yes to C5q11:</i> C4q07 Was getting referrals a big problem, a small problem, or not a problem?</p>	<p>(1) YES (2) NO (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C5Q12] [SKIP TO C5Q12] [SKIP TO C5Q12]</p> <p>(1) Big problem (2) Small problem (3) Not a problem (6) DON'T KNOW (7) REFUSED</p>
<p>C5q17 During the past 12 months, have you felt that you could have used extra help arranging or coordinating (S.C.)'s care among these different health care providers or services?</p> <p><i>If Yes to C5q17:</i> C5q09 During the past 12 months, how often did you get as much help as you wanted with arranging or coordinating (S.C.)'s care?</p>	<p>(1) YES (2) NO (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C5Q10] [SKIP TO C5Q10] [SKIP TO C5Q10]</p> <p>(1) Never (2) Sometimes (3) Usually (6) DON'T KNOW (7) REFUSED</p>
<p>C5q10 Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among (S.C.)'s doctors and other health care providers?</p>	<p>(1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied (5) NO COMMUNICATION NEEDED OR WANTED (6) DON'T KNOW (7) REFUSED</p>

2005/06 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<p>C5q05 Do (S.C.)’s doctors or other health care providers need to communicate with (his/her) school, early intervention program, child care providers, vocational education or rehabilitation program?</p> <p><i>If Yes to C5q05:</i></p> <p>C5q06 Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication?</p>	<p>(1) YES (2) NO (6) DON’T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C6Q02] [SKIP TO C6Q02] [SKIP TO C6Q02]</p> <p>(1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied (6) DON’T KNOW (7) REFUSED</p>
<u>SECTION 6A: FAMILY CENTERED CARE</u>	
<p>C6q02 During the past 12 months, how often did (S.C.)’s doctors and other health care providers spend enough time with (him/her)?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>
<p>C6q03 During the past 12 months, how often did (S.C.)’s doctors and other health care providers listen carefully to you?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>
<p>C6q04 When (S.C.) is seen by doctors or other health care providers, how often are they sensitive to your family’s values and customs?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>
<p>C6q05 During the past 12 months, how often did you get the specific information you needed from (S.C.)’s doctors and other health care providers?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>

2005/06 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<p>C6q06 During the past 12 months, how often did (S.C.)’s doctors or other health care providers help you feel like a partner in (his/her) care?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>
<p>S5q13 During the past 12 months, did you (or S.C.) need an interpreter to help speak with (his/her) doctors or other health care providers?</p> <p><i>If Yes to S5q13:</i></p> <p>S5q13a When you (or S.C.) needed an interpreter, how often were you able to get someone other than a family member to help you speak with (his/her) doctors or other health care providers?</p>	<p>(1) YES [SKIP TO S5Q13A] (2) NO [SKIP TO C6Q07] (6) DON’T KNOW [SKIP TO C6Q07] (7) REFUSED [SKIP TO C6Q07]</p> <p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>

**2005/2006 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

APPENDIX B_2: SPSS User Resources

Programming Code and Other Resources
for Medical Home Measurement

National Survey of Children with Special Health Care Needs (NS-CSHCN)

Weighted estimates* for Medical Home composite measure, the five sub-component scores and associated interim variables

	2001 NS-CSHCN	2005/06 NS-CSHCN	
	% CSHCN ages 0-17*	% CSHCN ages 0-17*	NOTES*
Meet overall criteria for having a Medical Home:	52.6	47.1	
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER			
1) <u>Child has a “personal doctor or nurse”</u>	89.0	93.5	1) Revised question wording used in 2005/06
ACCESSIBLE	--	--	--
FAMILY CENTERED			
2) <u>Child’s doctors and other health providers do each of the following:</u>	64.2	62.4	
a. <u>Usually or always</u> spend enough time with child and parent	80.0	74.7	f. New question on interpreter services added in 2005/06; only asked for households where primary language is not English
b. <u>Usually or always</u> listen carefully to child and parent	84.5	84.3	
c. <u>Usually or always</u> sensitive to family’s values and customs	82.2	84.4	
d. <u>Usually or always</u> provide needed information	77.4	78.9	
e. <u>Usually or always</u> make family feel like a partner in child’s care	82.2	83.2	
AND			
f. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	--	0.8	
CONTINUOUS	--	--	
COMPREHENSIVE			
3) <u>IF needed, no problems obtaining referrals</u>	38.8	26.0	3) Significant changes were made in 2005/06 to the question wording, placement, and skip patterns use to assess problems obtaining needed referrals
a. Needed referral during past 12 months	49.6	33.0	
4) <u>Have usual source(s) for both sick and well care</u>	90.5	92.9	
a. Child has a usual source for sick care	90.6	94.3	
b. Child has a usual source for preventive care	98.8	97.1	
COORDINATED			
5) <u>IF needed, gets effective care coordination</u>	4.5	46.0	5) Significant changes were made in 2005/06 in the content, wording, placement, and skip patterns of the questions used to assess effective care coordination
a. <u>Needed and received</u> professional help with care coordination	9.5	--	
b. <i>IF needed</i> care coordination, <u>excellent</u> communication btw doctors	5.1	--	
c. <i>IF needed</i> care coordination, doctor communication with school or other programs the child attends is <u>excellent</u>	3.0	--	
d. <u>Needed and usually got</u> extra help with care coordination	--	30.4	
e. <i>IF needed</i> , <u>very satisfied</u> with communication btw doctors	--	41.8	
f. <i>IF needed</i> , <u>very satisfied</u> with how doctors communicate with school or other programs the child attends	--	14.1	
COMPASSIONATE			Assessed under the Family Centered Care component†
CULTURALLY EFFECTIVE			Assessed under the Family Centered Care component†

* All estimated percentages are weighted to represent the U.S. non-institutionalized population of CSHCN ages 0-17 years

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.

-- Not assessed by the survey.

**2005/2006 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*SPSS Medical Home
scoring program*

Measuring Medical Home using Data Elements from the 2005/06 National Survey of Children with Special Health Care Needs (NS-CSHCN)

SPSS scoring program variable names for the five sub-component scores and
associated interim variables used to derive the Medical Home composite measure

2005/06 NS-CSHCN		
	SPSS Variable names	Survey items or interim variables used to construct:
Meet overall criteria for having a Medical Home:	MH_COMP	[PDN; FAMCENT; NOREFPRB; USUAL; CARECOOR]
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER		
1) <u>Child has at least one “personal doctor or nurse”</u>	PDN	C4q02a
ACCESSIBLE		
FAMILY CENTERED		
2) <u>Child’s doctors and other health providers do each of the following:</u>	FAMCENT	[TIME; LISTEN; SENSITIV; INFO; PARTNER; INTERPRET]
a. <u>Usually or always</u> spend enough time with child and parent	TIME	C6q02
b. <u>Usually or always</u> listen carefully to child and parent	LISTEN	C6q03
c. <u>Usually or always</u> sensitive to family’s values and customs	SENSITIV	C6q04
d. <u>Usually or always</u> provide needed information	INFO	C6q05
e. <u>Usually or always</u> make family feel like a partner in child’s care	PARTNER	C6q06
f. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	INTERPRET	S5q13; S5q13a
CONTINUOUS		
COMPREHENSIVE		
3) <u>IF needed, no problems obtaining referrals</u>	NOREFPRB	C5q11; C4q07
4) <u>Usual source(s) for both sick and well care</u>	USUAL	[SICK; WELL]
a. Child has a usual source for sick care	SICK	C4q0a; C4q0b
b. Child has a usual source for preventive care	WELL	C4q0d; C4q01; C4q02
COORDINATED		
5) <u>Gets effective care coordination when needed</u>	CARECOOR	[CAREHLP; DRCOMM; OTHERCOMM]
a. <i>Needed and usually got</i> extra help with care coordination	CAREHLP	C5q12, C5q17; C5q09
b. <i>IF needed, very satisfied</i> with communication btw doctors	DRCOMM	C5q10
c. <i>IF needed, very satisfied</i> with how doctors communicate with school or other programs the child attends	OTHERCOMM	C5q05; C5q06
COMPASSIONATE		
<i>Assessed under the Family Centered Care component†</i>		
CULTURALLY EFFECTIVE		
<i>Assessed under the Family Centered Care component†</i>		

-- Not assessed by the survey.

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes

2005/06 NS-CSHCN MEDICAL HOME Composite measure	
Survey Items Used	C4Q02a, C6Q02 – C6Q06, S5Q13, S5Q13a, C5Q11, C4Q07, C4Q0a, C4Q0b, C4Q0d, C4Q01, C4Q02, C5Q12, C5Q17, C5Q09, C5Q10, C5Q05, C5Q06
Numerator	Children with special health care needs (CSHCN) meeting scoring criteria for having a Medical Home
Denominator	Children with special health care needs (CSHCN) ages 0–17 years
Description	Percent of CSHCN ages 0–17 who have a primary care provider (e.g. personal doctor or nurse) AND usual sources for both sick and preventive care AND consistently get family-centered care from their doctors and other health care providers AND, if needed, receive effective care coordination AND, if needed, no problems getting referrals
Notes for Data-Users	
<p>The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of “medical home”. According to this definition, children ideally should have access to “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home.”</p> <p>The presence of medical home for CSHCN is one of the six performance measures or outcomes that states submit as part of the Title V Block Grant reporting requirements. The final medical home composite score used to measure this outcome is derived from the five sub-components constructed below.</p>	
SPSS Code and Annotation	
<p>*****Personal doctor or nurse (PDN) Component *****</p> <p>***PERSONAL DOCTOR or NURSE sub-component of MEDICAL HOME composite measure</p> <p>COMPUTE pdn = 99. IF (c4q02a = 1) pdn = 1. IF (c4q02a = 2) pdn = 1. IF (c4q02a = 3) pdn = 0. EXECUTE. VARIABLE LABEL pdn 'Personal Doctor or Nurse sub-component of MEDICAL HOME composite measure'. VALUE LABEL pdn 0 'Do not have a personal dr or nurse' 1 'Yes, have a personal dr or nurse' 99 'DK/REF/MISSING'. RECODE pdn (99=SYSMIS).</p>	

***** Family Centered Care Component *****

*** FAMILY-CENTERED CARE sub-component of MEDICAL HOME composite measure
 ***** Step 1: The following syntax sets up the interim variables used to derive the overall score
 for "Family-Centered Care" sub-component of MEDICAL HOME composite measure

MISSING VALUES c6q01r ().
 EXECUTE.

COMPUTE time = 99.
 IF (c6q02 = 1 or c6q02 = 2) time = 0.
 IF (c6q02 = 3 or c6q02 = 4) time = 1.
 IF (sysmis (c6q02)) time = 2.
 EXECUTE.
 VAR LABEL time 'Drs/other health providers spend enough time (c6q02 recoded)'.
 VALUE LABEL time
 0 'Never/sometimes'
 1 'Usually/always'
 2 'No dr visits past 12 mos'
 99 'DK/Ref'.

COMPUTE listen = 99.
 IF (c6q03 = 1 or c6q03 = 2) listen = 0.
 IF (c6q03 = 3 or c6q03 = 4) listen = 1.
 IF (sysmis (c6q03)) listen = 2.
 EXECUTE.
 VAR LABEL listen 'Drs/other health providers listen well (c6q03 recoded)'.
 VALUE LABEL listen
 0 'Never/sometimes'
 1 'Usually/always'
 2 'No dr visits past 12 mos'
 99 'DK/Ref'.

COMPUTE sensitiv = 99.
 IF (c6q04 = 1 or c6q04 = 2) sensitiv = 0.
 IF (c6q04 = 3 or c6q04 = 4) sensitiv = 1.
 IF (sysmis (c6q04)) sensitiv = 2.
 EXECUTE.
 VAR LABEL sensitiv 'Drs/other health providers sensitive to family values/customs (c6q04 recoded)'.
 VALUE LABEL sensitiv
 0 'Never/sometimes'
 1 'Usually/always'
 2 'No dr visits past 12 mos'
 99 'DK/Ref'.

COMPUTE info = 99.
 IF (c6q05 = 1 or c6q05 = 2) info = 0.
 IF (c6q05 = 3 or c6q05 = 4) info = 1.
 IF (sysmis (c6q05)) info = 2.
 EXECUTE.
 VAR LABEL info 'Drs/other health providers provide needed information (c6q05 recoded)'.
 VALUE LABEL info
 0 'Never/sometimes'
 1 'Usually/always'
 2 'No dr visits past 12 mos'
 99 'DK/Ref'.

```

COMPUTE partner = 99.
IF (c6q06 = 1 or c6q06 = 2) partner = 0.
IF (c6q06 = 3 or c6q06 = 4) partner = 1.
IF (sysmis (c6q06)) partner = 2.
EXECUTE.
VAR LABEL partner 'Drs/other health providers make family feel like a partner (c6q06 recoded)'.
VALUE LABEL partner
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

```

```

RECODE
S5q13A (SYSMIS = 999).
EXECUTE .

```

```

COMPUTE interpret = 99.
IF (S5q13A = 1 or S5q13A = 2) interpret = 0.
IF (S5q13A = 3 or s5q13A = 4) interpret = 1.
IF (S5q13A = 999) interpret = 2.
EXECUTE.
VAR LABEL interpret "Able to get interpreter if needed during ch's dr visits".
VALUE LABEL interpret
0 'Never/sometimes'
1 'Usually/always'
2 'Does not need interpreter'
99 'DK/Ref'.

```

***** Step 2: Construct "Family-Centered Care" sub-component of MEDICAL HOME composite measure

```

COMPUTE famcent = 99.
IF (time = 0) or (listen = 0) or (sensitiv = 0) or (info = 0) or (partner = 0) or (interpret = 0) famcent = 0.
IF (time = 1 or time = 2) and (listen = 1 or listen = 2) and (sensitiv = 1 or sensitiv = 2) and (info = 1 or info = 2)
and (partner = 1 or partner = 2) and ((interpret = 1) or (interpret = 1 or interpret = 2)) famcent = 1.
IF (time = 99 or listen = 99 or sensitiv = 99 or info = 99 or partner = 99 or interpret = 99) famcent = 99.
IF (c6q01r = 0) famcent = 2.
EXECUTE.
VARIABLE LABEL famcent 'Family-Centered Care sub-component of MEDICAL HOME composite
measure'.
VALUE LABEL famcent
0 'Does NOT have fcc'
1 'Yes, has fcc'
2 'Legitimate skip - no dr visit past 12 mos'
99 'DK/Ref to any'.
RECODE famcent (99=SYSMIS).

```

*****Comprehensive Care Component*****

*** GETTING NEEDED REFERRALS sub-component of MEDICAL HOME composite measure

***** Construct "No Problems Getting Needed Referrals " sub-component of MEDICAL HOME composite measure

RECODE C4Q07 (SYSMIS=999).
EXECUTE .

COMPUTE norefprb= 99.
IF (c4q07 = 1) or (c4q07 = 2)norefprb= 0.
IF (c4q07 = 3) norefprb= 1.
IF (c5q11 = 0) norefprb= 2.
VAR LABEL norefprb 'Getting Needed Referrals sub-component of MEDICAL HOME composite measure'.
VALUE LABEL norefprb
0 'Big or small problem getting referral, when needed'
1 'No problems getting referral, when needed'
99 'DK/REF/MISSING'.
2 'Legitimate skip b/c referrals are not needed'.
RECODE norefprb (99=SYSMIS).

***USUAL SOURCES FOR SICK AND WELL CARE sub-component of MEDICAL HOME composite measure

***** Step 1: The following syntax sets up the interim variables used to derive the overall score for "Usual Sources for Sick and Well Care" sub-component of MEDICAL HOME composite measure

COMPUTE sick = 99.
IF ((C4q0br = 1 or C4q0br = 3 or C4q0br = 4 or C4q0br = 5 or C4q0br = 6 or C4q0br = 8 or C4q0br =10))
sick = 1.
IF (c4q0a = 2) or ((c4q0br = 2 or c4q0br = 7 or c4q0br = 9)) sick = 0.
IF ((c4q0a = 6) or (c4q0a = 7)) or ((c4q0br = 96) or (c4q0br = 97)) sick = 99.
EXECUTE.
VARIABLE LABEL sick 'Ch. has usual place for sick care'.
VALUE LABEL sick
0 'No or ER or Mexico or no one place most often'
1 'Yes'
99 'DK/REF/MISSING'.

COMPUTE well = 99.
IF ((c4q0d= 1) or (c4q0d = 3)) and ((sick = 1) and (c4q01 = 1)) or (c4q02r = 1 or c4q02r = 3 or c4q02r = 4
or c4q02r = 5 or c4q02r= 6 or c4q02r = 8) well = 1.
IF (sick = 0) and (c4q01 = 1) well = 0.
IF (c4q0d = 2) or (c4q02r = 2 or c4q02r = 7 or c4q02r = 9) well = 0.
IF ((c4q0d= 1) or (c4q0d = 3)) and ((sick = 99) and (c4q01 = 1)) well = 99.
IF ((c4q0d= 1) or (c4q0d = 3)) and (c4q01 = 6 or c4q01 = 7) well = 99.
IF (c4q0d = 6 or c4q0d = 7) or (c4q02r = 96 or c4q02r = 97) well = 99.
EXECUTE.
VARIABLE LABEL well 'Ch. has usual place for well care'.
VALUE LABEL well
0 'No or ER or Mexico or no one place most often'
1 'Yes'
99 'DK/REF/MISSING'.

***** Step 2: Construct "Usual Sources for Sick and Well Care " sub-component of MEDICAL HOME composite measure

```

COMPUTE usual = 99.
IF (sick = 1 or sick = 99) and (well = 1 or well = 99) usual = 1.
IF (sick = 0) or (well = 0) usual = 0.
IF (well = 99) or (sick = 99) usual = 99.
EXECUTE.
EXECUTE .
VARIABLE LABEL usual ' Usual Sources for Sick and Well Care sub-component of MEDICAL HOME composite measure'.
VALUE LABEL usual
0 'Ch. does not have usual sources for sick and well care'
1 'Ch. DOES have usual sources for sick and well care'
99 'DK/REF/MISSING to all'.
RECODE usual (99=SYSMIS).

```

*****Coordinated Care Component *****

***EFFECTIVE CARE COORDINATION sub-component of MEDICAL HOME composite measure

***** Step 1: The following syntax sets up the interim variables used to derive the overall score for "Effective Care Coordination" sub-component of MEDICAL HOME composite measure

```

MISSING VALUES C5Q17 C5Q09 C5Q12 ().

```

```

RECODE
  C5Q17 C5Q09 C5Q12 (MISSING=999).
EXECUTE.
VALUE LABELS c5q09
1 'Never'
2 'Sometimes'
3 'Usually'
4 'Always'
6 'DK'
7 'Refused'
999 'SYSMIS'.
VALUE LABELS c5q17 c5q12
0 'No'
1 'Yes'
6 'DK'
7 'Refused'
999 'SYSMIS'.

```

** The variable TEST09 in the code below refers to a "patch" variable created to accommodate update changes made by NCHS to the missing cases status for C5Q09 prior to releasing the public use file for the 2005/06 NS-CSHCN. SPSS users will need this patch variable in order to successfully replicate the Effective Care Coordination sub-component. Contact cahmi@ohsu.edu to obtain a copy of the patch variable.

```

COMPUTE c5q09r = 99.
IF (C5Q09 = 1) c5q09r = 1.
IF (C5Q09 = 2) c5q09r = 2.
IF (C5Q09 = 3) c5q09r = 3.
IF (C5Q09 = 4) c5q09r = 4.
IF (C5Q09 = 6) c5q09r = 6.
IF (C5Q09 = 999) and (test09 = 0) c5q09r = 999.
IF (C5Q09 = 999) and (test09 = 1) c5q09r = 99.
EXECUTE.

```



```

COMPUTE carehlp = 99.
IF (C5Q12 = 1) and ( C5Q17 = 0) carehlp = 1.
IF (C5Q09r = 3 or C5Q09r = 4) carehlp = 1.
IF (C5Q09r = 1 or C5Q09r = 2) carehlp = 0.
IF (C5q12 = 0) and (C5q17 = 0) carehlp = 2.
IF (c5q12 = 999) carehlp = 2.
IF (C5Q09r = 6 or C5Q09r = 7) carehlp = 99.
IF (c5q12 = 6 or C5q12 = 7) and (C5q17 = 0) carehlp = 99.
IF (c5q09r = 6) or (C5q17 = 6 or c5q17 = 7) carehlp = 99.
IF (c5q09r = 99) carehlp = 99.
EXECUTE.
VAR LABEL carehlp 'Got some type of help with care coor'.
VALUE LABEL carehlp
0 'Needed extra help/did not get it'
1 'Gets help with care coor'
2 'Legit skip -- <2 services or did not need extra help'
99 'DK/Ref to any or MISSING'.

COMPUTE need_drcomm = 99.
IF (C4q05x02a = 1 or C4q05x02c = 1) or (C4q05x05a = 1 or C4q05x05c = 1) or (C4q05x06a = 1 or
C4q05x06c = 1)
or (C4q05x07a = 1 or C4q05x07c = 1) or (C4q05x08a = 1 or C4q05x08c = 1) need_drcomm = 1.
IF (C4q05_x02 = 0 or C4q05x02c = 0) and (C4q05_x05 = 0 or C4q05x05c = 0) and (C4q05_x06 = 0 or
C4q05x06c = 0)
and (C4q05_x07 = 0 or C4q05x07c = 0 or (SYSMISS (C4q05_x07))) and (C4q05_x08 = 0 or C4q05x08c =
0) need_drcomm = 0.
EXECUTE.
VAR LABEL need_drcomm 'Used some or all specialist care, MH, PT/OT/Speech, sub abuse, or home
hlth care'.
VALUE LABEL need_drcomm
1 'Used 1 or more services for dr comm denominator'
0 'Did not use services for dr comm denominator'
99 'DK/Ref'.

MISSING VALUES C5q10 ().

RECODE
C5q10 (SYSMIS = 999).
EXECUTE.
VALUE LABEL c5q10
1 'Very satisfied'
2 'Somewhat satisfied'
3 'Somewhat dissatisfied'
4 'Very dissatisfied'
5 'No communication needed or wanted'
6 'DK'
7 'Refused'
999 'SYSMISS'.

```

```

COMPUTE drcomm = 99.
IF (C5q10 = 1) and (need_drcomm = 1) drcomm = 1.
IF (C5q10 = 2 or C5q10 = 3 or C5q10 = 4) and (need_drcomm = 1) drcomm = 0.
IF (C5q10 = 5) and (need_drcomm = 1) drcomm = 2.
IF (C5q10 = 6 or C5q10 = 7) and (need_drcomm = 1) drcomm = 99.
IF (C5q10 = 999) drcomm = 2.
IF (test09 = 1 or test10 = 1) drcomm = 99.
IF (need_drcomm = 0) drcomm = 2.

IF (need_drcomm = 99) drcomm = 99.
EXECUTE.
VAR LABEL drcomm 'Level of satisfaction with dr to dr communication'.
VALUE LABEL drcomm
0 'Less than very satisfied'
1 'Very satisfied'
2 'Legit skip -- no comm needed or did not use required services'
99 'DK/Ref to any'.

MISSING VALUES c5q05 c5q06 (.).

RECODE
C5q06 C5q05 (SYSMIS = 999).
EXECUTE.
VALUE LABEL c5q06
1 'Very satisfied'
2 'Somewhat satisfied'
3 'Somewhat dissatisfied'
4 'Very dissatisfied'
5 'No communication needed or wanted'
6 'DK'
7 'Refused'
999 'SYSMISS'.
VALUE LABEL c5q05
0 'No'
1 'Yes'
6 'DK'
7 'Refused'
999 'SYSMISS'.

COMPUTE othercomm = 99.
IF (C5q05 = 0) othercomm = 2.
IF (C5q05 = 6 or C5Q05 = 7) othercomm = 99.
IF (C5q05 = 999) othercomm = 2.
IF (test09 = 1) or (test10 = 1) othercomm = 99.
IF (C5q06 = 1) othercomm = 1.
IF (C5q06 = 2 or C5q06 = 3 or C5q06 = 4) othercomm = 0.
IF (C5q06 = 6 or C5q06 = 7) othercomm = 99.
EXECUTE.
VAR LABEL othercomm 'If needed, level of satisfaction w/ dr comm to other providers or programs'.
VALUE LABEL othercomm
0 'Less than very satisfied'
1 'Very satisfied'
2 'Legit skip -- used >2 services'
99 'DK/Ref to any'.

```

***** Step 2: Construct "EFFECTIVE CARE COORDINATION " sub-component of MEDICAL HOME composite measure

```

COMPUTE carecoor = 99.
IF ((carehlp = 1) or (carehlp = 2)) and ((drcomm = 1) or (drcomm = 2)) and ((othercomm = 1) or
(othercomm = 2)) carecoor = 1.
IF (carehlp = 0) or (drcomm = 0) or (othercomm = 0) carecoor = 0.
IF (carehlp = 2) and (drcomm = 2) and (othercomm = 2) carecoor = 2.
IF (carehlp = 99) or (drcomm = 99) or (othercomm = 99) carecoor = 99.
EXECUTE.
VAR LABEL carecoor 'Effective Care Coordination sub-component of MEDICAL HOME composite
measure'.
VALUE LABEL carecoor
0 'Did not meet 1 or more needed elements of care coor'
1 'Met all needed components of care coor or legitimate skip'
2 'Legit skip -- no one helps with care coor or >2 services used past 12 mos'
99 'DK/REF/MISSING to any'.
RECODE carecoor (99=SYSMIS).

```

***** MEDICAL HOME COMPOSITE MEASURE*****

***The following code uses the five sub-components created above to derive the MEDICAL HOME composite measure using the ON EVERY scoring approach

```

COMPUTE mh_comp= 999.
IF (pdn = 1) and (usual = 1) and (carecoor = 1 or carecoor = 2) and (noreferpblm = 1 or noreferpblm = 2)
and (famcent = 1 or famcent = 2) mh_comp = 1.
IF (pdn = 0) or (usual = 0) or (carecoor = 0) or (noreferpblm = 0) or (famcent = 0) mh_comp = 0.
IF ((SYSMIS (pdn)) or (SYSMIS (usual)) or (SYSMIS (famcent)) or (SYSMIS (noreferpblm)) or (SYSMIS
(carecoor))) mh_comp =99.
EXECUTE.

```

```

VAR LABEL mh_comp '% CSHCN receiving coordinated, ongoing, comprehensive care within a medical
home' .
VALUE LABEL mh_comp
0 'Care DOES NOT meet medical home criteria'
1 'Care MEETS medical home criteria'
99 'DK/Ref to any'.
MISSING VALUES mh_comp (99).
FORMATS mh_comp(f2.0).

```

**2005/2006 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*Unweighted frequency distributions for the
Medical Home sub-components, related interim variables and
composite measure generated by the
SPSS scoring program*

Personal Doctor or Nurse (PDN) Component

**PDN sub-component score (PDN)

pdn Personal Doctor or Nurse sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Do not have a personal dr or nurse	2300	5.6	5.7	5.7
	1 Yes, have a personal dr or nurse	38358	94.2	94.3	100.0
	Total	40658	99.8	100.0	
Missing	System	65	.2		
Total		40723	100.0		

Family-Centered Care Component

**Interim variables for Family-Centered Care sub-component

time Drs/other health providers spend enough time (c6q02 recoded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	7478	18.4	18.4	18.4
	1 Usually/always	31287	76.8	76.8	95.2
	2 No dr visits past 12 mos	1808	4.4	4.4	99.6
	99 DK/Ref	150	.4	.4	100.0
Total		40723	100.0	100.0	

listen Drs/other health providers listen well (c6q03 recoded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	3990	9.8	9.8	9.8
	1 Usually/always	34819	85.5	85.5	95.3
	2 No dr visits past 12 mos	1808	4.4	4.4	99.7
	99 DK/Ref	106	.3	.3	100.0
Total		40723	100.0	100.0	

sensitiv Drs/other health providers sensitive to family values/customs (c6q04 recorded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	3809	9.4	9.4	9.4
	1 Usually/always	34746	85.3	85.3	94.7
	2 No dr visits past 12 mos	1808	4.4	4.4	99.1
	99 DK/Ref	360	.9	.9	100.0
	Total	40723	100.0	100.0	

info Drs/other health providers provide needed information (c6q05 recorded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	6406	15.7	15.7	15.7
	1 Usually/always	32367	79.5	79.5	95.2
	2 No dr visits past 12 mos	1808	4.4	4.4	99.7
	99 DK/Ref	142	.3	.3	100.0
	Total	40723	100.0	100.0	

partner Drs/other health providers make family feel like a partner (c6q06 recorded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	4445	10.9	10.9	10.9
	1 Usually/always	34380	84.4	84.4	95.3
	2 No dr visits past 12 mos	1808	4.4	4.4	99.8
	99 DK/Ref	90	.2	.2	100.0
	Total	40723	100.0	100.0	

interpret Able to get interpreter if needed during ch's dr visits

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	172	.4	.4	.4
	1 Usually/always	248	.6	.6	1.0
	2 Does not need interpreter	40302	99.0	99.0	100.0
	99 DK/Ref	1	.0	.0	100.0
	Total	40723	100.0	100.0	

Family-Centered Care sub-component score (FAMCENT**)

famcent Family-Centered Care sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Does NOT have fcc	12332	30.3	30.8	30.8
	1 Yes, has fcc	25910	63.6	64.7	95.5
	2 Legitimate skip - no dr visit past 12 mos	1808	4.4	4.5	100.0
	Total	40050	98.3	100.0	
Missing	System	673	1.7		
Total		40723	100.0		

Comprehensive Care Component

** No Problems Getting Needed Referrals sub-component score (**NOREFPRB**)

norefprb Getting Needed Referrals sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Big or small problem getting referral, when needed	2683	6.6	6.6	6.6
	1 No problems getting referral, when needed	10675	26.2	26.4	33.0
	2	27101	66.5	67.0	100.0
	Total	40459	99.4	100.0	
Missing	System	264	.6		
Total		40723	100.0		

**Interim variables Usual Sources for Sick and Well Care sub-component

sick Ch. has usual place for sick care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No or ER or Mexico or no one place most often	2108	5.2	5.2	5.2
	1 Yes	38506	94.6	94.6	99.7
	99 DK/REF/MISSING	109	.3	.3	100.0
	Total	40723	100.0	100.0	

well Ch. has usual place for well care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No or ER or Mexico or no one place most often	1118	2.7	2.7	2.7
	1 Yes	39508	97.0	97.0	99.8
	99 DK/REF/MISSING	97	.2	.2	100.0
	Total	40723	100.0	100.0	

Usual Sources for Sick and Well Care sub-component score (USUAL**)

usual Usual Sources for Sick and Well Care sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Ch. does not have usual sources for sick and well care	2721	6.7	6.7	6.7
	1 Ch. DOES have usual sources for sick and well care	37830	92.9	93.3	100.0
	Total	40551	99.6	100.0	
Missing	System	172	.4		
	Total	40723	100.0		

Coordinated Care Component

**Interim variables Effective Care Coordination sub-component

c5q09r

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	2796	6.9	6.9	6.9
	2	2755	6.8	6.8	13.6
	3	1456	3.6	3.6	17.2
	6	24	.1	.1	17.3
	99	72	.2	.2	17.4
	999	33620	82.6	82.6	100.0
	Total	40723	100.0	100.0	

carehlp Got some type of help with care coor

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Needed extra help/did not get it	5551	13.6	13.6	13.6
	1 Gets help with care coor	12252	30.1	30.1	43.7
	2 Legit skip -- <2 services or did not need extra help	22619	55.5	55.5	99.3
	99 DK/Ref to any or MISSING	301	.7	.7	100.0
	Total	40723	100.0	100.0	

need_drcomm Used some or all specialist care, MH, PT/OT/Speech, sub abuse, or home hlth care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not use services for dr comm denominator	13466	33.1	33.1	33.1
	1 Used 1 or more services for dr comm denominator	27073	66.5	66.5	99.5
	99 DK/Ref	184	.5	.5	100.0
	Total	40723	100.0	100.0	

drcomm Level of satisfaction with dr to dr communication

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Less than very satisfied	9636	23.7	23.7	23.7
	1 Very satisfied	17070	41.9	41.9	65.6
	2 Legit skip -- no comm needed or did not use required services	13749	33.8	33.8	99.3
	99 DK/Ref to any	268	.7	.7	100.0
	Total	40723	100.0	100.0	

othercomm If needed, level of satisfaction w/ dr comm to other providers or programs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Less than very satisfied	5387	13.2	13.2	13.2
	1 Very satisfied	5690	14.0	14.0	27.2
	2 Legit skip -- used >2 services	29256	71.8	71.8	99.0
	99 DK/Ref to any	390	1.0	1.0	100.0
	Total	40723	100.0	100.0	

****Effective Care Coordination sub-component score (CARECOOR)****carecoor Effective Care Coordination sub-component of MEDICAL HOME composite measure**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not meet 1 or more needed elements of care coor	12576	30.9	31.6	31.6
	1 Met all needed components of care coor or legitimate skip	18395	45.2	46.2	77.8
	2 Legit skip -- no one helps with care coor or >2 services used past 12 mos	8862	21.8	22.2	100.0
	Total	39833	97.8	100.0	
Missing	System	890	2.2		
	Total	40723	100.0		

Medical Home Composite Measure

**Medical Home Composite Measure score (MH_COMP)

mh_comp % CSHCN receiving coordinated, ongoing, comprehensive care within a medical home

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Care DOES NOT meet medical home criteria	19909	48.9	51.2	51.2
	1 Care MEETS medical home criteria	18977	46.6	48.8	100.0
	Total	38886	95.5	100.0	
Missing	99 DK/Ref to any	1837	4.5		
Total		40723	100.0		

**2005/2006 NATIONAL SURVEY OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

*Full text and response options for questions
used to assess Medical Home*

2005/06 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<u>SECTION 4: ACCESS TO CARE -- UTILIZATION AND UNMET NEEDS</u>	
<p>C4q0a Is there a place that (S.C.) USUALLY goes when (he/she) is sick or you need advice about (his/her) health?</p> <p><i>If Yes to C4q0a:</i></p> <p>C4q0b Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?</p>	<p>(1) YES (2) THERE IS NO PLACE [SKIP TO C4Q0D] (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW [SKIP TO C4Q0D] (7) REFUSED [SKIP TO C4Q0D]</p> <p>(01) DOCTOR'S OFFICE [SKIP TO C4Q0D] (02) HOSPITAL EMERGENCY ROOM [SKIP TO C4Q0D] (03) HOSPITAL OUTPATIENT DEPARTMENT [SKIP TO C4Q0D] (04) CLINIC OR HEALTH CENTER [SKIP TO C4Q0D] (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) [SKIP TO C4Q0D] (06) FRIEND/RELATIVE [SKIP TO C4Q0D] (07) MEXICO/OTHER LOCATIONS OUT OF US [SKIP TO C4Q0D] (08) SOME OTHER PLACE [SKIP TO C4Q0C] (09) DOES NOT GO TO ONE PLACE MOST OFTEN [SKIP TO C4Q0D] (96) DON'T KNOW [SKIP TO C4Q0D] (97) REFUSED [SKIP TO C4Q0D]</p>
<p>C4q0d Is there a place that (S.C.) USUALLY goes when (he/she) needs routine preventive care, such as a physical examination or well-child check-up?</p> <p><i>If Yes to C4q0d:</i></p> <p>C4q01 Is the [place selected in C4q0b] that (S.C.) goes to when (he/she) is sick the same place (S.C.) usually goes for routine preventive care?</p>	<p>(1) YES [SKIP TO C4Q02A] (2) THERE IS NO PLACE [SKIP TO C4Q02A] (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A]</p> <p>(1) YES [SKIP TO C4Q02A] (2) NO (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A]</p>
<p>C4q02 What kind of place does (S.C.) go to most often when (he/she) needs routine preventive care?</p>	<p>(01) DOCTOR'S OFFICE (02) HOSPITAL EMERGENCY ROOM (03) HOSPITAL OUTPATIENT DEPARTMENT (04) CLINIC OR HEALTH CENTER (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (06) FRIEND/RELATIVE (07) MEXICO/OTHER LOCATIONS OUT OF US (08) SOME OTHER PLACE [SKIP TO C4Q02_1] (09) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED</p>

2005/06 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<p>C4q02a A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as (S.C.)'s personal doctor or nurse?</p>	<p>(1) YES, ONE PERSON (2) YES, MORE THAN ONE PERSON (3) NO (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C4Q03] [SKIP TO C4Q03] [SKIP TO C4Q03]</p>
SECTION 5: CARE COORDINATION	
<p>C5q11 During the past 12 months, did (S.C.) need a referral to see any doctors or receive any services?</p> <p><i>If Yes to C5q11:</i> C4q07 Was getting referrals a big problem, a small problem, or not a problem?</p>	<p>(1) YES (2) NO (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C5Q12] [SKIP TO C5Q12] [SKIP TO C5Q12]</p> <p>(1) Big problem (2) Small problem (3) Not a problem (6) DON'T KNOW (7) REFUSED</p>
<p>C5q17 During the past 12 months, have you felt that you could have used extra help arranging or coordinating (S.C.)'s care among these different health care providers or services?</p> <p><i>If Yes to C5q17:</i> C5q09 During the past 12 months, how often did you get as much help as you wanted with arranging or coordinating (S.C.)'s care?</p>	<p>(1) YES (2) NO (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C5Q10] [SKIP TO C5Q10] [SKIP TO C5Q10]</p> <p>(1) Never (2) Sometimes (3) Usually (6) DON'T KNOW (7) REFUSED</p>
<p>C5q10 Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among (S.C.)'s doctors and other health care providers?</p>	<p>(1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied (5) NO COMMUNICATION NEEDED OR WANTED (6) DON'T KNOW (7) REFUSED</p>

2005/06 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<p>C5q05 Do (S.C.)’s doctors or other health care providers need to communicate with (his/her) school, early intervention program, child care providers, vocational education or rehabilitation program?</p> <p><i>If Yes to C5q05:</i></p> <p>C5q06 Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication?</p>	<p>(1) YES (2) NO (6) DON’T KNOW (7) REFUSED</p> <p>[SKIP TO C6Q02] [SKIP TO C6Q02] [SKIP TO C6Q02]</p> <p>(1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied (6) DON’T KNOW (7) REFUSED</p>
<u>SECTION 6A: FAMILY CENTERED CARE</u>	
<p>C6q02 During the past 12 months, how often did (S.C.)’s doctors and other health care providers spend enough time with (him/her)?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>
<p>C6q03 During the past 12 months, how often did (S.C.)’s doctors and other health care providers listen carefully to you?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>
<p>C6q04 When (S.C.) is seen by doctors or other health care providers, how often are they sensitive to your family’s values and customs?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>
<p>C6q05 During the past 12 months, how often did you get the specific information you needed from (S.C.)’s doctors and other health care providers?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>

2005/06 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<p>C6q06 During the past 12 months, how often did (S.C.)’s doctors or other health care providers help you feel like a partner in (his/her) care?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>
<p>S5q13 During the past 12 months, did you (or S.C.) need an interpreter to help speak with (his/her) doctors or other health care providers?</p> <p><i>If Yes to S5q13:</i> S5q13a When you (or S.C.) needed an interpreter, how often were you able to get someone other than a family member to help you speak with (his/her) doctors or other health care providers?</p>	<p>(1) YES (2) NO (6) DON’T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO S5Q13A] [SKIP TO C6Q07] [SKIP TO C6Q07] [SKIP TO C6Q07]</p> <p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED</p>

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

APPENDIX C_1: SAS User Resources

Programming Code and Other Resources
for Medical Home Measurement

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

*Weighted Estimates for Medical Home composite measure,
the six sub-component scores and associated
interim variables*

2003 National Survey of Children's Health (NSCH)

Weighted estimates* for Medical Home composite measure, the six sub-component scores
and associated interim variables

2003 NSCH			
	% all children ages 0-17*	% CSHCN only ages 0-17*	NOTES*
Meet overall criteria for having a Medical Home:	46.1	44.2	
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER	83.3	90.0	1) Asked for all children
1) <u>Child has at least one "personal doctor or nurse"</u>			
ACCESSIBLE	--	--	
FAMILY CENTERED			
2) <u>Child's personal doctor or nurse does both of the following:</u>	65.2	73.4	2) Family centered care questions are asked only for children with at least one personal doctor or nurse
a. <u>Usually or always</u> spends enough time with child and parent	66.2	75.1	
b. <u>Usually or always</u> explains things so parent and child understand <i>AND</i>	77.6	84.1	
c. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	0.1	0.8	
CONTINUOUS	--	--	
COMPREHENSIVE			
3) <u>Preventive care visit during past 12 months</u>	77.8	86.5	3) Asked for all children
4) <u>IF needed, consistent access to urgent care and/or phone advice from personal doctor or nurse (PDN)</u>	40.1	55.3	4) & 5) Asked only for children with at least one personal doctor or nurse AND need for the specific type of care being assessed
a. <u>Usually or always</u> gets urgently needed care from PDN	23.2	36.8	
b. <u>Usually or always</u> gets needed phone advice from PDN	32.6	46.9	
5) <u>IF needed, no problems getting specialist care and/or specialized health services or equipment</u>	19.2	42.7	
a. <u>No problems</u> getting needed care from specialist doctor(s)	15.1	33.0	
b. <u>No problems</u> getting needed specialized health services or equipment	5.7	18.1	
COORDINATED			
6) <u>Gets effective care coordination when needed</u>	12.9	29.4	6) Asked only for children with at least one personal doctor or nurse AND a need for specialist care or specialized services/equip or both during the past 12 months
a. Personal doctor or nurse <u>usually or always</u> follows up with family after child gets needed care from a specialist doctor or doctors	12.0	27.6	
b. Personal doctor or nurse <u>usually or always</u> follows up with the family after child gets needed specialized health services or equipment	4.3	15.3	
COMPASSIONATE	<i>Assessed under the Family Centered Care component†</i>		
CULTURALLY EFFECTIVE	<i>Assessed under the Family Centered Care component†</i>		

* All estimated percentages are weighted to represent the U.S. non-institutionalized child population ages 0-17 years

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.

-- Not assessed by the survey.

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

SAS scoring program variable names for the six sub-component scores and associated interim variables used to derive the Medical Home composite measure

Measuring Medical Home using Data Elements from the 2003 National Survey of Children's Health (NSCH)

SAS scoring program variable names for the six sub-component scores and
associated interim variables used to derive the Medical Home composite measure

2003 NSCH		
	SAS Variable names	Survey items or variables used to construct:
MEDICAL HOME COMPOSITE MEASURE:	MH_COMP	[S5Q01; PDNCOM_2; PC_2; CARE_2; ACC_2; COOR_2]
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER		
1) <u>Child has at least one "personal doctor or nurse"</u>	S5Q01	[S5q01]
ACCESSIBLE	--	
FAMILY CENTERED		
2) <u>Child's personal doctor or nurse does both of the following:</u>	PDNCOM_2	[ADEQTIME; EXPLAIN; INTERPRT]
a. <u>Usually or always</u> spends enough time with child and parent	ADEQTIME	S5q02
b. <u>Usually or always</u> explains things so parent and child understand <i>AND</i>	EXPLAIN	S5q04
c. IF needed, interpreter services are <u>usually or always</u> available	INTERPRT	S5q13; S5q13a
CONTINUOUS	--	
COMPREHENSIVE		
3) <u>Preventive care visit during past 12 months</u>	PC_2	[S4q03r]
4) <u>IF needed, consistent access to urgent care and/or phone advice from personal doctor or nurse (PDN)</u>	CARE_2	[GETCARE; PHONEHLP]
a. <u>Usually or always</u> able to get urgently needed care from PDN	GETCARE	S5q06; S5q06a
b. <u>Usually or always</u> able to get needed phone advice from PDN	PHONEHLP	S5q07; S5q07a
5) <u>IF needed, no problems getting specialist care and/or specialized health services or equipment</u>	ACC_2	[SPECIALIST; SERVICES]
a. <u>No problems</u> getting needed care from specialist doctor(s)	SPECIAL	S5q09; S5q09a
b. <u>No problems</u> getting needed specialized health services or equipment	SERVICES	S5q10; S5q10a
COORDINATED		
6) <u>Gets effective care coordination when needed</u>	COOR_2	[FU_SPEC; FU_SERVE]
a. Personal doctor or nurse <u>usually or always</u> follows up with family after child gets needed care from a specialist doctor or doctors	FU_SPEC	S5q09c
b. Personal doctor or nurse <u>usually or always</u> follows up with the family after child gets needed specialized health services or equipment	FU_SERVE	S5q10c
COMPASSIONATE	<i>Assessed under the Family Centered Care component†</i>	
CULTURALLY EFFECTIVE	<i>Assessed under the Family Centered Care component†</i>	

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.

-- Not assessed by the survey.

MEDICAL HOME Composite Measure	How many children/youth receive health care that meets the American Academy of Pediatrics (AAP) definition of medical home?
Survey Items Used	S4Q01 and S4Q03; SA5Q01 – S5Q13a
Numerator	Children/youth meeting scoring criteria for having a Medical Home
Denominator	Children/youth ages 0–17 years
Description	Percent of children/youth ages 0–17 who have a primary care provider (e.g. personal doctor or nurse) AND one or more preventive care visits during past 12 months AND consistently received all needed care from their primary care provider.
Notes for Data-Users	
<p>The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of “medical home.” According to this definition, all children ideally should have access to “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home.”</p> <p>For additional information about the questions in the medical home section (Section 5) of the 2003 National Survey of Children’s Health, go to: www.cdc.gov/nchs/data/slaits/NSCH_Methodology_Report.pdf</p> <p>We are indebted to Deborah Rosenberg, PhD, Research Associate Professor of Epidemiology, School of Public Health, University of Illinois at Chicago, for translating the SPSS Medical Home scoring program developed by CAHMI into SAS format.</p>	
SAS Code and Annotation	
Formats	
<p>**** The following program sets the formats for the medical home sub-components, associated interim variables, and the overall medical home composite measure created by the SAS scoring program</p> <pre> proc format library = library name; value s5q0one /*format for PDN sub-component - S5Q01*/ 0 = 'No' 1 = 'Yes' 6 = 'DK' 7 = 'Refused'; value pc_tw /*format for: PREVENTIVE CARE VISIT sub-component - pc_2*/ 0 = 'Unknown' 1 = 'No preventive care visit' 2 = 'One or more prev care visits'; value subcomp /*format for HOW OFTEN sub-components*/ 0 = 'Less than usually/always' 1 = 'Usually/always'; value acc_tw /*format for ACC_2 sub-component*/ 0 = 'Problems' 1 = 'No problems'; </pre>	

```

value mh_yn /*format for MEDICAL HOME composite measure WITHOUT prev care visit added*/
0 = 'No PDN or has PDN & <75pts on 1 or more needed sub-comps'
1 = 'Has PDN & 75pts or above on every needed sub-comp';

value mh_comp /*format for MEDICAL HOME composite measure*/
1 = 'Care MEETS MEDICAL HOME definition'
2 = 'Care DOES NOT meet MEDICAL HOME definition';
run;

```

Scoring program

```

*****Personal Doctor or Nurse (PDN) Component*****

/**PERSONAL DOCTOR or NURSE sub-component of MEDICAL HOME composite measure**/

*** Note: Use question S5Q01***

*****Family Centered Care Component *****

/**Communication with PDN sub-component of MEDICAL HOME composite measure**/

/**Step 1: Set up the interim variables used to derive the Communication
with PDN sub-component of the MEDICAL HOME composite measure**/
adeqtime = .;
IF s5q02 = .L then adeqtime = .L;
if s5q02 eq 1 then adeqtime = 0;
if s5q02 eq 2 then adeqtime = 25;
if s5q02 eq 3 then adeqtime = 75;
if s5q02 eq 4 then adeqtime = 100;
if s5q02 eq 6 then adeqtime = 6;
if s5q02 eq 7 then adeqtime = 7;
if adeqtime in (6,7) then adeqtime = .;
label adeqtime = 'How often does PDN spend enough time with them';

explain = .;
if s5q04 eq 1 then explain = 0;
if s5q04 eq 2 then explain = 25;
if s5q04 eq 3 then explain = 75;
if s5q04 eq 4 then explain = 100;
if s5q04 eq 6 then explain = 6;
if s5q04 eq 7 then explain = 7;
if s5q04 in (6,7) then explain = .;
label explain = 'How often does PDN explain things so parent or ch understands';

interpr = .;
if s5q01 eq 1 and s5q13a eq 1 then interpr = 0;
if s5q01 eq 1 and s5q13a eq 2 then interpr = 25;
if s5q01 eq 1 and s5q13a eq 3 then interpr = 75;
if s5q01 eq 1 and s5q13a eq 4 then interpr = 100;
if s5q01 eq 1 and s5q13a eq 6 then interpr = 6;
if s5q01 eq 1 and s5q13a eq 7 then interpr = 7;
if interpr eq 6 then interpr = .;
if interpr eq 7 then interpr = .;
label interpr = "How often able to get needed interpreter services";

```



```

/**Step 2: Construct the "Communication with PDN" sub-component of MEDICAL HOME composite
measure**/
pdn_cnt = 0;
if adeqtime in (0,25,75,100) then pdn_cnt = pdn_cnt + 1;
if explain in (0,25,75,100) then pdn_cnt = pdn_cnt + 1;
if interprt in (0,25,75,100) then pdn_cnt = pdn_cnt + 1;
label pdn_cnt = "Number of PDN communication elements needed ";

pdn_sum = sum(adeqtime,explain,interprt);
label pdn_sum = "Total points across all needed elements of comm w/ PDN";

if pdn_cnt ne 0 then do; pdn100 = pdn_sum / pdn_cnt; end;
if pdn_cnt eq 0 then do; pdn100 = .; end;
label pdn100 = "Average score for communication with PDN sub-component of MEDICAL HOME";

pdncom_2 = .;
if pdn100 >= 0 and pdn100 <= 67 then pdncom_2 = 0;
if pdn100 >= 75 then pdncom_2 = 1;
label pdncom_2 = "PDN communication sub-component for MEDICAL HOME composite measure";

*****Comprehensive Care Component *****

/**PREVENTIVE CARE VISIT sub-component of MEDICAL HOME composite measure**/

pc_2 =0.;
if s4q01 eq 0 or s4q03r eq 0 then pc_2 = 1;
if s4q03r >= 1 then pc_2 = 2;
if s4q03r in (96,97) then pc_2 = 0;
label pc_2 = 'Preventive care visit sub-component';

/**GETTING NEEDED CARE/ADVICE sub-component of MEDICAL HOME composite measure**/

/**Step 1: The following syntax sets up the interim variables used to derive the "Getting needed care from
PDN" sub-component of MEDICAL HOME composite measure**/
phonehlp = .;
if s5q06a eq 1 then phonehlp = 0;
if s5q06a eq 2 then phonehlp = 25;
if s5q06a eq 3 then phonehlp = 75;
if s5q06a eq 4 then phonehlp = 100;
if s5q06a eq 6 then phonehlp = 6;
if s5q06a eq 7 then phonehlp = 7;
if s5q06a in (6,7) then phonehlp = .;
label phonehlp = "How often get advice over phone from ch's PDN when needed";

getcare = .;
if s5q07a eq 1 then getcare = 0;
if s5q07a eq 2 then getcare = 25;
if s5q07a eq 3 then getcare = 75;
if s5q07a eq 4 then getcare = 100;
if s5q07a eq 6 then getcare = 6;
if s5q07a eq 7 then getcare = 7;
if s5q07a in (6,7) then getcare = .;
label getcare = "How often get needed care right away from ch's PDN";

```

```

/**Step 2: Construct the "GETTING NEEDED CARE/ADVICE" sub-component of MEDICAL HOME
composite measure**/
care_cnt = 0;
if phonehlp in (0,25,75,100) then care_cnt = care_cnt + 1;
if getcare in (0,25,75,100) then care_cnt = care_cnt + 1;
label care_cnt = "Number of getting care elements needed";

care_sum = sum(phonehlp,getcare);
label care_sum = "Total points across needed elements of getting phone or urgent care from PDN";

if care_cnt ne 0 then do; care100 = care_sum / care_cnt; end;
if care_cnt eq 0 then do; care100 = .; end;
label care100 = "Average score for Getting Needed Care sub-component of MEDICAL HOME";

care_2 = .;
if care100 >= 0 and care100 <= 67 then care_2 = 0;
if care100 >= 75 then care_2 = 1;
label care_2 = "Getting Needed Care sub-component for MEDICAL HOME composite measure";

/**ACCESS to SPECIALIST CARE & SERVICES sub-component of MEDICAL HOME composite
measure**/

/**Step 1: The following syntax sets up the interim variables used to derive the "ACCESS to SPECIALIST
CARE & SERVICES" sub-component of MEDICAL HOME composite measure**/
special = .;
if s5q09a eq 1 then special = 0;
if s5q09a eq 2 then special = 25;
if s5q09a eq 3 then special = 75;
if s5q09a eq 4 then special = 100;
if s5q09a eq 6 then special = 6;
if s5q09a eq 7 then special = 7;
if s5q09a in (6,7) then special = .;
label special = "Problems getting needed care from specialist dr.";

services = .;
if s5q10a eq 1 then services = 0;
if s5q10a eq 2 then services = 25;
if s5q10a eq 3 then services = 75;
if s5q10a eq 4 then services = 100;
if s5q10a eq 6 then services = 6;
if s5q10a eq 7 then services = 7;
if s5q10a in (6,7) then services = .;
label services = "Problems getting needed services or equip";

/**Step 2: Construct the "ACCESS to SPECIALIST CARE & SERVICES" sub-component of MEDICAL
HOME composite measure**/
acc_cnt = 0;
if special in (0,25,75,100) then acc_cnt = acc_cnt + 1;
if services in (0,25,75,100) then acc_cnt = acc_cnt + 1;
label acc_cnt = "Number of access to care elements needed ";

acc_sum = sum(special,services);
label acc_sum = "Total points across accessing needed specialist care/services elements of MEDICAL
HOME";

```

```

if acc_cnt ne 0 then do; acc100 = acc_sum / acc_cnt; end;
if acc_cnt eq 0 then do; acc100 = .; end;
label acc100 = "Average score for access to needed specialist care/services sub-component of MEDICAL HOME";

acc_2 = .;
if acc100 >= 0 and acc100 <= 67 then acc_2 = 0;
if acc100 >= 75 then acc_2 = 1;
label acc_2 = "Access to needed specialist care/services sub-component for Med Home composite measure";

*****Coordinated Care Component*****

/**FOLLOW UP w/ FAMILY sub-component of MEDICAL HOME composite measure**/

/**Step 1: Set up the interim variables used to derive the FOLLOW UP w/ FAMILY sub-component of the MEDICAL HOME composite measure**/
fu_spec = .;
if s5q09c eq 1 then fu_spec = 0;
if s5q09c eq 2 then fu_spec = 25;
if s5q09c eq 3 then fu_spec = 75;
if s5q09c eq 4 then fu_spec = 100;
if s5q09c eq 6 then fu_spec = 6;
if s5q09c eq 7 then fu_spec = 7;
if s5q09c in (6,7) then fu_spec = .;
label fu_spec = "How often PDN follows up w/ family after specialist visit";

fu_serve = .;
if s5q10c eq 1 then fu_serve = 0;
if s5q10c eq 2 then fu_serve = 25;
if s5q10c eq 3 then fu_serve = 75;
if s5q10c eq 4 then fu_serve = 100;
if s5q10c eq 6 then fu_serve = 6;
if s5q10c eq 7 then fu_serve = 7;
if s5q10c in (6,7) then fu_serve = .;
label fu_serve = "How often PDN follows up w/ family after special services/equip";

/**Step2: Construct the "FOLLOW UP w/ FAMILY" sub-component of MEDICAL HOME composite measure;**/
coor_cnt = 0;
if fu_spec in (0,25,75,100) then coor_cnt = coor_cnt + 1;
if fu_serve in (0,25,75,100) then coor_cnt = coor_cnt + 1;
label coor_cnt = "Number of coor care follow up components";

coor_sum = sum(fu_spec,fu_serve);
label coor_sum = "Total points on needed follow up care elements of MEDICAL HOME";

if coor_cnt ne 0 then do; coor100 = coor_sum / coor_cnt; end;
if coor_cnt eq 0 then do; coor100 = .; end;
label coor100 = "Average score on follow up care from PDN coor care component of MEDICAL HOME";

coor_2 = .;
if coor100 >= 0 and coor100 <= 67 then coor_2 = 0;
if coor100 >= 75 then coor_2 = 1;
label coor_2 = "Coor care component for Med Home composite measure";

```

*****MEDICAL HOME Composite Measure*****

The following code uses the 6 sub-components created above to derive the MEDICAL HOME composite measure using 75pts or above on EVERY needed sub-component scoring approach**/

/Step1: Construct MEDICAL HOME composite measure WITHOUT preventive care visit criterion**/**

```

mh_cnt = 0;
if pdncom_2 in (0,1) then mh_cnt = mh_cnt + 1;
if care_2 in (0,1) then mh_cnt = mh_cnt + 1;
if acc_2 in (0,1) then mh_cnt = mh_cnt + 1;
if coor_2 in (0,1) then mh_cnt = mh_cnt + 1;
label mh_cnt = "Number of needed components of Medical Home care";

mh_cnt2 = 0;
if pdncom_2 in (1) then mh_cnt2 = mh_cnt2 + 1;
if care_2 in (1) then mh_cnt2 = mh_cnt2 + 1;
if acc_2 in (1) then mh_cnt2 = mh_cnt2 + 1;
if coor_2 in (1) then mh_cnt2 = mh_cnt2 + 1;
label mh_cnt2 = "Number needed Medical Home sub-components with score of 75pts or above";

if mh_cnt ne 0 then do; mh2_scor = (mh_cnt2 / mh_cnt) * 100; end;
if mh_cnt eq 0 then do; mh2_scor = .; end;
label mh2_scor = "Percent of needed MEDICAL HOME sub-components with score 75pts or above";

mh_yn = 0;
if mh2_scor eq 100 then mh_yn = 1;
if mh2_scor < 100 and mh2_scor >=0 then mh_yn = 0;
if mh2_scor eq . and (s5q01 eq 6 or s5q01 eq 7) then mh_yn = 9;
if mh_yn eq 9 then mh_yn = .;
label mh_yn = "% meet MED HOME threshold of 75pt or above on EVERY needed component of care-prev care not included";

```

/Step2: Construct MEDICAL HOME composite measure with at least 1 preventive care visit/last 12 mos criteria added**/**

```

mh_comp = .;
if mh_yn eq 0 and pc_2 >= 1 then mh_comp = 0;
if mh_yn eq 1 and pc_2 eq 1 then mh_comp = 0;
if mh_yn eq 1 and pc_2 eq 2 then mh_comp = 1;
if mh_comp eq 0 then mh_comp = 2; /*RECODE from 0,1 to 1,2*/
label mh_comp = "How many children/youth (ages 0-17) receive health care meeting the AAP definition of medical home?";
run;

```

PROC FREQ DATA = dataset name;

```

  FORMAT   S5q01 s5q0one.
           pc_2 pc_tw.
           pdncom_2 subcomp.
           care_2 subcomp.
           coor_2 subcomp.
           acc_2 acc_tw.
           mh_yn mh_yn.
           mh_comp mh_comp.;

```

```

  TABLES S5q01 pc_2 pdncom_2 care_2 coor_2 acc_2 mh_yn mh_comp ;
run;

```

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

*Unweighted frequency distributions for the
Medical Home sub-components, related interim variables
and composite measure generated by the
SAS scoring program*

Personal Doctor or Nurse (PDN) Component

**PDN sub-component score (S5Q01)

Do you have one or more persons you think of as [S.C.]'s
personal doctor or nurse?

S5Q01	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	14568	14.23	14568	14.23
1	87491	85.48	102059	99.71
6	267	0.26	102326	99.97
7	26	0.03	102352	100.00

Frequency Missing = 1

Family Centered Care Component

**Interim variables for Communication with PDN sub-component

How often does PDN spend enough time with them

adeqtime	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	2006	2.31	2006	2.31
25	13379	15.39	15385	17.70
75	17414	20.04	32799	37.74
100	54117	62.26	86916	100.00

Frequency Missing = 15437

How often does PDN explain things so parent or ch understands

explain	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	756	0.87	756	0.87
25	3644	4.18	4400	5.05
75	12003	13.77	16403	18.81
100	70790	81.19	87193	100.00

Frequency Missing = 15160

How often able to get needed interpreter services

interpr	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	138	12.33	138	12.33
25	335	29.94	473	42.27
75	99	8.85	572	51.12
100	547	48.88	1119	100.00

Frequency Missing = 101234

Number of PDN communication elements needed

pdn_cnt	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	14966	14.62	14966	14.62
1	643	0.63	15609	15.25
2	85647	83.68	101256	98.93
3	1097	1.07	102353	100.00

Total points across all needed elements of comm w/ PDN

pdn_sum	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	333	0.38	333	0.38
25	711	0.81	1044	1.19
50	1983	2.27	3027	3.46
75	545	0.62	3572	4.09
100	5070	5.80	8642	9.89
125	8341	9.54	16983	19.43
150	5286	6.05	22269	25.48
175	14730	16.86	36999	42.34
200	49820	57.01	86819	99.35
225	203	0.23	87022	99.58
250	34	0.04	87056	99.62
275	100	0.11	87156	99.74
300	231	0.26	87387	100.00

Frequency Missing = 14966

Average score for communication with PDN sub-component of
MEDICAL HOME composite measure

pdn100	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	333	0.38	333	0.38
8.3	10	0.01	343	0.39
12.5	622	0.71	965	1.10
16.7	34	0.04	999	1.14
25.0	2087	2.39	3086	3.53
33.3	22	0.03	3108	3.56
37.5	367	0.42	3475	3.98
41.6	93	0.11	3568	4.08
50.0	4759	5.45	8327	9.53
58.3	42	0.05	8369	9.58
62.5	8248	9.44	16617	19.02
66.7	143	0.16	16760	19.18
75.0	5486	6.28	22246	25.46
83.3	34	0.04	22280	25.50
87.5	14688	16.81	36968	42.30
91.7	100	0.11	37068	42.42
100.0	50319	57.58	87387	100.00

Frequency Missing = 14966

****Communication with PDN sub-component score (PDNCOM_2)**

PDN communication sub-component for MEDICAL HOME composite measure

pdncom_2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	16760	19.18	16760	19.18
1	70627	80.82	87387	100.00

Frequency Missing = 14966

Comprehensive Care Component

** Preventive Medical Care Visit sub-component score (CARE_2)

Preventive care visit sub-component

pc_2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	908	0.89	908	0.89
1	22255	21.74	23163	22.63
2	79190	77.37	102353	100.00

**Interim variables Getting Needed Care sub-component

How often get advice over phone from ch's PDN when needed

phonehlp	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	362	0.94	362	0.94
25	1682	4.35	2044	5.28
75	5416	14.00	7460	19.29
100	31221	80.71	38681	100.00

Frequency Missing = 63672

How often get needed care right away from ch's PDN

getcare	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	553	2.02	553	2.02
25	1572	5.75	2125	7.78
75	5120	18.74	7245	26.52
100	20074	73.48	27319	100.00

Frequency Missing = 75034

Number of getting care elements needed

care_cnt	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	54335	53.09	54335	53.09
1	30036	29.35	84371	82.43
2	17982	17.57	102353	100.00

Total points across needed elements of getting phone or
urgent care from PDN

care_sum	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	472	0.98	472	0.98
25	1566	3.26	2038	4.24
50	292	0.61	2330	4.85
75	4693	9.77	7023	14.63
100	24205	50.41	31228	65.03
125	647	1.35	31875	66.38
150	1091	2.27	32966	68.65
175	3204	6.67	36170	75.33
200	11848	24.67	48018	100.00

Frequency Missing = 54335

Average score for Getting Needed Care sub-component of
MEDICAL HOME composite measure

care100	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	472	0.98	472	0.98
12.5	132	0.27	604	1.26
25.0	1726	3.59	2330	4.85
37.5	92	0.19	2422	5.04
50.0	609	1.27	3031	6.31
62.5	647	1.35	3678	7.66
75.0	5692	11.85	9370	19.51
87.5	3204	6.67	12574	26.19
100.0	35444	73.81	48018	100.00

Frequency Missing = 54335

****Getting Needed Care sub-component score (CARE_2)**

Getting Needed Care sub-component for MEDICAL HOME composite measure

care_2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	3678	7.66	3678	7.66
1	44340	92.34	48018	100.00

Frequency Missing = 54335

****Interim variables Access to Specialist Care & Services sub-component**

Problems getting needed care from specialist dr.

special	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	966	4.48	966	4.48
25	1593	7.39	2559	11.88
75	2118	9.83	4677	21.71
100	16870	78.29	21547	100.00

Frequency Missing = 80806

Problems getting needed services or equip

services	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	638	6.96	638	6.96
25	782	8.54	1420	15.50
75	1036	11.31	2456	26.81
100	6705	73.19	9161	100.00

Frequency Missing = 93192

Number of access to care elements needed

acc_cnt	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	77340	75.56	77340	75.56
1	19318	18.87	96658	94.44
2	5695	5.56	102353	100.00

Total points across accessing needed specialist care/services
elements of MEDICAL HOME

acc_sum	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	918	3.67	918	3.67
25	1456	5.82	2374	9.49
50	146	0.58	2520	10.07
75	1884	7.53	4404	17.61
100	15920	63.65	20324	81.25
125	453	1.81	20777	83.06
150	208	0.83	20985	83.90
175	680	2.72	21665	86.61
200	3348	13.39	25013	100.00

Frequency Missing = 77340

Average score for access to needed specialist care/services
sub-component of MEDICAL HOME

acc100	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	918	3.67	918	3.67
12.5	127	0.51	1045	4.18
25.0	1475	5.90	2520	10.07
37.5	109	0.44	2629	10.51
50.0	457	1.83	3086	12.34
62.5	453	1.81	3539	14.15
75.0	1983	7.93	5522	22.08
87.5	680	2.72	6202	24.80
100.0	18811	75.20	25013	100.00

Frequency Missing = 77340

****Access to Specialist Care & Services sub-component score (ACC_2)**

Access to needed specialist care/services sub-component for
MEDICAL HOME composite measure

acc_2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	3539	14.15	3539	14.15
1	21474	85.85	25013	100.00

Frequency Missing = 77340

Coordinated Care Component

****Interim variables Follow Up with Family sub-component**

How often PDN follows up w/ family after specialist visit

fu_spec	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	4349	20.54	4349	20.54
25	3646	17.22	7995	37.76
75	3526	16.65	11521	54.41
100	9652	45.59	21173	100.00

Frequency Missing = 81180

How often PDN follows up w/ family after special services/equip

fu_serve	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	2247	24.82	2247	24.82
25	1857	20.51	4104	45.33
75	1306	14.43	5410	59.76
100	3643	40.24	9053	100.00

Frequency Missing = 93300

Number of coor care follow up components

coor_cnt	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	77722	75.94	77722	75.94
1	19036	18.60	96758	94.53
2	5595	5.47	102353	100.00

Total points on needed follow up care elements of MEDICAL HOME

coor_sum	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	4969	20.17	4969	20.17
25	3698	15.01	8667	35.19
50	547	2.22	9214	37.41
75	3130	12.71	12344	50.12
100	9208	37.38	21552	87.50
125	369	1.50	21921	89.00
150	437	1.77	22358	90.77
175	486	1.97	22844	92.74
200	1787	7.26	24631	100.00

Frequency Missing = 77722

Average score on FOLLOW UP w/ FAMILY coor care sub-component
of MEDICAL HOME

coor100	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	4969	20.17	4969	20.17
12.5	456	1.85	5425	22.03
25.0	3789	15.38	9214	37.41
37.5	155	0.63	9369	38.04
50.0	679	2.76	10048	40.79
62.5	369	1.50	10417	42.29
75.0	3412	13.85	13829	56.14
87.5	486	1.97	14315	58.12
100.0	10316	41.88	24631	100.00

Frequency Missing = 77722

****Follow Up with Family sub-component score (COOR_2)**

FOLLOW UP w/ FAMILY sub-component for MEDICAL HOME composite measure

coor_2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	10417	42.29	10417	42.29
1	14214	57.71	24631	100.00

Frequency Missing = 77722

Medical Home Composite Measure

****Interim variables for Medical Home Composite Measure**

Number of needed sub-components of Medical Home

mh_cnt	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	14941	14.60	14941	14.60
1	32130	31.39	47071	45.99
2	30402	29.70	77473	75.69
3	7405	7.23	84878	82.93
4	17475	17.07	102353	100.00

Number needed Medical Home sub-components with score of 75pts or above

mh_cnt2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	24383	23.82	24383	23.82
1	30895	30.18	55278	54.01
2	29831	29.15	85109	83.15
3	8878	8.67	93987	91.83
4	8366	8.17	102353	100.00

Percent of needed MEDICAL HOME sub-components with score 75pts or above

mh2_scor	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	9442	10.80	9442	10.80
25.0	720	0.82	10162	11.63
33.3	1262	1.44	11424	13.07
50.0	7115	8.14	18539	21.21
66.7	3038	3.48	21577	24.68
75.0	5970	6.83	27547	31.51
100.0	59865	68.49	87412	100.00

Frequency Missing = 14941

% meet MED HOME threshold of 75pt or above on EVERY needed sub-component - prev care visit NOT included

mh_yn	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	42195	41.34	42195	41.34
1	59865	58.66	102060	100.00

Frequency Missing = 293

****Medical Home Composite Measure score (MH_COMP)**

How many children/youth (ages 0-17) receive health care meeting the AAP definition of medical home?

mh_comp	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	49089	48.51	49089	48.51
2	52105	51.49	101194	100.00

Frequency Missing = 1159

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

*Full text and response options for questions
used to assess Medical Home*

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE OPTIONS AND SKIP PATTERNS
<u>SURVEY SECTION 4: HEALTH CARE ACCESS AND UTILIZATION</u>	
S4q03 During the past 12 months, how many times did (S.C.) see a doctor, nurse, or other health care professional for preventive medical care such as a physical exam or well-child check-up?	<p style="text-align: right;">_____ TIMES [RANGE CHECK: 000 – 995]</p> <p>(996) DON'T KNOW</p> <p>(997) REFUSED</p>
<u>SURVEY SECTION 5: MEDICAL HOME</u>	
<p>S5q01 A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant.</p> <p style="text-align: center;">Do you have one or more persons you think of as (S.C.)'s personal doctor or nurse?</p>	<p>(0) NO [SKIP TO S5Q13]</p> <p>(1) YES</p> <p>(6) DON'T KNOW [SKIP TO S5Q13]</p> <p>(7) REFUSED [SKIP TO S5Q13]</p>
<i>The remaining questions are asked ONLY if the response to S5Q01 is "Yes".</i>	
S5q02 How often does (S.C.)'s personal doctor or nurse spend enough time with him/her?	<p>(1) Never</p> <p>(2) Sometimes</p> <p>(3) Usually</p> <p>(4) Always</p> <p>(6) DON'T KNOW</p> <p>(7) REFUSED</p>
S5q04 How often does (S.C.)'s personal doctor or nurse explain things in a way that you and (S.C.) can understand?	<p>(1) Never</p> <p>(2) Sometimes</p> <p>(3) Usually</p> <p>(4) Always</p> <p>(6) DON'T KNOW</p> <p>(7) REFUSED</p>
<p>S5q06 During the past 12 months, have you needed to call (S.C.)'s personal doctor or nurse for help or advice over the phone?</p> <p><i>If Yes to S5q06:</i></p> <p>S5q06a When you have called (S.C.)'s personal doctor or nurse for help or advice over the phone, how often were you able to get the help or advice you needed for him/her?</p>	<p>(0) NO [SKIP TO S5Q07]</p> <p>(1) YES</p> <p>(6) DON'T KNOW [SKIP TO S5Q07]</p> <p>(7) REFUSED [SKIP TO S5Q07]</p> <p>(1) Never</p> <p>(2) Sometimes</p> <p>(3) Usually</p> <p>(4) Always</p> <p>(6) DON'T KNOW</p> <p>(7) REFUSED</p>

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE OPTIONS AND SKIP PATTERNS
<p>S5q07 During the past 12 months, has (S.C.) needed care right away from his/her personal doctor or nurse for an illness or injury?</p> <p><i>If Yes to S5q07:</i> S5q07a When (S.C.) needed care right away for an illness or injury, how often did he/she get this care from his/her personal doctor or nurse as soon as you wanted?</p>	<p>(0) NO [SKIP TO S5Q08A] (1) YES (6) DON'T KNOW [SKIP TO S5Q08A] (7) REFUSED [SKIP TO S5Q08A]</p> <p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED</p>
<p>S5q09 Specialists are doctors like surgeons, heart doctors, allergy doctors, psychiatrists, skin doctors, and others who specialize in one area of health care.</p> <p>During the past 12 months, did you or (S.C.)'s personal doctor or nurse think that he/she needed to see any specialist doctor or doctors?</p> <p><i>If Yes to S5q09:</i> S5q09a How much of a problem, if any, was it to get the care from the specialist doctor or doctors?</p> <p><i>If Yes to S5q09:</i> S5q09c How often did (S.C.)'s personal doctor or nurse talk with you about what happens during his/her visits to a specialist doctor or doctors?</p>	<p>(0) NO [SKIP TO S5Q10] (1) YES [SKIP TO S5Q10] (6) DON'T KNOW [SKIP TO S5Q10] (7) REFUSED [SKIP TO S5Q10]</p> <p>(1) A big problem (2) A moderate problem (3) A small problem (4) No problem at all (6) DON'T KNOW (7) REFUSED</p> <p>(1) Never (2) Sometimes (3) Usually (4) Always (5) NO VISITS TO SPECIALIST DOCTOR (6) DON'T KNOW (7) REFUSED</p>
<p>S5q10 Children sometimes need other special types of services that they can't get from their personal doctor or nurse. For example: children may need special services like physical therapy, medical equipment like wheel chairs, special education services or counseling.</p> <p>During the past 12 months, did (S.C.) need any type of special services, equipment, or other care for his/her health?</p> <p><i>If Yes to S5q10:</i> S5q10a How much of a problem, if any, did you have getting the special services, equipment, or other care he/she needed?</p>	<p>(0) NO [SKIP TO S5Q13] (1) YES [SKIP TO S5Q13] (6) DON'T KNOW [SKIP TO S5Q13] (7) REFUSED [SKIP TO S5Q13]</p> <p>(1) A big problem (2) A moderate problem (3) A small problem (4) No problem at all (6) DON'T KNOW (7) REFUSED</p>

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE OPTIONS AND SKIP PATTERNS																						
<p><i>If Yes to S5q10:</i></p> <p>S5q10c How often did (S.C.)'s personal doctor or nurse talk with you about the special care or equipment that (he/she) gets?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (5) NO SPECIAL CARE OR EQUIPMENT RECEIVED (6) DON'T KNOW (7) REFUSED</p>																						
<p><i>(Asked only for children living in households (HH) reporting a primary language other than English)</i></p> <p>S5q13 During the past 12 months, did you or (S.C.) need an interpreter to help speak with his or her doctors or nurses?</p> <p><i>If Yes to S5q13:</i></p> <p>S5q13a When you or (S.C.) needed an interpreter, how often were you able to get someone other than a family member to help you speak with the doctors or nurses?</p>	<table style="width: 100%;"> <tr> <td>(0) NO</td> <td style="text-align: right;">[SKIP TO S6Q08]</td> </tr> <tr> <td>(1) YES</td> <td></td> </tr> <tr> <td>(6) DON'T KNOW</td> <td style="text-align: right;">[SKIP TO S6Q08]</td> </tr> <tr> <td>(7) REFUSED</td> <td style="text-align: right;">[SKIP TO S6Q08]</td> </tr> <tr><td colspan="2"> </td></tr> <tr> <td>(1) Never</td> <td></td> </tr> <tr> <td>(2) Sometimes</td> <td></td> </tr> <tr> <td>(3) Usually</td> <td></td> </tr> <tr> <td>(4) Always</td> <td></td> </tr> <tr> <td>(6) DON'T KNOW</td> <td></td> </tr> <tr> <td>(7) REFUSED</td> <td></td> </tr> </table>	(0) NO	[SKIP TO S6Q08]	(1) YES		(6) DON'T KNOW	[SKIP TO S6Q08]	(7) REFUSED	[SKIP TO S6Q08]			(1) Never		(2) Sometimes		(3) Usually		(4) Always		(6) DON'T KNOW		(7) REFUSED	
(0) NO	[SKIP TO S6Q08]																						
(1) YES																							
(6) DON'T KNOW	[SKIP TO S6Q08]																						
(7) REFUSED	[SKIP TO S6Q08]																						
(1) Never																							
(2) Sometimes																							
(3) Usually																							
(4) Always																							
(6) DON'T KNOW																							
(7) REFUSED																							

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

APPENDIX C_2: SPSS User Resources

Programming Code and Other Resources
for Medical Home Measurement

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

*Weighted Estimates for Medical Home composite measure,
the six sub-component scores and associated interim
variables*

2003 National Survey of Children's Health (NSCH)

Weighted estimates* for Medical Home composite measure, the six sub-component scores
and associated interim variables

2003 NSCH			
	% all children ages 0-17*	% CSHCN only ages 0-17*	NOTES*
Meet overall criteria for having a Medical Home:	46.1	44.2	
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER			1) Asked for all children
1) <u>Child has at least one "personal doctor or nurse"</u>	83.3	90.0	
ACCESSIBLE	--	--	
FAMILY CENTERED			
2) <u>Child's personal doctor or nurse does both of the following:</u>	65.2	73.4	2) Family centered care questions are asked only for children with at least one personal doctor or nurse
a. <u>Usually or always</u> spends enough time with child and parent	66.2	75.1	
b. <u>Usually or always</u> explains things so parent and child understand AND	77.6	84.1	
c. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	0.1	0.8	
CONTINUOUS	--	--	
COMPREHENSIVE			
3) <u>Preventive care visit during past 12 months</u>	77.8	86.5	3) Asked for all children
4) <u>IF needed, consistent access to urgent care and/or phone advice from personal doctor or nurse (PDN)</u>	40.1	55.3	4) & 5) Asked only for children with at least one personal doctor or nurse AND need for the specific type of care being assessed
a. <u>Usually or always</u> gets urgently needed care from PDN	23.2	36.8	
b. <u>Usually or always</u> gets needed phone advice from PDN	32.6	46.9	
5) <u>IF needed, no problems getting specialist care and/or specialized health services or equipment</u>	19.2	42.7	
a. <u>No problems</u> getting needed care from specialist doctor(s)	15.1	33.0	
b. <u>No problems</u> getting needed specialized health services or equipment	5.7	18.1	
COORDINATED			6) Asked only for children with at least one personal doctor or nurse AND a need for specialist care or specialized services/equip or both during the past 12 months
6) <u>Gets effective care coordination when needed</u>	12.9	29.4	
a. Personal doctor or nurse <u>usually or always</u> follows up with family after child gets needed care from a specialist doctor or doctors	12.0	27.6	
b. Personal doctor or nurse <u>usually or always</u> follows up with the family after child gets needed specialized health services or equipment	4.3	15.3	
COMPASSIONATE	<i>Assessed under the Family Centered Care component†</i>		
CULTURALLY EFFECTIVE	<i>Assessed under the Family Centered Care component†</i>		

* All estimated percentages are weighted to represent the U.S. non-institutionalized child population ages 0-17 years

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.

-- Not assessed by the survey.

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

SPSS scoring program variable names for the six sub-component scores and associated interim variables used to derive the Medical Home composite measure

Measuring Medical Home using Data Elements from the 2003 National Survey of Children's Health (NSCH)

SPSS scoring program variable names for the six sub-component scores and
associated interim variables used to derive the Medical Home composite measure

		2003 NSCH
		Survey items or interim variables used to construct:
MEDICAL HOME COMPOSITE MEASURE:	MH_COMP	[S5Q01; PDNCOM_2; PREVCARE_2; GETCARE_2; ACCESS_2; COOR_2]
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER		
1) <u>Child has at least one “personal doctor or nurse”</u>	S5Q01	[S5Q01]
ACCESSIBLE		
--		
FAMILY CENTERED		
2) <u>Child’s personal doctor or nurse does both of the following:</u>	PDNCOM_2	[ADEQTIME; EXPLAIN; INTERPRET]
a. <u>Usually or always</u> spends enough time with child and parent	ADEQTIME	S5q02
b. <u>Usually or always</u> explains things so parent and child understand <i>AND</i>	EXPLAIN	S5q04
c. IF needed, interpreter services are <u>usually or always</u> available	INTERPRET	S5q13; S5q13a
CONTINUOUS		
--		
COMPREHENSIVE		
3) <u>Preventive care visit during past 12 months</u>	PREVCARE_2	[S4Q03r]
4) <u>IF needed, consistent access to urgent care and/or phone advice from personal doctor or nurse (PDN)</u>	GETCARE_2	[GETCARE; PHONEHLP]
a. <u>Usually or always</u> gets urgently needed care from PDN	GETCARE	S5q06; S5q06a
b. <u>Usually or always</u> gets needed phone advice from PDN	PHONEHLP	S5q07; S5q07a
5) <u>IF needed, no problems getting specialist care and/or specialized health services or equipment</u>	ACCESS_2	[SPECIALIST; SERVICES]
a. <u>No problems</u> getting needed care from specialist doctor(s)	SPECIALIST	S5q09; S5q09a
b. <u>No problems</u> getting needed specialized health services or equipment	SERVICES	S5q10; S5q10a
COORDINATED		
6) <u>Gets effective care coordination when needed</u>	COOR_2	[FU_SPECIALIST; FU_SERVE]
a. Personal doctor or nurse <u>usually or always</u> follows up with family after child gets needed care from a specialist doctor or doctors	FU_SPECIALIST	S5q09c
b. Personal doctor or nurse <u>usually or always</u> follows up with the family after child gets needed specialized health services or equipment	FU_SERVE	S5q10c
COMPASSIONATE		
<i>Assessed under the Family Centered Care component†</i>		
CULTURALLY EFFECTIVE		
<i>Assessed under the Family Centered Care component†</i>		

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.
-- Not assessed by the survey.

MEDICAL HOME Composite Measure		How many children/youth receive health care that meets the American Academy of Pediatrics (AAP) definition of medical home?
Survey Items Used	S4Q01 and S4Q03; SA5Q01 – S5Q13a	
Numerator	Children/youth meeting scoring criteria for having a Medical Home	
Denominator	Children/youth ages 0–17 years	
Description	Percent of children/youth ages 0–17 who have a primary care provider (e.g. personal doctor or nurse) AND one or more preventive care visits during past 12 months AND consistently received all needed care from their primary care provider.	
Notes for Data-Users		
<p>The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of “medical home”. According to this definition, all children ideally should have access to “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home.”</p> <p>For additional information about the questions in the medical home section (Section 5) of the 2003 National Survey of Children’s Health, go to: www.cdc.gov/nchs/data/slaits/NSCH_Methodology_Report.pdf</p>		
SPSS Code and Annotations		
<pre>*****Personal doctor or nurse (PDN) Component ***** ***Personal doctor or nurse sub-component of medical home composite measure *NOTE: Use all responses to S5q01, including 6=DK and 7=Refused MISSING VALUES S5Q01 (.). ***** Family Centered Care Component ***** *** COMMUNICATION with PDN sub-sub-component of MEDICAL HOME composite measure ***** Step 1: The following syntax sets up the interim variables needed to construct overall score for "Communication with PDN" sub-component of MEDICAL HOME composite measure RECODE S5Q02 S5Q04 (1 = 0) (2=25) (3=75) (4=100) (6=6) (7=7) INTO adeqtime explain . VARIABLE LABEL adeqtime "How often does ch's PDN spend enough time with them?". VARIABLE LABEL explain "How often does ch's PDN explain things so parent or ch understands?". VALUE LABEL adeqtime explain 0 'Never' 25 'Sometimes' 75 'Usually' 100 'Always' 6 'DK' 7 'Refused'. MISSING VALUES adeqtime explain (6,7). RECODE adeqtime explain (6=SYSMIS) (7=SYSMIS). EXECUTE .</pre>		

```

COMPUTE interpret = 99.
IF (s5q01 = 1) and (s5q13a = 1) interpret = 0.
IF (s5q01 = 1) and (s5q13a = 2) interpret = 25.
IF (s5q01 = 1) and (s5q13a = 3) interpret = 75.
IF (s5q01 = 1) and (s5q13a = 4) interpret = 100.
IF (s5q01 = 1) and (s5q13a = 6) interpret = 6.
VAR LABEL interpret 'How often able to get needed interpreter other than family member for grp with PDN'.
VALUE LABEL interpret 0 'Never' 25 'Sometimes' 75 'Usually' 100 'Always' 6 'DK'.
MISSING VALUES interpret (6).

```

```

RECODE
interpret (99=SYSMIS).
EXECUTE .

```

***** Step 2: Construct "Communication with PDN" sub-component of MEDICAL HOME composite measure

```

COUNT
pdncomm_cnt = adeqtime explain interpret (0, 25, 75, 100).
VAR LABEL pdncomm_cnt 'Number of PDN communication elements needed'.
EXECUTE.

```

```

COMPUTE pdn_sum = SUM (adeqtime, explain, interpret).
VAR LABEL pdn_sum 'Total points across all needed elements of comm with PDN'.
EXECUTE.

```

```

DO IF (pdncomm_cnt>0).
COMPUTE pdncom100 = (pdn_sum / pdncomm_cnt).
END IF.
VAR LABEL pdncom100 'Average score for communication with PDN sub-component of MEDICAL HOME'.
EXECUTE.

```

```

RECODE
pdncom100
(0 thru 67=0) (75 thru Highest=1) INTO pdncom_2 .
VAR LABEL pdncom_2 'PDN communication sub-component for Med Home composite measure'.
VALUE LABEL pdncom_2 0 'Comm happens less than usually/always' 1 'Usually/always get needed communication'.
EXECUTE .

```

*****Comprehensive Care Component*****

***ONE OR MORE PREVENTIVE medical care visits sub-component of MEDICAL HOME composite measure

```

MISSING VALUES s4q01 (6, 7).
MISSING VALUES s4q03r (96, 97).

```

```

COMPUTE prevcare_2 = 0.
IF (s4q01 = 0) or (s4q03r = 0) prevcare_2 = 1.
IF (s4q03r >=1) prevcare_2 = 2.
VAR LABELS prevcare_2 'At least 1 Preventive care visit during past 12 mos'.
VAL LABELS prevcare_2 0 'Unknown' 1 'None in past 12 months' 2 'Had preventive care visit in past 12 months'.
EXECUTE.

```

***GETTING CARE / advice from ch's PDN sub-component of MEDICAL HOME composite measure
(questions only asked for grp with PDN)

***** Step 1: The following syntax sets up the interim variables needed to construct overall score for "Getting needed care from PDN" sub-component of MEDICAL HOME composite measure

```
RECODE S5Q06A S5Q07A
  (6=6) (7=7) (1 = 0) (2 = 25) (3 = 75) (4=100) (ELSE=SYSMIS) INTO phonehp getcare .
VAR LABELS phonehp "How often able to get advice over phone from ch's PDN when needed".
VAR LABELS getcare "How often able to get needed care right away from ch's PDN".
VALUE LABELS phonehp getcare 0 'Never' 25 'Sometimes' 75 'Usually' 100 'Always' 6 'DK' 7 'Refused'.
RECODE
phonehp getcare (6=SYSMIS) (7=SYSMIS) (999 = SYSMIS).
EXECUTE .
```

***** Step 2: Construct "Getting needed care from PDN" scoring sub-component of MEDICAL HOME composite measure

```
COUNT
getcare_cnt = phonehp getcare (0, 25, 75, 100).
VAR LABEL getcare_cnt 'Number of getting care elements needed'.
EXECUTE.
```

```
COMPUTE getcare_sum = SUM (phonehp, getcare).
VAR LABEL getcare_sum 'Total points across needed elements of getting phone or urgent care from PDN'.
EXECUTE.
```

```
DO IF (getcare_cnt>0).
COMPUTE getcare100 = (getcare_sum / getcare_cnt).
END IF.
VAR LABEL getcare100 'Average score for needed care sub-component of MEDICAL HOME' .
EXECUTE.
```

```
RECODE getcare100
  (0 thru 67=0) (75 thru Highest=1) INTO getcare_2 .
VAR LABEL getcare_2 'Getting needed phone/urgent care from PDN sub-component for Med Home composite measure'.
VALUE LABEL getcare_2 0 'Care or advice available less than usually/always' 1 'Usually/always get needed care or advice'.
EXECUTE .
```

***ACCESS TO NEEDED SPECIALIST & SERVICES sub-component of MEDICAL HOME composite measure
(questions only asked for grp with PDN)

***** Step 1: The following syntax sets up the interim variables needed to construct overall score for "ACCESS to NEEDED SPECIALIST & SERVICES " sub-component of MEDICAL HOME composite measure

```
RECODE S5Q09A S5Q10A
  (6=6) (7=7) (1 = 0) (2 = 25) (3 = 75) (4=100) (ELSE=SYSMIS) INTO specialist services .
VAR LABEL specialist "Problems getting needed care from specialist dr".
VAR LABEL services "Problems getting needed services or equip".
VALUE LABEL specialist services 0 'Big problem' 25 'Moderate problem' 75 'Small problem' 100 'No problem' 6 'DK' 7 'Refused'.
```

```

RECODE
specialist services (99=SYSMIS) (6=SYSMIS) (7 = SYSMIS).
EXECUTE .

```

***** Step 2: Construct "ACCESS to NEEDED SPECIALIST & SERVICES " sub-component of MEDICAL HOME composite measure

```

COUNT
access_cnt = specialist services (0, 25, 75, 100).
VAR LABEL access_cnt 'Number of access to care elements needed'.
EXECUTE.

```

```

COMPUTE access_sum = SUM (specialist, services).
VAR LABEL access_sum 'Total points across accessing needed specialist care or services elements of
MEDICAL HOME' .
EXECUTE.

```

```

DO IF (access_cnt>0).
COMPUTE access100 = (access_sum / access_cnt).
END IF.
VAR LABEL access100 'Average score for access to needed specialist care/services sub-component of
MEDICAL HOME' .
EXECUTE.

```

```

RECODE access100
(0 thru 67=0) (75 thru Highest=1) INTO access_2 .
VAR LABEL access_2 'Access to needed specialist care/services sub-component for Med Home composite
measure'.
VALUE LABEL access_2 0 'Significant problems accessing care' 1 'Few or no problems accessing care'.
EXECUTE .

```

*****Coordinated Care Component *****

*** FOLLOW UP w/ FAMILY sub-component of MEDICAL HOME composite measure (questions only asked for group with PDN and needing specialist and/or specialized services)

***** Step 1: The following syntax sets up the interim variables needed to construct overall score for "FOLLOW UP w/ FAMILY " sub-component of MEDICAL HOME composite measure

```

RECODE S5Q09C S5Q10C
(1=0) (2=25) (3=75) (4=100) (ELSE = SYSMIS) INTO fu_specialist fu_serve .
VAR LABEL fu_specialist 'How often PDN follows up w/ family after specialist visit'.
VAR LABEL fu_serve 'How often PDN follows up w/ family after special services/equip'.
VALUE LABEL fu_specialist fu_serve 0 'Never' 25 'Sometimes' 75 'Usually' 100 'Always'.
EXECUTE .

```

***** Step 2: Construct "FOLLOW UP w/ FAMILY" sub-component of MEDICAL HOME composite measure

```

COUNT
coor_cnt = fu_specialist fu_serve (0, 25, 75, 100).
VAR LABEL coor_cnt 'Number of coor care follow up elements needed'.
EXECUTE.

```

```

COMPUTE coor_sum = SUM (fu_specialist, fu_serve).
VAR LABEL coor_sum 'Total points on needed follow up care elements of MEDICAL HOME' .
EXECUTE.

DO IF (coor_cnt>0).
COMPUTE coor100 = (coor_sum / coor_cnt).
END IF.
VAR LABEL coor100 'Average score on follow up care from PDN coor care sub-component of MEDICAL HOME' .
EXE.

RECODE coor100
(0 thru 67=0) (75 thru Highest=1) INTO coor_2 .
VAR LABEL coor_2 'Coor care sub-component for Med Home composite measure'.
VALUE LABEL coor_2 0 'PDN follows up less than usually/always' 1 'PDN usually/always follows up'.
EXECUTE .

***** MEDICAL HOME COMPOSITE MEASURE*****

***The following code uses the 5 sub-components created above to derive the MEDICAL HOME composite measure using score of 75 pts or above on EVERY needed sub-component scoring approach

*****Step 1: Construct medical home composite measure without the preventive care visit criterion

COUNT
mh_cnt = pdncom_2 getcare_2 access_2 coor_2 (0,1).
VAR LABEL mh_cnt 'Number of sub-components of Medical Home needed'.
EXECUTE.

COUNT
mh_cnt2 = pdncom_2 getcare_2 access_2 coor_2 (1).
VAR LABEL mh_cnt2 'Number needed Medical Home sub-components with score of 75pt or above'.
EXECUTE.

DO IF (mh_cnt>0).
COMPUTE mh2_score = (mh_cnt2 / mh_cnt) * 100.
END IF.
VAR LABEL mh2_score '% of needed MEDICAL HOME sub-components with score 75pt or above' .
EXECUTE.

COMPUTE mh_yn = 0.
IF ((SYSMIS (mh2_score)) and ((s5q01 = 6) or (s5q01 = 7))) mh_yn = 999.
IF (mh2_score = 100) mh_yn = 1.
IF (mh2_score < 100) mh_yn = 0.
VAR LABEL mh_yn "% meet MED HOME threshold of 75pts or above on EVERY needed sub-component - prev care visit not included" .
VALUE LABEL mh_yn 0 "No PDN or PDN & less than 75pts on 1 or more needed sub-components"
1 "PDN & 75 pts or above on EVERY needed sub-component" 999 "DK or Refused to PDN" .
EXECUTE.

RECODE mh_yn
(999 = SYSMIS).
EXECUTE.

```

*****Step 2: Construct MEDICAL HOME composite measure with at least one preventive care visit during last 12 mos criterion added

```
COMPUTE MH_comp = 999.
```

```
IF ((mh_yn= 0) and (prevcare_2 >= 1)) MH_comp = 0.
```

```
IF ((mh_yn= 1) and (prevcare_2 = 1)) MH_comp = 0.
```

```
IF ((mh_yn= 1) and (prevcare_2 = 2)) MH_comp = 1.
```

```
VAR LABEL MH_comp "How many children/youth (ages 0-17) receive health care that meets the AAP definition of medical home?".
```

```
VALUE LABEL MH_comp
```

```
0 'Care DOES NOT meet medical home definition'
```

```
1 'Care MEETS medical home definition'.
```

```
RECODE MH_comp
```

```
(999 = SYSMIS).
```

```
EXECUTE.
```


2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

*Unweighted frequency distributions for the
Medical Home sub-components, related interim variables
and composite measure generated by the
SPSS scoring program*

Personal Doctor or Nurse (PDN) Component

**PDN sub-component score (S5Q01)

S5Q01 Do you have one or more persons you think of as [S.C.]'s personal doctor or nurse?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No	14568	14.2	14.2	14.2
	1 Yes	87491	85.5	85.5	99.7
	6 Don't Know	267	.3	.3	100.0
	7 Refused	26	.0	.0	100.0
	Total	102352	100.0	100.0	
Missing	System	1	.0		
Total		102353	100.0		

Family Centered Care Component

**Interim variables for Communication with PDN sub-component

adeqtime How often does ch's PDN spend enough time with them?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never	2006	2.0	2.3	2.3
	25 Sometimes	13379	13.1	15.4	17.7
	75 Usually	17414	17.0	20.0	37.7
	100 Always	54117	52.9	62.3	100.0
	Total	86916	84.9	100.0	
Missing	System	15437	15.1		
Total		102353	100.0		

explain How often does ch's PDN explain things so parent or ch understands?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never	756	.7	.9	.9
	25 Sometimes	3644	3.6	4.2	5.0
	75 Usually	12003	11.7	13.8	18.8
	100 Always	70790	69.2	81.2	100.0
	Total	87193	85.2	100.0	
Missing	System	15160	14.8		
Total		102353	100.0		

interpret How often able to get needed interpreter other than family member for grp with PDN

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never	138	.1	12.3	12.3
	25 Sometimes	335	.3	29.9	42.3
	75 Usually	99	.1	8.8	51.1
	100 Always	547	.5	48.9	100.0
	Total	1119	1.1	100.0	
Missing	6 DK	8	.0		
	System	101226	98.9		
	Total	101234	98.9		
Total		102353	100.0		

pdncomm_cnt Number of needed PDN communication components

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	14966	14.6	14.6	14.6
	1	643	.6	.6	15.3
	2	85647	83.7	83.7	98.9
	3	1097	1.1	1.1	100.0
	Total	102353	100.0	100.0	

**pdn_sum Total points across all needed elements of comm with
PDN**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	333	.3	.4	.4
	25	711	.7	.8	1.2
	50	1983	1.9	2.3	3.5
	75	545	.5	.6	4.1
	100	5070	5.0	5.8	9.9
	125	8341	8.1	9.5	19.4
	150	5286	5.2	6.0	25.5
	175	14730	14.4	16.9	42.3
	200	49820	48.7	57.0	99.4
	225	203	.2	.2	99.6
	250	34	.0	.0	99.6
	275	100	.1	.1	99.7
	300	231	.2	.3	100.0
	Total	87387	85.4	100.0	
Missing	System	14966	14.6		
Total		102353	100.0		

**pdncom100 Average score for communication with PDN
component of MEDICAL HOME**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	333	.3	.4	.4
	8	10	.0	.0	.4
	13	622	.6	.7	1.1
	17	34	.0	.0	1.1
	25	2087	2.0	2.4	3.5
	33	22	.0	.0	3.6
	38	367	.4	.4	4.0
	42	93	.1	.1	4.1
	50	4759	4.6	5.4	9.5
	58	42	.0	.0	9.6
	63	8248	8.1	9.4	19.0
	67	143	.1	.2	19.2
	75	5486	5.4	6.3	25.5
	83	34	.0	.0	25.5
	88	14688	14.4	16.8	42.3
	92	100	.1	.1	42.4
	100	50319	49.2	57.6	100.0
	Total	87387	85.4	100.0	
Missing	System	14966	14.6		
Total		102353	100.0		

****Communication with PDN sub-component score (PDNCOM_2)**

pdncom_2 PDN communication component for Med Home index

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Comm happens less than usually/always	16760	16.4	19.2	19.2
	1 Usually/always get needed communication	70627	69.0	80.8	100.0
	Total	87387	85.4	100.0	
Missing	System	14966	14.6		
Total		102353	100.0		

Comprehensive Care Component

**** Preventive Medical Care Visit sub-component score (PREVCARE_2)**

prevcare_2 At least 1 Preventive care visit during past 12 mos

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Unknown	908	.9	.9	.9
	1 None in past 12 months	22255	21.7	21.7	22.6
	2 Had preventive care visit in past 12 months	79190	77.4	77.4	100.0
	Total	102353	100.0	100.0	

****Interim variables Getting Needed Care sub-component**

phonehlp How often able to get advice over phone from ch's PDN when needed

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never	362	.4	.9	.9
	25 Sometimes	1682	1.6	4.3	5.3
	75 Usually	5416	5.3	14.0	19.3
	100 Always	31221	30.5	80.7	100.0
	Total	38681	37.8	100.0	
Missing	System	63672	62.2		
Total		102353	100.0		

getcare How often able to get needed care right away from ch's PDN

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never	553	.5	2.0	2.0
	25 Sometimes	1572	1.5	5.8	7.8
	75 Usually	5120	5.0	18.7	26.5
	100 Always	20074	19.6	73.5	100.0
	Total	27319	26.7	100.0	
Missing	System	75034	73.3		
Total		102353	100.0		

getcare_cnt Number of getting needed care sub-components

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	54335	53.1	53.1	53.1
	1	30036	29.3	29.3	82.4
	2	17982	17.6	17.6	100.0
	Total	102353	100.0	100.0	

getcare_sum Total points across needed elements of getting phone or urgent care from PDN

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	472	.5	1.0	1.0
	25	1566	1.5	3.3	4.2
	50	292	.3	.6	4.9
	75	4693	4.6	9.8	14.6
	100	24205	23.6	50.4	65.0
	125	647	.6	1.3	66.4
	150	1091	1.1	2.3	68.7
	175	3204	3.1	6.7	75.3
	200	11848	11.6	24.7	100.0
	Total	48018	46.9	100.0	
Missing	System	54335	53.1		
Total		102353	100.0		

**getcare100 Average score for needed care sub-component of
MEDICAL HOME**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	472	.5	1.0	1.0
	13	132	.1	.3	1.3
	25	1726	1.7	3.6	4.9
	38	92	.1	.2	5.0
	50	609	.6	1.3	6.3
	63	647	.6	1.3	7.7
	75	5692	5.6	11.9	19.5
	88	3204	3.1	6.7	26.2
	100	35444	34.6	73.8	100.0
	Total	48018	46.9	100.0	
Missing	System	54335	53.1		
Total		102353	100.0		

****Getting Needed Care sub-component score (GETCARE_2)**

**getcare_2 Getting needed phone/urgent care from PDN sub-component for Med
Home composite measure**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Care or advice available less than usually/always	3678	3.6	7.7	7.7
	1 Usually/always get needed care or advice	44340	43.3	92.3	100.0
	Total	48018	46.9	100.0	
Missing	System	54335	53.1		
Total		102353	100.0		

**Interim variables Access to Specialist Care & Services sub-component

specialist Problems getting needed care from specialist dr

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Big problem	966	.9	4.5	4.5
	25 Moderate problem	1593	1.6	7.4	11.9
	75 Small problem	2118	2.1	9.8	21.7
	100 No problem	16870	16.5	78.3	100.0
	Total	21547	21.1	100.0	
Missing	System	80806	78.9		
Total		102353	100.0		

services Problems getting needed services or equip

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Big problem	638	.6	7.0	7.0
	25 Moderate problem	782	.8	8.5	15.5
	75 Small problem	1036	1.0	11.3	26.8
	100 No problem	6705	6.6	73.2	100.0
	Total	9161	9.0	100.0	
Missing	System	93192	91.0		
Total		102353	100.0		

access_cnt Number of needed access to care elements

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	77340	75.6	75.6	75.6
	1	19318	18.9	18.9	94.4
	2	5695	5.6	5.6	100.0
Total		102353	100.0	100.0	

**access_sum Total points across accessing needed specialist
care or services elements of MEDICAL HOME**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	918	.9	3.7	3.7
	25	1456	1.4	5.8	9.5
	50	146	.1	.6	10.1
	75	1884	1.8	7.5	17.6
	100	15920	15.6	63.6	81.3
	125	453	.4	1.8	83.1
	150	208	.2	.8	83.9
	175	680	.7	2.7	86.6
	200	3348	3.3	13.4	100.0
	Total	25013	24.4	100.0	
Missing	System	77340	75.6		
Total		102353	100.0		

**access100 Average score for access to needed specialist
care/services sub-component of MEDICAL HOME**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	918	.9	3.7	3.7
	13	127	.1	.5	4.2
	25	1475	1.4	5.9	10.1
	38	109	.1	.4	10.5
	50	457	.4	1.8	12.3
	63	453	.4	1.8	14.1
	75	1983	1.9	7.9	22.1
	88	680	.7	2.7	24.8
	100	18811	18.4	75.2	100.0
	Total	25013	24.4	100.0	
Missing	System	77340	75.6		
Total		102353	100.0		

****Access to Specialist Care & Services sub-component score (ACCESS_2)**

access_2 Access to needed specialist care/services sub-component for Med Home composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Significant problems accessing care	3539	3.5	14.1	14.1
	1 Few or no problems accessing care	21474	21.0	85.9	100.0
	Total	25013	24.4	100.0	
Missing	System	77340	75.6		
Total		102353	100.0		

Coordinated Care Component

****Interim variables Follow Up with Family sub-component**

fu_specialist How often PDN follows up w/ family after specialist visit

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never	4349	4.2	20.5	20.5
	25 Sometimes	3646	3.6	17.2	37.8
	75 Usually	3526	3.4	16.7	54.4
	100 Always	9652	9.4	45.6	100.0
	Total	21173	20.7	100.0	
Missing	System	81180	79.3		
Total		102353	100.0		

fu_serve How often PDN follows up w/ family after special services/equip

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never	2247	2.2	24.8	24.8
	25 Sometimes	1857	1.8	20.5	45.3
	75 Usually	1306	1.3	14.4	59.8
	100 Always	3643	3.6	40.2	100.0
	Total	9053	8.8	100.0	
Missing	System	93300	91.2		
Total		102353	100.0		

coor_cnt Number of coor care follow up elements needed

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	77722	75.9	75.9	75.9
	1	19036	18.6	18.6	94.5
	2	5595	5.5	5.5	100.0
	Total	102353	100.0	100.0	

coor_sum Total points on needed follow up care elements of MEDICAL HOME

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	4969	4.9	20.2	20.2
	25	3698	3.6	15.0	35.2
	50	547	.5	2.2	37.4
	75	3130	3.1	12.7	50.1
	100	9208	9.0	37.4	87.5
	125	369	.4	1.5	89.0
	150	437	.4	1.8	90.8
	175	486	.5	2.0	92.7
	200	1787	1.7	7.3	100.0
	Total	24631	24.1	100.0	
Missing	System	77722	75.9		
Total		102353	100.0		

coor100 Average score on follow up care from PDN coor care sub-component of MEDICAL HOME

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	4969	4.9	20.2	20.2
	13	456	.4	1.9	22.0
	25	3789	3.7	15.4	37.4
	38	155	.2	.6	38.0
	50	679	.7	2.8	40.8
	63	369	.4	1.5	42.3
	75	3412	3.3	13.9	56.1
	88	486	.5	2.0	58.1
	100	10316	10.1	41.9	100.0
	Total	24631	24.1	100.0	
Missing	System	77722	75.9		
Total		102353	100.0		

****Follow Up with Family sub-component score (COOR_2)**

coor_2 Coor care sub-component for Med Home composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 PDN follows up less than usually/always	10417	10.2	42.3	42.3
	1 PDN usually/always follows up	14214	13.9	57.7	100.0
	Total	24631	24.1	100.0	
Missing	System	77722	75.9		
Total		102353	100.0		

Medical Home Composite Measure

****Interim variables for Medical Home Composite Measure**

mh_cnt Number of sub-components of Medical Home needed

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	14941	14.6	14.6	14.6
	1	32130	31.4	31.4	46.0
	2	30402	29.7	29.7	75.7
	3	7405	7.2	7.2	82.9
	4	17475	17.1	17.1	100.0
	Total	102353	100.0	100.0	

mh_cnt2 Number needed Medical Home sub-components with score of 75pt or above

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	24383	23.8	23.8	23.8
	1	30895	30.2	30.2	54.0
	2	29831	29.1	29.1	83.2
	3	8878	8.7	8.7	91.8
	4	8366	8.2	8.2	100.0
	Total	102353	100.0	100.0	

mh2_score % of needed MEDICAL HOME sub-components with score 75pt or above

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	9442	9.2	10.8	10.8
	25	720	.7	.8	11.6
	33	1262	1.2	1.4	13.1
	50	7115	7.0	8.1	21.2
	67	3038	3.0	3.5	24.7
	75	5970	5.8	6.8	31.5
	100	59865	58.5	68.5	100.0
	Total	87412	85.4	100.0	
Missing	System	14941	14.6		
Total		102353	100.0		

mh_yn % meet MED HOME threshold of 75pts or above on EVERY needed sub-components - prev care not included

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No PDN or PDN & less than 75pts on 1 or more needed sub-components	42195	41.2	41.3	41.3
	1 PDN & 75 pts or above on EVERY needed sub-component	59865	58.5	58.7	100.0
	Total	102060	99.7	100.0	
Missing	System	293	.3		
Total		102353	100.0		

****Medical Home Composite Measure score (MH_COMP)**

medhome_comp How many children/youth (ages 0-17) receive health care that meets the AAP definition of medical home?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Care DOES NOT meet medical home definition	52105	50.9	51.5	51.5
	1 Care MEETS medical home definition	49089	48.0	48.5	100.0
	Total	101194	98.9	100.0	
Missing	System	1159	1.1		
Total		102353	100.0		

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH

*Full text and response options for questions
used to assess Medical Home*

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE OPTIONS AND SKIP PATTERNS
<u>SURVEY SECTION 4: HEALTH CARE ACCESS AND UTILIZATION</u>	
S4q03 During the past 12 months, how many times did (S.C.) see a doctor, nurse, or other health care professional for preventive medical care such as a physical exam or well-child check-up?	_____ TIMES (996) DON'T KNOW (997) REFUSED [RANGE CHECK: 000 – 995]
<u>SURVEY SECTION 5: MEDICAL HOME</u>	
S5q01 A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as (S.C.)'s personal doctor or nurse?	(0) NO (1) YES (6) DON'T KNOW (7) REFUSED [SKIP TO S5Q13] [SKIP TO S5Q13] [SKIP TO S5Q13]
<i>The remaining questions are asked ONLY if the response to S5Q01 is "Yes".</i>	
S5q02 How often does (S.C.)'s personal doctor or nurse spend enough time with him/her?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED
S5q04 How often does (S.C.)'s personal doctor or nurse explain things in a way that you and (S.C.) can understand?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED
S5q06 During the past 12 months, have you needed to call (S.C.)'s personal doctor or nurse for help or advice over the phone? <i>If Yes to S5q06:</i> S5q06a When you have called (S.C.)'s personal doctor or nurse for help or advice over the phone, how often were you able to get the help or advice you needed for him/her?	(0) NO (1) YES (6) DON'T KNOW (7) REFUSED [SKIP TO S5Q07] [SKIP TO S5Q07] [SKIP TO S5Q07] (1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSE

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE OPTIONS AND SKIP PATTERNS
<p>S5q07 During the past 12 months, has (S.C.) needed care right away from his/her personal doctor or nurse for an illness or injury?</p> <p><i>If Yes to S5q07:</i></p> <p>S5q07a When (S.C.) needed care right away for an illness or injury, how often did he/she get this care from his/her personal doctor or nurse as soon as you wanted?</p>	<p>(0) NO [SKIP TO S5Q08A] (1) YES (6) DON'T KNOW [SKIP TO S5Q08A] (7) REFUSED [SKIP TO S5Q08A]</p> <p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED</p>
<p>S5q09 Specialists are doctors like surgeons, heart doctors, allergy doctors, psychiatrists, skin doctors, and others who specialize in one area of health care.</p> <p>During the past 12 months, did you or (S.C.)'s personal doctor or nurse think that he/she needed to see any specialist doctor or doctors?</p> <p><i>If Yes to S5q09:</i></p> <p>S5q09a How much of a problem, if any, was it to get the care from the specialist doctor or doctors?</p> <p><i>If Yes to S5q09:</i></p> <p>S5q09c How often did (S.C.)'s personal doctor or nurse talk with you about what happens during his/her visits to a specialist doctor or doctors?</p>	<p>(0) NO [SKIP TO S5Q10] (1) YES (6) DON'T KNOW [SKIP TO S5Q10] (7) REFUSED [SKIP TO S5Q10]</p> <p>(1) A big problem (2) A moderate problem (3) A small problem (4) No problem at all (6) DON'T KNOW (7) REFUSED</p> <p>(1) Never (2) Sometimes (3) Usually (4) Always (5) NO VISITS TO SPECIALIST DOCTOR (6) DON'T KNOW (7) REFUSED</p>

2003 NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE OPTIONS AND SKIP PATTERNS
<p>S5q10 Children sometimes need other special types of services that they can't get from their personal doctor or nurse. For example: children may need special services like physical therapy, medical equipment like wheel chairs, special education services or counseling.</p> <p>During the past 12 months, did (S.C.) need any type of special services, equipment, or other care for his/her health?</p> <p><i>If Yes to S5q10:</i> S5q10a How much of a problem, if any, did you have getting the special services, equipment, or other care he/she needed?</p>	<p>(0) NO [SKIP TO S5Q13] (1) YES (6) DON'T KNOW [SKIP TO S5Q13] (7) REFUSED [SKIP TO S5Q13]</p> <p>(1) A big problem (2) A moderate problem (3) A small problem (4) No problem at all (6) DON'T KNOW (7) REFUSED</p>
<p><i>If Yes to S5q10:</i> S5q10c How often did (S.C.)'s personal doctor or nurse talk with you about the special care or equipment that (he/she) gets?</p>	<p>(1) Never (2) Sometimes (3) Usually (4) Always (5) NO SPECIAL CARE OR EQUIPMENT RECEIVED (6) DON'T KNOW (7) REFUSED</p>
<p><i>(Asked only for children living in households (HH) reporting a primary language other than English)</i></p> <p>S5q13 During the past 12 months, did you or (S.C.) need an interpreter to help speak with his or her doctors or nurses?</p> <p><i>If Yes to S5q13:</i> S5q13a When you or (S.C.) needed an interpreter, how often were you able to get someone other than a family member to help you speak with the doctors or nurses?</p>	<p>(0) NO [SKIP TO S6Q08] (1) YES (6) DON'T KNOW [SKIP TO S6Q08] (7) REFUSED [SKIP TO S6Q08]</p> <p>(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED</p>

2007 National Survey of Children's Health

APPENDIX D_1: SPSS User Resources

Programming Code and Other Resources
for Medical Home Measurement

2007 National Survey of Children's Health (NSCH)

Weighted estimates* for Medical Home composite measure, the five sub-component scores
and associated interim variables

2007 NSCH		
	<i>% All children ages 0-17*</i>	<i>% CSHCN only ages 0-17*</i>
Meet overall criteria for having a Medical Home:	57.5	49.8
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER		
1) <u>Child has a "personal doctor or nurse"</u>	92.2	94.7
ACCESSIBLE		
--		
FAMILY CENTERED		
2) <u>Child's doctors and other health providers do each of the following:</u>	65.1	64.8
a. <u>Usually or always</u> spend enough time with child and parent	76.7	79.0
b. <u>Usually or always</u> listen carefully to child and parent	86.5	87.0
c. <u>Usually or always</u> sensitive to family's values and customs	86.3	87.8
d. <u>Usually or always</u> provide needed information	82.1	81.8
e. <u>Usually or always</u> make family feel like a partner in child's care	84.8	84.8
AND		
f. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	2.7	1.9
CONTINUOUS		
--		
COMPREHENSIVE		
3) <u>IF needed, no problems obtaining needed referrals</u>	13.1	25.2
(Needed a referral to see other doctors or get services, past 12 months)	(15.9)	(32.2)
4) <u>Has usual sources of care</u>	93.1	94.8
COORDINATED		
5) <u>Gets all needed aspects of care coordination</u>	28.3	43.4
(Needed 1 or more of the three aspects of care coordination below)	(41.2)	(73.1)
a. <i>IF needed, gets help with help with care coordination</i>	15.1	22.1
b. <i>IF needed, very satisfied</i> with communication btw doctors	19.0	39.4
c. <i>IF needed, very satisfied</i> with how doctors communicate with school or other programs the child attends	7.1	16.9
COMPASSIONATE		
	<i>Assessed under the Family Centered Care component†</i>	
CULTURALLY EFFECTIVE		
	<i>Assessed under the Family Centered Care component†</i>	

* All estimated percentages are weighted to represent the U.S. non-institutionalized population of children ages 0-17 years

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.

-- Not assessed by the survey.

2007 National Survey of Children's Health

SPSS scoring program variable names for the six sub-component scores and associated interim variables used to derive the Medical Home composite measure

Measuring Medical Home using Data Elements from the 2007 National Survey of Children's Health (NSCH)

SPSS scoring program variable names for the five sub-component scores and
associated interim variables used to derive the Medical Home composite measure

2007 NSCH		
	SPSS Variable names	Survey items or interim variables used to construct:
Meet overall criteria for having a Medical Home:	MH_COMP	[PDN; FAMCENT; NOREFPRB; USUAL; CARECOOR]
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER		
1) <u>Child has at least one "personal doctor or nurse"</u>	PDN	K4Q04
ACCESSIBLE		
--		
FAMILY CENTERED		
2) <u>Child's doctors and other health providers do each of the following:</u>	FAMCENT	[TIME; LISTEN; SENSITIV; INFO; PARTNER; INTERPRET]
a. <u>Usually or always</u> spend enough time with child and parent	TIME	K5q40
b. <u>Usually or always</u> listen carefully to child and parent	LISTEN	K5q41
c. <u>Usually or always</u> sensitive to family's values and customs	SENSITIV	K5q42
d. <u>Usually or always</u> provide needed information	INFO	K5q43
e. <u>Usually or always</u> make family feel like a partner in child's care	PARTNER	K5q44
f. <i>IF needed</i> , interpreter services are <u>usually or always</u> available	INTERPRET	K5q45; K5q46
CONTINUOUS		
--		
COMPREHENSIVE		
3) <u>IF needed, no problems obtaining referrals</u>	NOREFPRB	K5Q10, K5Q11
4) <u>Usual source(s) of care</u>	USUAL	K4q01; K4q02r
COORDINATED		
5) <u>Gets effective care coordination when needed</u>	CARECOOR	[CAREHLP; DRCOMM; OTHCOMM]
a. <i>Needed and usually got</i> extra help with care coordination	CAREHLP	K5q20r, K5q21r, K5q22
b. <i>IF needed, very satisfied</i> with communication btw doctors	DRCOMM	K5q30
c. <i>IF needed, very satisfied</i> with how doctors communicate with school or other programs the child attends	OTHERCOMM	K5q31; K5q32
COMPASSIONATE		
<i>Assessed under the Family Centered Care component†</i>		
CULTURALLY EFFECTIVE		
<i>Assessed under the Family Centered Care component†</i>		

-- Not assessed by the survey.

† Questions assessing these concepts are combined under the Family Centered Care component for scoring purposes.

2007 National Survey of Children's Health

SPSS scoring program

**2007 NSCH
MEDICAL HOME
Composite Measure** **How many children/youth receive health care that meets the American Academy of Pediatrics (AAP) definition of medical home?**

Survey Items Used	K4Q04 K5Q40 K5Q41 K5Q42 K5Q43 K5Q44 K5Q46 K5Q11 K5Q10 K4Q01 K4Q02R K4Q22 K4Q24 K5Q30 K5Q31 K5Q32 K4Q20 K4Q21 K4Q25 K5Q20 K5Q21 K5Q22
Numerator	Children/youth meeting scoring criteria for having a Medical Home
Denominator	Children/youth ages 0–17 years
Description	Percent of children ages 0–17 who have a primary care provider (e.g. personal doctor or nurse) AND usual sources of care AND consistently get family-centered care from their doctors and other health care providers AND, if needed, receive effective care coordination AND, if needed, no problems getting referrals

Notes for Data-Users

The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of “medical home”. According to this definition, children ideally should have access to “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home.”

The final medical home composite score used to measure this outcome is derived from the five sub-components constructed below.

SPSS Code and Annotation

```
*****MEDICAL HOME COMPOSITE MEASURE***2007 NSCH*****
*****

*** Sub-component #1 *****
*** PERSONAL DOCTOR OR NURSE *****
*** MEETS sub-component #1 criteria if: pdn=1 *****

COMPUTE pdn = 99.
IF (K4Q04 = 1) pdn = 1.
IF (K4Q04 = 2) pdn = 1.
IF (K4Q04 = 3) pdn = 0.
EXECUTE.
VARIABLE LABELS pdn "Personal Doctor or Nurse sub-component of MEDICAL HOME composite measure".
VALUE LABELS pdn
  0 "No, does not have PDN"
  1 "YES, has at least one PDN".
FORMATS pdn (f4.0).
RECODE pdn (99=SYSMIS).
EXECUTE.
```

*** Sub-component #2 *****
*** FAMILY-CENTERED CARE *****
*** MEETS sub-component #2 criteria if: (famcent=1 or famcent=2) *****

*STEP 1 – Construct 7 interim variables used to score Family-Centered Care measure

COMPUTE time = 99.
IF (K5Q40 = 1 or K5Q40 = 2) time = 0.
IF (K5Q40 = 3 or K5Q40 = 4) time = 1.
IF (sysmis (K5Q40)) time = 2.
EXECUTE.
VARIABLE LABELS time "Doctor spends enough time, past 12 months".

COMPUTE listen = 99.
IF (K5Q41 = 1 or K5Q41 = 2) listen = 0.
IF (K5Q41 = 3 or K5Q41 = 4) listen = 1.
IF (sysmis (K5Q41)) listen = 2.
EXECUTE.
VARIABLE LABELS listen "Doctor listens carefully, past 12 months".

COMPUTE sensitiv = 99.
IF (K5Q42 = 1 or K5Q42 = 2) sensitiv = 0.
IF (K5Q42 = 3 or K5Q42 = 4) sensitiv = 1.
IF (sysmis (K5Q42)) sensitiv = 2.
EXECUTE.
VARIABLE LABELS sensitiv "Doctor is sensitive to family values and customs".

COMPUTE info = 99.
IF (K5Q43 = 1 or K5Q43 = 2) info = 0.
IF (K5Q43 = 3 or K5Q43 = 4) info = 1.
IF (sysmis (K5Q43)) info = 2.
EXECUTE.
VARIABLE LABELS info "Doctor provides needed information, past 12 months".

COMPUTE partner = 99.
IF (K5Q44 = 1 or K5Q44 = 2) partner = 0.
IF (K5Q44 = 3 or K5Q44 = 4) partner = 1.
IF (sysmis (K5Q44)) partner = 2.
EXECUTE.
VARIABLE LABELS partner "Doctor makes parent feel like partner in child's care, past 12 months".

VALUE LABELS time listen sensitiv info partner
0 "Sometimes/Never"
1 "Usually/Always"
2 "No qualifying services".

RECODE K5Q46 (SYSMIS = 999).
COMPUTE interpret = 99.
IF (K5Q46 = 1 or K5Q46 = 2) interpret = 0.
IF (K5Q46 = 3 or K5Q46 = 4) interpret = 1.
IF (K5Q46 = 999) interpret = 2.
EXECUTE.
VARIABLE LABELS interpret "Interpreter provided when needed (primary household language not English)".
VALUE LABELS interpret

0 "Sometimes/Never"
1 "Usually/Always"
2 "Interpreter not needed".

*STEP 2 - Family-Centered Care

MISSING VALUES time listen sensitiv info partner interpret ().

COMPUTE famcent = 99.

IF (time = 0) or (listen = 0) or (sensitiv = 0) or (info = 0) or (partner = 0) or (interpret = 0) famcent = 0.

IF (time = 1 or time = 2) and (listen = 1 or listen = 2) and (sensitiv = 1 or sensitiv = 2) and (info = 1 or info = 2) and (partner = 1 or partner = 2) and ((interpret = 1) or (interpret = 1 or interpret = 2)) famcent = 1.

IF (time = 2) and (listen = 2) and (sensitiv = 2) and (info = 2) and (partner = 2) famcent = 2.

IF (time = 99 or listen = 99 or sensitiv = 99 or info = 99 or partner = 99 or interpret = 99) famcent= 99.

EXECUTE.

VARIABLE LABELS famcent "Family-Centered Care sub-component of MEDICAL HOME measure".

VALUE LABELS famcent

0 "No, does not have FCC"

1 "YES, has Family-Centered Care"

2 "No qualifying services, past 12 months".

FORMATS famcent (f4.0).

RECODE famcent (99=SYSMIS).

*****Comprehensive Care*****

*** Sub-component #3 *****

*** GETTING NEEDED REFERRALS *****

*** MEETS sub-component #3 criteria if: (norefprb=1 or norefprb=2) *****

RECODE K5Q11 (SYSMIS=999).

EXECUTE.

COMPUTE norefprb = 99.

IF (K5Q11 = 1) or (K5Q11 = 2) norefprb = 0.

IF (K5Q11 = 3) norefprb = 1.

IF (K5Q10 = 0) norefprb = 2.

EXECUTE .

VARIABLE LABELS norefprb "Getting Needed Referrals sub-component of MEDICAL HOME measure".

VALUE LABELS norefprb

0 "Big or small problem getting needed referral"

1 "No problem getting needed referral"

2 "Referral not needed".

FORMATS norefprb (f4.0).

RECODE norefprb (99=SYSMIS).

*** Sub-component #4 *****

*** USUAL SOURCES OF CARE *****

*** MEETS sub-component #4 criteria if: usual=1 *****

COMPUTE usual = 99.

IF (K4Q01 = 1 or K4Q01 = 3) and (K4Q02R = 1 or K4Q02R = 3 or K4Q02R = 4 or K4Q02R = 5 or K4Q02R = 6 or K4Q02R = 8 or K4Q02R = 10) usual = 1.

IF (K4Q01 = 2) or (K4Q02R = 2) or (K4Q02R = 7) or (K4Q02R = 9) usual = 0.

IF (K4Q01 >= 6) or (K4Q02R = 996 or K4Q02R = 997) usual = 99.

EXECUTE.

VARIABLE LABELS usual "Usual Sources of Care sub-component of MEDICAL HOME measure".
VALUE LABELS usual
0 "No usual source of care"
1 "YES, has usual source of care".
FORMATS usual (f4.0).
RECODE usual (99=SYSMISS).

*****Coordinated Care*****

*** Sub-component #5 *****
*** EFFECTIVE CARE COORDINATION *****
*** MEETS sub-component #5 criteria if: (carecoor=1 or carecoor=2) *****

*STEP 1 – Construct 3 interim variables used to score Effective Care Coordination

* #1 Communication among health providers – two parts: NEED and SATISFACTION
* NEED for communication among health providers

RECODE K4Q22 (1=1) (0=0) (SYSMISS=999) (6=99) (7=99) INTO K4Q22r.

EXECUTE.

VARIABLE LABELS K4Q22r "Received counseling or treatment from mental health professional, last 12 months, age 2-17".

VALUE LABELS K4Q22r

0 "No"

1 "Yes"

99 "DK/REF"

999 "Under 2 yrs or missing".

FORMATS K4Q22r (f4.0).

COMPUTE need_drcomm = 999.

IF (K4Q22r = 0) or (K4Q24 = 0) need_drcomm = 0.

IF (K4Q22r = 1) or (K4Q24 = 1) need_drcomm = 1.

IF (K4Q22r = 999) and (K4Q24 = 0) need_drcomm = 0.

IF (K4Q22r = 999) and (K4Q24 = 1) need_drcomm = 1.

IF (K4Q22r = 99) and (K4Q24 = 6 or K4Q24 = 7) need_drcomm = 99.

EXECUTE.

VARIABLE LABELS need_drcomm "Received mental health and/or specialist care during past 12 months (drcomm denominator)".

VALUE LABELS need_drcomm

0 "No, did not receive either"

1 "Yes, received one or both"

99 "DK/Ref to both"

999 "SYSMISS to both".

FORMATS need_drcomm (f4.0).

* SATISFACTION with communication between 2 or more health providers

RECODE K5Q30 (1=1) (2=2) (3=3) (4=4) (5=5) (SYSMIS=999) (6=99) (7=99) into K5Q30r.

EXECUTE.

VARIABLE LABELS K5Q30r "Satisfaction with communication among doctors, received two or more service types in past 12 months".

VALUE LABELS K5Q30r

1 "Very satisfied"

2 "Somewhat satisfied"

3 "Somewhat dissatisfied"
4 "Very dissatisfied"
5 "Not needed or not wanted"
99 "DK/REF"
999 "Less than 2 service types".
FORMATS K5Q30r (f4.0).

COMPUTE drcomm = 99.
IF (K5Q30r = 1) and (need_drcomm = 1) drcomm = 1.
IF (K5Q30r = 2 or K5Q30r = 3 or K5Q30r = 4) and (need_drcomm = 1) drcomm = 0.
IF (K5Q30r = 5) and (need_drcomm = 1) drcomm = 2.
IF (need_drcomm = 0) drcomm = 2.
IF (K5Q30r = 999) and (need_drcomm = 1) drcomm = 2.
EXECUTE.

VARIABLE LABELS drcomm "Very satisfied with communication among doctors".
VALUE LABELS drcomm
0 "No, less than very satisfied"
1 "YES, very satisfied"
2 "Not needed"
99 "DK/Ref/missing to any".
FORMATS drcomm (f4.0).

* #2 Communication between doctor and school or other services – 2 parts: NEED and SATISFACTION
* NEED for communication between doctor and school or other services

RECODE K5Q31 (1=1) (0=0) (SYSMIS=999) (6=99) (7=99) into K5Q31r.
EXECUTE.

VARIABLE LABELS K5Q31r "Needed doctor to communicate with school or other services, past 12 months".
VALUE LABELS K5Q31r
0 "No"
1 "Yes"
99 "DK/REF"
999 "No health services".
FORMATS K5Q31r (f4.0).

* SATISFACTION with communication between doctor and school or other services

COMPUTE othcomm = 99.
IF (K5Q31r = 0 or K5Q31r = 999) othcomm = 2.
IF (K5Q32 = 1) othcomm = 1.
IF (K5Q32 = 2 or K5Q32 = 3 or K5Q32 = 4) othcomm = 0.
IF (K5Q32 = 5) othcomm = 2.
EXECUTE.
VARIABLE LABELS othcomm "Very satisfied with communication between doctors and school or other services".
VALUE LABELS othcomm
0 "No, less than very satisfied"
1 "YES, very satisfied"
2 "Not needed"
99 "DK/Ref/missing to any".
FORMATS othcomm (f4.0).

* #3 Care coordination help – two parts: NEED and RECEIVE
* NEED for care coordination or help with care coordination

*numb_services - counts types of services used in previous 12 months;
*used in skip pattern for care coordination items K5Q20, K5Q21, K5Q22

```
COMPUTE numb_services = 0.  
IF (K4Q20r >0 and K4Q20r <100) numb_services = numb_services +1.  
IF (K4Q21r >0 and K4Q21r <100) numb_services = numb_services +1.  
IF (K4Q22 = 1) numb_services = numb_services +1.  
IF (K4Q24 = 1) numb_services = numb_services +1.  
IF (K4Q25 = 1) numb_services = numb_services +1.  
EXECUTE.  
VARIABLE LABELS numb_services "Number of types of services used in past 12 months (medical, dental,  
mental health, specialist)".  
VALUE LABELS numb_services  
0 "Used none"  
1 "Used 1 of four"  
2 "Used 2 of four"  
3 "Used 3 of four"  
4 "Used all 4 service types".  
FORMATS numb_services (f4.0).
```

```
RECODE K5Q20 K5Q21 (0=0) (1=1) (6=99) (7=99) (SYSMIS=999) into K5Q20r K5Q21r.  
EXECUTE.
```

```
VARIABLE LABELS  
K5Q20r "Does anyone help to arrange or coordinate child's health care"/  
K5Q21r "Could use extra help to arrange/coordinate child's health care".  
VALUE LABELS K5Q20r K5Q21r  
0 "No"  
1 "Yes"  
99 "DK/REF"  
999 "Less than 2 service types, past 12 months".  
FORMATS K5Q20r K5Q21r (f4.0).
```

* RECEIVES care coordination help

```
COMPUTE carehelp = 99.  
IF (K5Q20r = 0) and (K5Q21r = 0) carehelp = 2.  
IF (numb_services <=1) carehelp = 2.  
IF (K5Q20r = 1) and (K5Q21r = 0) carehelp = 1.  
IF ((K5Q20r = 99) and (K5Q21r = 0)) or (K5Q21r = 99) or (K5Q22 >=6) carehelp = 99.  
IF (K5Q22 = 3) carehelp = 1.  
IF (K5Q22 = 1) or (K5Q22 = 2) carehelp = 0.  
EXECUTE.  
VARIABLE LABELS carehelp "Gets help or extra help with care coordination when needed, past 12  
months".  
VALUE LABELS carehelp  
0 "No, did not get needed help"  
1 "YES, received needed help"  
2 "Help and/or coordination not needed"  
99 "DK/REF/MISSING to any".  
FORMATS carehelp (f4.0).
```

*STEP 2: Effective Care Coordination

```
COMPUTE carecoor = 99.
IF ((carehelp = 1) or (carehelp = 2)) and ((drcomm = 1) or (drcomm = 2)) and ((othcomm = 1) or (othcomm = 2)) carecoor = 1.
IF (carehelp = 0) or (drcomm = 0) or (othcomm = 0) carecoor = 0.
IF (carehelp = 2) and (drcomm = 2) and (othcomm = 2) carecoor = 2.
IF (carehelp = 99) or (drcomm = 99) or (othcomm = 99) carecoor = 99.
EXECUTE.
VARIABLE LABELS carecoor "Effective Care Coordination sub-component of MEDICAL HOME measure".
VALUE LABELS carecoor
  0 "No, does not have effective care coordination"
  1 "YES, has effective care coordination"
  2 "None needed OR less than 2 service types".
RECODE carecoor (99=SYSMIS).
FORMATS carecoor (f4.0).
```

***** MEDICAL HOME COMPOSITE MEASURE*****

*MEDICAL HOME measure based on the 5 sub-components, using "ON EVERY" scoring approach
*pdn and usual criteria must be met;
*famcent, norefprb, and carecoor must each either be met or legitimate skip

```
COMPUTE MH_comp = 999.
IF ((pdn = 1) and (usual = 1)) and (carecoor = 1 or carecoor = 2) and (norefprb = 1 or norefprb = 2) and (famcent = 1 or famcent = 2) MH_comp = 1.
IF (pdn = 0) or (usual = 0) or (carecoor = 0) or (norefprb = 0) or (famcent = 0) MH_comp = 0.
IF ((SYSMIS (pdn)) or (SYSMIS (usual)) or (SYSMIS (famcent)) or (SYSMIS (norefprb)) or (SYSMIS (carecoor))) MH_comp = 99.
EXECUTE.
VARIABLE LABELS MH_comp "Child's health care meets criteria for all 5 sub-components of medical home measure: personal doctor or nurse, family centered care, getting referrals when needed, usual source of care, and effective care coordination when needed".
VALUE LABELS MH_comp
  0 "No, care DOES NOT meet Medical Home criteria"
  1 "YES, care MEETS ALL Medical Home criteria".
  99 "DK/Ref/missing to 1 or more of 5 sub-components".
MISSING VALUES MH_comp (99).
FORMATS MH_comp (f4.0).
```


2007 National Survey of Children's Health

Unweighted frequency distributions for the
Medical Home sub-components, related interim variables
and composite measure generated by the
SPSS scoring program

Personal Doctor or Nurse (PDN) Component

**PDN sub-component score (PDN)

PERSONAL DOCTOR OR NURSE (PDN)					
Sub-component of MEDICAL HOME composite measure					
pdn		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, does not have a personal doctor or nurse	6203	6.8	6.8	6.8
	1 YES, has at least one personal doctor or nurse	85177	92.9	93.2	100.0
	Total	91380	99.7	100.0	
Missing	System	262	.3		
Total		91642	100.0		

Family-Centered Care Component

**Interim variables for Family-Centered Care sub-component

Doctor spends enough time, past 12 months					
time		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes/Never	14933	16.3	16.4	16.4
	1 Usually/Always	73499	80.2	80.9	97.3
	2 No qualifying services	2472	2.7	2.7	100.0
	Total	90904	99.2	100.0	
Missing	99 DK/REF	738	.8		
Total		91642	100.0		

Doctor listens carefully, past 12 months					
listen		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes/Never	7802	8.5	8.6	8.6
	1 Usually/Always	80807	88.2	88.7	97.3
	2 No qualifying services	2472	2.7	2.7	100.0
	Total	91081	99.4	100.0	
Missing	99 DK/REF	561	.6		
Total		91642	100.0		

Doctor is sensitive to family values and customs

sensitiv		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes/Never	7313	8.0	8.1	8.1
	1 Usually/Always	81019	88.4	89.2	97.3
	2 No qualifying services	2472	2.7	2.7	100.0
	Total	90804	99.1	100.0	
Missing	99 DK/REF	838	.9		
Total		91642	100.0		

Doctor provides needed information, past 12 months

info		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes/Never	11591	12.6	12.7	12.7
	1 Usually/Always	76955	84.0	84.5	97.3
	2 No qualifying services	2472	2.7	2.7	100.0
	Total	91018	99.3	100.0	
Missing	99 DK/REF	624	.7		
Total		91642	100.0		

Doctor makes parent feel like partner in child's care, past 12 months

partner		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes/Never	9380	10.2	10.3	10.3
	1 Usually/Always	79242	86.5	87.0	97.3
	2 No qualifying services	2472	2.7	2.7	100.0
	Total	91094	99.4	100.0	
Missing	99 DK/REF	548	.6		
Total		91642	100.0		

Interpreter provided when needed (primary household language not English)

interpret		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Sometimes/Never	733	.8	.8	.8
	1 Usually/Always	1254	1.4	1.4	2.2
	2 Interpreter not needed	89647	97.8	97.8	100.0
	Total	91634	100.0	100.0	
Missing	99 DK/REF	8	.0		
Total		91642	100.0		

****Family-Centered Care sub-component score (FAMCENT)**

FAMILY-CENTERED CARE (FCC)
Sub-component of MEDICAL HOME composite measure

famcent		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, does not have family-centered care	24461	26.7	27.3	27.3
	1 YES, has family-centered care	62528	68.2	69.9	97.2
	2 No qualifying services, past 12 months	2472	2.7	2.8	100.0
	Total	89461	97.6	100.0	
Missing	System	2181	2.4		
Total		91642	100.0		

Comprehensive Care Component

**** No Problems Getting Needed Referrals sub-component score (NOREFPRB)**

GETTING NEEDED REFERRALS
Sub-component of MEDICAL HOME composite measure

norefprb		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Big or small problem getting needed referral	2538	2.8	2.8	2.8
	1 No problem getting needed referral	12527	13.7	13.7	16.5
	2 Referral not needed	76297	83.3	83.5	100.0
	Total	91362	99.7	100.0	
Missing	System	280	.3		
Total		91642	100.0		

****Usual Sources of Care sub-component score (USUAL)**

USUAL SOURCES OF CARE
Sub-component of MEDICAL HOME composite measure

usual		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No usual source of care	4635	5.1	5.1	5.1
	1 YES, has one or more usual source of care	86809	94.7	94.9	100.0
	Total	91444	99.8	100.0	
Missing	System	198	.2		
Total		91642	100.0		

Coordinated Care Component

****Interim variables Effective Care Coordination sub-component**

Received mental health and/or specialist care, past 12 months (drcomm denominator)

need_drcomm		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, did not receive either	64590	70.5	70.5	70.5
	1 Yes, received one or both	27024	29.5	29.5	100.0
	Total	91614	100.0	100.0	
Missing	99 DK/Ref to both	13	.0		
	999 SYSMISS to both	15	.0		
	Total	28	.0		
Total		91642	100.0		

Very satisfied with communication among doctors

drcomm		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, less than very satisfied	7343	8.0	8.0	8.0
	1 YES, very satisfied	19067	20.8	20.8	28.8
	2 Not needed	65140	71.1	71.2	100.0
	Total	91550	99.9	100.0	
Missing	99 DK/Ref/missing to any	92	.1		
Total		91642	100.0		

Very satisfied with communication between doctors and school or other services

othcomm		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, less than very satisfied	3931	4.3	4.3	4.3
	1 YES, very satisfied	6409	7.0	7.0	11.4
	2 Not needed	80593	87.9	88.6	100.0
	Total	90933	99.2	100.0	
Missing	99 DK/Ref/missing to any	709	.8		
Total		91642	100.0		

Gets help or extra help with care coordination when needed, past 12 months

carehelp		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, did not get needed help	3948	4.3	4.3	4.3
	1 YES, received needed help	13768	15.0	15.1	19.4
	2 Help and/or coordination not needed	73630	80.3	80.6	100.0
	Total	91346	99.7	100.0	
Missing	99 DK/REF/MISSING to any	296	.3		
Total		91642	100.0		

****Effective Care Coordination sub-component score (CARECOOR)**

**EFFECTIVE CARE COORDINATION
Sub-component of MEDICAL HOME composite measure**

carecoor		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, does have effective care coordination	11264	12.3	12.4	12.4
	1 YES, has effective care coordination	26742	29.2	29.5	42.0
	2 None needed OR less than 2 service types, past 12 months	52573	57.4	58.0	100.0
	Total	90579	98.8	100.0	
Missing	System	1063	1.2		
Total		91642	100.0		

Medical Home Composite Measure

**Medical Home Composite Measure score (MH_COMP)

MEDICAL HOME: Children who receive coordinated, ongoing, comprehensive care within a medical home

mh_comp		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, care DOES NOT meet medical home criteria	33669	36.7	38.2	38.2
	1 Care MEETS ALL medical home criteria	54393	59.4	61.8	100.0
	Total	88062	96.1	100.0	
Missing	99 DK/Ref/missing to any	3580	3.9		
Total		91642	100.0		

2007 National Survey of Children's Health

SAS scoring program

2007 NSCH MEDICAL HOME Composite Measure	
Survey Items Used	K4Q04 K5Q40 K5Q41 K5Q42 K5Q43 K5Q44 K5Q46 K5Q11 K5Q10 K4Q01 K4Q02R K4Q22 K4Q24 K5Q30 K5Q31 K5Q32 K4Q20 K4Q21 K4Q25 K5Q20 K5Q21 K5Q22
Numerator	Children/youth meeting scoring criteria for having a Medical Home
Denominator	Children/youth ages 0–17 years
Description	Percent of children ages 0–17 who have a primary care provider (e.g. personal doctor or nurse) AND usual sources of care AND consistently get family-centered care from their doctors and other health care providers AND, if needed, receive effective care coordination AND, if needed, no problems getting referrals
Notes for Data-Users	
<p>The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of “medical home”. According to this definition, children ideally should have access to “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home.”</p> <p>The final medical home composite score used to measure this outcome is derived from the five sub-components constructed below.</p> <p>We are indebted to Deborah Rosenberg, PhD, Research Associate Professor of Epidemiology, School of Public Health, University of Illinois at Chicago, for translating the SPSS Medical Home scoring program developed by CAHMI into SAS format.</p>	
SAS Code and Annotation	
Format statements	
<pre>proc format library = library name; value medhome /*mh_comp*/ 0 = "One or more criteria not met" 1 = "Met all Medical Home criteria"; value pdn_yn /*pdn*/ 0 = "Do not have personal doctor or nurse" 1 = "Yes, has personal doctor or nurse"; value norerefpb /*norefprb*/ 0 = "Big or small problem" 1 = "No problem" 2 = "No referral needed"; value usual /*usuals*/ 0 = "No usual source" 1 = "Yes, has usual source";</pre>	

```

value medhome_yn /*K4Q22R K5Q31R K5Q20R K5Q21R*/
0 = "No"
1 = "Yes";

value need_drcom /*doccommneed*/
0 = "No specialist or mental health"
1 = "Used 1 or both ";

value drsatis /*drcomm_sat*/
0 = "Less than very satisfied"
1 = "Very satisfied"
2 = "Services not used or not needed";

value othcom
0 = "Less than very satisfied"
1 = "Very satisfied"
2 = "Services not used or not needed";

value carehelp /*carehelp*/
0 = "Needed but did not get extra help"
1 = "Got help with and/or extra help needed"
2 = "Less than 2 service types or help not needed";

value care_coor /*carecoor*/
0 = "Did NOT receive all care coordination needed"
1 = "Received all needed components of care coordination"
2 = "Did not need coordination or less than 2 service types";

value fcc /*time listen sensitiv info partner interpret*/
0 = "Sometimes/never"
1 = "Always/usually"
2 = "Did not see doctor";

value famcent_care /*famcent*/
0 = "Does not have FCC"
1 = "Yes, has FCC"
2 = "Did not see doctor";
run;

```

Scoring program

```

data nsch.new;
set nsch.nsch2007_drc;

/*****Personal doctor or nurse (PDN) Component *****/

/*PERSONAL DOCTOR or NURSE sub-component of MEDICAL HOME measure*/
pdn=.;
if K4Q04 in (1,2) then pdn = 1;
else if K4Q04 = 3 then pdn = 0;
else if K4Q04 in (6,7,.M) then pdn = .;
label pdn = "Personal Doctor or Nurse sub-component of MEDICAL HOME measure";

```

```

/*****Comprehensive Care Component *****/

/*GETTING NEEDED REFERRALS sub-component of MEDICAL HOME measure*/
norefprb = .;
if K5Q10 = 0 then norefprb = 2;
else if K5Q10 in (6,7,.M) then norefprb = .;
else if K5Q11 in (1,2) then norefprb = 0;
else if K5Q11 = 3 then norefprb = 1;
else if K5Q11 in (6,7,.M) then norefprb = .;
label norefprb = "Getting Needed Referrals sub-component of MEDICAL HOME
measure";

/*USUAL SOURCES FOR SICK AND WELL CARE sub-component of MEDICAL HOME measure*/
usuals = .;
if K4Q01 in (1,3) and K4Q02R in (1,3,4,5,6,8,10) then usuals = 1;
else if K4Q01 = 2 or K4Q02R in (2,7,9) then usuals = 0;
else if K4Q01 in (6,7) or K4Q02R in (.M,96,97) then usuals = .;
label usuals = "Usual Sources for Sick and Well Care sub-component of MEDICAL
HOME measure";

/*****Coordinated Care Component *****/

/*EFFECTIVE CARE COORDINATION sub-component of MEDICAL HOME measure*/
K4Q22R = K4Q22;
if K4Q22 in (6,7) then K4Q22R = .;
label K4Q22R = "Received counseling or tx from mental hlth professional, last
12 mos";

if K4Q22 = 1 or K4Q24 = 1 then doccommneed = 1;
else if K4Q22 = 0 or K4Q24 = 0 then doccommneed = 0;
else doccommneed = .;
label doccommneed = "Doctor communication needed if specialist, MH, PT/OT/ST,
sub abuse, or home hlth care used";

drcomm_sat = .;
if doccommneed = 0 then drcomm_sat = 2;
else if doccommneed = . then drcomm_sat = .;
else if K5Q30 = 1 then drcomm_sat = 1;
else if K5Q30 in (2,3,4) then drcomm_sat = 0;
else if K5Q30 = 5 then drcomm_sat = 2;
else if K5Q30 in (6,7,.M) then drcomm_sat = .;
else if K5Q30 = .L then drcomm_sat = 2;
label drcomm_sat = "Level of satisfaction with doctor to doctor
communication";

K5Q31R = K5Q31;
if K5Q31 in (6,7) then K5Q31R = .;
label K5Q31R = "Needed doctor communication w/ school or other services"

othcomm = .;
if K5Q31 = 0 then othcomm = 2;
else if K5Q31 in (6,7) then othcomm = .;
else if K5Q32 = 1 then othcomm = 1;
else if K5Q32 in (2,3,4) then othcomm = 0;
else if K5Q32 = 5 then othcomm = 2;

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else if K5Q32 in (6,7,.M) then othcomm = .;
else if K5Q32 = .L then othcomm = 2;
label othcomm = "Level of satisfaction with dr communication w/ school or
other services";

K5Q20R = K5Q20;
if K5Q20 in (6,7) then K5Q20R = .;
label K5Q20R = "Does anyone help to arrange or coordinate child's health
care";

K5Q21R = K5Q21;
if K5Q21 in (6,7) then K5Q21R = .;
label K5Q21R = "Could use extra help to arrange/coordinate child's health
care"

carehelp = .;
if K5Q20 = .L then carehelp = 2;
else if K5Q20 = .M then carehelp = .;
else if K5Q20 = 0 and K5Q21 = 0 then carehelp = 2;
else if K5Q20 in (6,7) and K5Q21 = 0 then carehelp = .;
else if K5Q21 in (6,7) then carehelp = .;
else if K5Q22 in (6,7) then carehelp = .;
else if K5Q20 = 1 and K5Q21 = 0 then carehelp = 1;
else if K5Q22 = 3 then carehelp = 1;
else if K5Q22 in (1,2) then carehelp = 0;
label carehelp = "Gets help with care coordination when needed";

carecoor = .;
if carehelp = . or drcomm_sat = . or othcomm = . then carecoor = .;
else if carehelp = 2 and drcomm_sat = 2 and othcomm = 2 then carecoor = 2;
else if carehelp in (1,2) and drcomm_sat in (1,2) and othcomm in (1,2) then
carecoor = 1;
else if carehelp = 0 or drcomm_sat = 0 or othcomm = 0 then carecoor = 0;
label carecoor = "Effective Care Coordination sub-component of MEDICAL HOME
measure";

/***** Family Centered Care Component *****/
/*FAMILY-CENTERED CARE sub-component of MEDICAL HOME measure*/

time=.;
if K5Q40 in (6,7) then time = .;
else if K5Q40 = .L then time = 2;
else if K5Q40 = 1 or K5Q40 = 2 then time = 0;
else if K5Q40 = 3 or K5Q40 = 4 then time = 1;
label time = "How often doctor spends enough time";

listen=.;
if K5Q41 in (6,7) then listen = .;
else if K5Q41 = .L then listen = 2;
else if K5Q41 = 1 or K5Q41 = 2 then listen = 0;
else if K5Q41 = 3 or K5Q41 = 4 then listen = 1;
label listen = "How often doctor listens carefully";

sensitiv=.;

```



```

if K5Q42 in (6,7) then sensitiv = .;
else if K5Q42 = .L then sensitiv = 2;
else if K5Q42 = 1 or K5Q42 = 2 then sensitiv = 0;
else if K5Q42 = 3 or K5Q42 = 4 then sensitiv = 1;
label sensitiv = "How often doctor sensitive to family values and customs";

info=.;
if K5Q43 in (6,7) then info = .;
else if K5Q43 = .L then info = 2;
else if K5Q43 = 1 or K5Q43 = 2 then info = 0;
else if K5Q43 = 3 or K5Q43 = 4 then info = 1;
label info = "How often doctor provides needed information";

partner=.;
if K5Q44 in (6,7) then partner = .;
else if K5Q44 = .L then partner = 2;
else if K5Q44 = 1 or K5Q44 = 2 then partner = 0;
else if K5Q44 = 3 or K5Q44 = 4 then partner = 1;
label partner = "How often doctor makes parent feel like partner in child's
care ";

interpret=.;
if K5Q46 in (6,7) then interpret = .;
else if K5Q46 = .L then interpret = 2;
else if K5Q46 = 1 or K5Q46 = 2 then interpret = 0;
else if K5Q46 = 3 or K5Q46 = 4 then interpret = 1;
label interpret = "How often able to access interpreter help, if needed (non-
Eng PHL only)";

famcent = .;
if time = . or listen = . or sensitiv = . or info = . or partner = . or
interpret = . then famcent = .;
else if time = 2 then famcent = 2;
else if time in (1,2) and listen in (1,2) and sensitiv in (1,2) and info in
(1,2) and
partner in (1,2) and interpret in (1,2) then famcent = 1;
else if time = 0 or listen = 0 or sensitiv = 0 or info = 0 or partner = 0 or
interpret = 0 then famcent = 0;
label famcent = "Family-centered care sub-component of MEDICAL HOME measure";

/***** MEDICAL HOME COMPOSITE MEASURE*****/

mh_comp = .;
if pdn = . or usuals = . or famcent = . or norefprb = . or carecoor = . then
mh_comp = .;
else if pdn = 2 and usuals = 2 and famcent = 2 and norefprb = 2 and carecoor =
2 then mh_comp = .;
else if pdn = 1 and usuals = 1 and norefprb in (1,2) and famcent in (1,2) and
carecoor in (1,2) then mh_comp = 1;
else if pdn = 0 or usuals = 0 or norefprb = 0 or famcent = 0 or carecoor = 0
then mh_comp = 0;
label mh_comp = "Children whose health care meets criteria for all 5
components of medical home: personal doctor or nurse, usual source of care,
family centered care, getting referrals when needed, and effective care
coordination when needed";

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2007 National Survey of Children's Health

Unweighted frequency distributions for the
Medical Home sub-components, related interim variables
and composite measure generated by the
SAS scoring program

Personal Doctor or Nurse (PDN) Component

**PDN sub-component score (PDN)

Personal Doctor or Nurse sub-component of MEDICAL HOME measure

pdn	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Do not have personal dr or nurse	6203	6.79	6203	6.79
Yes, has personal dr or nurse	85177	93.21	91380	100.00

Frequency Missing = 262

Family-Centered Care Component

**Interim variables for Family-Centered Care sub-component

Doctors usually or always spend enough time, past 12 months

time	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/never	14933	16.43	14933	16.43
Always/usually	73499	80.85	88432	97.28
Did not see doctor	2472	2.72	90904	100.00

Frequency Missing = 738

Doctors usually or always listen carefully, past 12 months

listen	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/never	7802	8.57	7802	8.57
Always/usually	80807	88.72	88609	97.29
Did not see doctor	2472	2.71	91081	100.00

Frequency Missing = 561

Doctors are usually or always sensitive to values and customs

sensitiv	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/never	7313	8.05	7313	8.05
Always/usually	81019	89.22	88332	97.28
Did not see doctor	2472	2.72	90804	100.00

Frequency Missing = 838

Doctors usually or always provide needed information, past 12 months

info	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/never	11591	12.73	11591	12.73
Always/usually	76955	84.55	88546	97.28
Did not see doctor	2472	2.72	91018	100.00

Frequency Missing = 624

Doctors usually or always make the family feel like a partner, past 12 months

partner	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/never	9380	10.30	9380	10.30
Always/usually	79242	86.99	88622	97.29
Did not see doctor	2472	2.71	91094	100.00
Frequency Missing = 548				

An interpreter is usually or always available when needed, past 12 months

interpret	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Sometimes/never	733	0.80	733	0.80
Always/usually	1254	1.37	1987	2.17
Did not see doctor	89647	97.83	91634	100.00
Frequency Missing = 8				

****Family-Centered Care sub-component score (FAMCENT)**

Family-centered care sub-component of MEDICAL HOME measure

famcent	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Does not have FCC	24461	27.34	24461	27.34
Yes, has FCC	62528	69.89	86989	97.24
Did not see doctor	2472	2.76	89461	100.00
Frequency Missing = 2181				

Comprehensive Care Component

**** No Problems Getting Needed Referrals sub-component score (NOREFPRB)**

Getting Needed Referrals sub-component of MEDICAL HOME measure

norefprb	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Big or small problem	2538	2.78	2538	2.78
No problem	12527	13.71	15065	16.49
No referral needed	76297	83.51	91362	100.00
Frequency Missing = 280				

****Usual Sources of Care sub-component score (USUAL)**

Usual Sources for Sick & Well Care sub-component of MEDICAL HOME measure

usuals	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No usual source	4635	5.07	4635	5.07
Yes, has usual source	86809	94.93	91444	100.00
Frequency Missing = 198				

Coordinated Care Component

**Interim variables Effective Care Coordination sub-component

Doctor communication needed if used specialist, mental health, physical, occupational or other special therapy, substance abuse, or home health care

doccommneed	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No specialist or mental health	64590	70.50	64590	70.50
Used 1 or both	27024	29.50	91614	100.00
Frequency Missing = 28				

Level of satisfaction with doctor to doctor communication

drcomm_sat	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Less than very satisfied	7343	8.02	7343	8.02
Very satisfied	19067	20.83	26410	28.85
Not needed or did not use services	65140	71.15	91550	100.00
Frequency Missing = 92				

Level of satisfaction with dr communication with school or other services

othcomm	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Less than very satisfied	3931	4.32	3931	4.32
Very satisfied	6409	7.05	10340	11.37
Not needed or did not use services	80593	88.63	90933	100.00
Frequency Missing = 709				

Gets help with care coordination when needed

carehelp	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Needed but did not get extra help	3948	4.32	3948	4.32
Got help with and/or extra help needed	13768	15.07	17716	19.39
Less than 2 service types or help not needed	73630	80.61	91346	100.00
Frequency Missing = 296				

**Effective Care Coordination sub-component score (CARECOOR)

Effective Care Coordination sub-component of MEDICAL HOME measure

carecoor	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No, needed but did not receive	11264	12.44	11264	12.44
Yes, received effective coordination	26742	29.52	38006	41.96
No need or less than 2 service types	52573	58.04	90579	100.00
Frequency Missing = 1063				

Medical Home Composite Measure

**Medical Home Composite Measure score (MH_COMP)

Children whose health care meets criteria for all 5 medical home components:
personal doctor or nurse, usual source of care, family centered care,
getting referrals when needed, and effective care coordination when needed

mh_comp	Frequency	Percent	Cumulative Frequency	Cumulative Percent
<i>ff</i>				
One or more criteria not met	33669	38.23	33669	38.23
Met all Medical Home criteria	54393	61.77	88062	100.00

Frequency Missing = 3580

2007 NATIONAL SURVEY OF CHILDREN'S HEALTH

Full text and response options for questions
used to assess Medical Home

2007 NSCH

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<u>SECTION 4: HEALTH CARE ACCESS AND UTILIZATION</u>	
<p>K4Q01: Is there a place that (S.C.) USUALLY goes when (he/she) is sick or you need advice about (his/her) health?</p> <p><i>If Yes to K4Q01:</i> K4q02: What kind of place is it?</p>	<p>(1) YES (2) THERE IS NO PLACE [SKIP TO K4Q04] (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW [SKIP TO K4Q04] (7) REFUSED [SKIP TO K4Q04]</p> <p>(01) DOCTOR'S OFFICE (02) HOSPITAL EMERGENCY ROOM (03) HOSPITAL OUTPATIENT DEPARTMENT (04) CLINIC OR HEALTH CENTER (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (06) FRIEND/RELATIVE (07) MEXICO/OTHER LOCATIONS OUT OF US (08) SOME OTHER PLACE (09) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED</p>
<p>K4Q04: A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant.</p> <p>Do you have one or more persons you think of as (S.C.)'s personal doctor or nurse?</p>	<p>(1) YES, ONE PERSON (2) YES, MORE THAN ONE PERSON (3) NO (6) DON'T KNOW (7) REFUSED</p>
<u>SECTION 5: MEDICAL HOME</u>	
<p>K5Q10: During the past 12 months, did (S.C.) need a referral to see any doctors or receive any services?</p> <p><i>If Yes to K5Q10:</i> K5Q11: Was getting referrals a big problem, a small problem, or not a problem?</p>	<p>(1) YES [SKIP TO K5Q20] (2) NO [SKIP TO K5Q20] (6) DON'T KNOW [SKIP TO K5Q20] (7) REFUSED [SKIP TO K5Q20]</p> <p>(1) Big problem (2) Small problem (3) Not a problem (6) DON'T KNOW (7) REFUSED</p>

2007 NSCH

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<p>CATI INSTRUCTION: Sum up the number of services from Section 4, Subdomain 2</p> <p>DEFINE VARIABLE NUMB_SERVICES = 0. IF K4Q20 ≥ 1, NUMB_SERVICES = NUMB_SERVICES + 1 IF K4Q21 ≥ 1, NUMB_SERVICES = NUMB_SERVICES + 1 IF K4Q22 = 1, NUMB_SERVICES = NUMB_SERVICES + 1 IF K4Q24 = 1, NUMB_SERVICES = NUMB_SERVICES + 1 IF K4Q25 = 1, NUMB_SERVICES = NUMB_SERVICES + 1</p> <p>CATI INSTRUCTION (K5Q20): IF NUMB_SERVICES IS < 2, THEN SKIP TO K5Q31.</p> <p>K5Q20: Does anyone help you arrange or coordinate (S.C.)’s care among the different doctors or services that (he/she) uses?</p> <p>K5Q21: During the past 12 months, have you felt that you could have used extra help arranging or coordinating (S.C.)’s care among these different health care providers or services?</p> <p><i>If Yes to K5Q21:</i></p> <p>K5Q22: During the past 12 months, how often did you get as much help as you wanted with arranging or coordinating (S.C.)’s care?</p>	<p>(1) YES (2) NO (6) DON’T KNOW (7) REFUSED</p> <p>(1) YES (2) NO (6) DON’T KNOW (7) REFUSED</p> <p>[SKIP TO K5Q30] [SKIP TO K5Q30] [SKIP TO K5Q30]</p> <p>(1) Never (2) Sometimes (3) Usually (6) DON’T KNOW (7) REFUSED</p>
<p>K5Q30: Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among (S.C.)’s doctors and other health care providers?</p>	<p>(1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied (5) NO COMMUNICATION NEEDED OR WANTED (6) DON’T KNOW (7) REFUSED</p>

2007 NSCH

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<p>CATI INSTRUCTION (K5Q31): IF NUMB_SERVICES = 0, THEN SKIP TO K5Q45.</p> <p>K5Q31: Do (S.C.)’s doctors or other health care providers need to communicate with:</p> <ul style="list-style-type: none"> (a) Child care providers or early intervention program (<i>ages 0-2 years</i>)? (b) Child care providers, school, or special education program (<i>ages 3-5 years</i>)? (c) School or special education program (<i>ages 6-17 years, non-</i> (d) School or special education program (<i>ages 6-11 years, CSHCN</i>)? (e) School, special education program, or vocational education program (<i>ages 12-17 years, CSHCN</i>)? <p><i>If Yes to K5Q31:</i></p> <p>K5Q32: Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication?</p>	<ul style="list-style-type: none"> (1) YES (2) NO (6) DON’T KNOW (7) REFUSED <p style="text-align: right;">[SKIP TO K5Q40] [SKIP TO K5Q40] [SKIP TO K5Q40]</p> <ul style="list-style-type: none"> (1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied (5) NO COMMUNICATION NEEDED OR WANTED (6) DON’T KNOW (7) REFUSED
<p>K5Q40: During the past 12 months, how often did (S.C.)’s doctors and other health care providers spend enough time with (him/her)?</p>	<ul style="list-style-type: none"> (1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED
<p>K5Q41: During the past 12 months, how often did (S.C.)’s doctors and other health care providers listen carefully to you?</p>	<ul style="list-style-type: none"> (1) Never (2) Sometimes (3) Usually (4) Always (6) DON’T KNOW (7) REFUSED

2007 NSCH

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
K5Q42: When (S.C.) is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED
K5Q43: During the past 12 months, how often did you get the specific information you needed from (S.C.)'s doctors and other health care providers?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED
K5Q44: During the past 12 months, how often did (S.C.)'s doctors or other health care providers help you feel like a partner in (his/her) care?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED
K5Q45: During the past 12 months, did you (or S.C.) need an interpreter to help speak with (his/her) doctors or other health care providers? <i>If Yes to K5Q45:</i> K5Q46: When you (or S.C.) needed an interpreter, how often were you able to get someone other than a family member to help you speak with (his/her) doctors or other health care providers?	(1) YES (2) NO (6) DON'T KNOW (7) REFUSED (1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED

APPENDIX E

List of selected Publications using
Medical Home measures from the
NS-CSHCN and the NSCH

Medical home articles using 2001 NS-CSHCN:

Baruffi G, Miyashiro L, Prince CB, Heu P. Factors associated with ease of using community-based systems of care for CSHCN in Hawai'i. *Maternal and Child Health Journal*, 2005; 9, Supplement 2: S99-S108.

Benedict RE. Quality medical homes: meeting children's needs for therapeutic and supportive services. *Pediatrics* 2008; 121(1):e1-e8.

Bethell CD, Read D, & Brockwood K. Using existing population-based data sets to measure the American Academy of Pediatrics definition of medical home for all children and children with special health care needs. *Pediatrics* 2004; 113(Suppl):1529-1537.

Fulda KG, Lykens K, Bae S, Singh K. Factors for accessing a medical home vary among CSHCN from different levels of socioeconomic status. *Maternal and Child Health Journal* 2009; 13:445-456.

Lewis C, Robertson AS, Phelps S. Unmet dental care needs among children with special health care needs: implications for the medical home. *Pediatrics* 2005; 116(3):e426-31.

McPherson M, Weissman G, Strickland BB, van Dyck PC, Blumberg SJ, Newacheck PW. Implementing community-based systems of services for children and youths with special health care needs: how well are we doing? *Pediatrics* 2004; 113, Supplement: 1538-1544.

Nageswaran S, Roth MS, Kluttz-Hile CE, & Farel A. Medical homes for children with special healthcare needs in North Carolina. *North Carolina Medical Journal* 2006; 67(2):103-9.

Oswald DP, Bodurtha JN, Willis JH, Moore MB. Underinsurance and key health outcomes for children with special health care needs. *Pediatrics*. 2007; 119(2):e341-7.

Rosenberg D, Onufer C, Clark G, Wilkin T, Rankin K, Gupta K. The need for care coordination among children with special health care needs in Illinois. *Maternal and Child Health Journal*, 2005; 9, Supplement 2: S41-S47.

Strickland B, McPherson M, Weissman G, van Dyck P, Huang ZJ, Newacheck PW. Access to the medical home: results of the National Survey of Children with Special Health Care Needs. *Pediatrics* 2004; 113, Supplement: 1485-1492.

Tippy K, Meyer K, Aronson R, Wall T. Characteristics of coordinated ongoing comprehensive care within a medical home in Maine. *Maternal and Child Health Journal*, 2005; 9, Supplement 2: S13-S21.

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics. *Progress toward Implementing Community-Based Systems of Services for Children with Special Health Care Needs*. Washington, DC. 2003.

Wang G, & Watts C. Genetic counseling, insurance status, and elements of medical home: analysis of the national survey of children with special health care needs. *Maternal and Child Health Journal* 2007 11(6):559-67. Epub 2007 Feb 27.

Medical home articles using 2003 NSCH:

Allred NJ, Wooten KG, Kong Y. The association of health insurance and continuous primary care in the medical home on vaccination coverage for 19- to 35-month-old children. *Pediatrics*. 2007; 119, Supplement: S4-S11.

Bethell, CD, Read, D, & Brockwood, K. Using existing population-based data sets to measure the American Academy of Pediatrics definition of medical home for all children and children with special health care needs. *Pediatrics* 2004; 113(5Suppl):1529-1537.

Brachlow AE, Ness KK, McPheeters ML, Gurney, J.G. Comparison of indicators for a primary care medical home between children with autism or asthma and other special health care needs: National Survey of Children's Health. *Archives of Pediatrics and Adolescent Medicine*. 2007; 161, 4: 399-405.

Bramlett MD, Radal LF, Blumberg SJ. The health and well-being of adopted children. *Pediatrics*. 2007; 119, Supplement 1; S54-S60.

Mulvihill BA, Altarac M, Swaminathan S, Kirby RS, Kulczycki A, Ellis DE. Does access to a medical home differ according to child and family characteristics, including special-health-care-needs status, among children in Alabama? *Pediatrics*. 2007; 119, Supplement: S107-S113.

Zeni MB, Sappenfield W, Thompson D, Chen H. Factors associated with not having a personal health care provider for children in Florida. *Pediatrics* 2007; 119, Supplement : S61-S67.

