CAHPS 2.5H Child Survey

A method for modifying the CAHPS 2.0H Child Survey to measure experience of care for children with ongoing health conditions

Measure Work-Up

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CAHPS 2.5H Child Survey Measure Work-up

Background and Acknowledgements

The components of the proposed CAHPS 2.5H Child Survey allowing the measurement of experience of care for children with ongoing health conditions were developed under the auspices of the Child and Adolescent Health Measurement Initiative's (CAHMI) Living with Illness Task Force and in collaboration with the CAHPS research team. Its development has been largely funded by FACCT—The Foundation for Accountability through grant support from the David and Lucile Packard Foundation and The Robert Wood Johnson Foundation. The Agency for Healthcare Research and Quality (AHRQ) provided funding for the CAHPS® research team participation. Taken together, the CAHPS 2.5H Child Survey components specific to the measurement of care for children with ongoing health conditions has been called the Children with Special Health Care Needs (CSHCN) Module in the context of the CAHMI/CAHPS collaboration. The CSHCN Module is formally endorsed by the National Advisory Committee of the Child and Adolescent Health Measurement Initiative (CAHMAC) and recommended to NCQA for inclusion in HEDIS. See Attachment A for a list of CAHMAC members and copies of letters endorsing this effort from the CAHMAC and the AHRQ/CAHPS research team.

The following individuals have provided substantial and ongoing input regarding the development and testing of the Children with Special Health Care Needs screening tool, sampling strategy and supplemental survey items and measures included in the proposed CAHPS 2.5H Child Survey methodology. See Attachment A for a full list of Living With Illness Task Force Members.

- Julie Brown, RAND
- Paul Cleary, Harvard Medical School
- Susan Epstein, New England SERVE
- Shirley Girouard, formerly of NACHRI
- Jack Fowler, University of Massachusetts
- John Hochheimer, National Committee for Quality Assurance
- Charles Homer, Boston Children's Hospital
- Debbie Klein Walker, Massachusetts Department of Public Health
- Peggy McManus, Maternal and Child Health Policy Research Center
- Merle McPherson, Maternal and Child Health Bureau
- John Neff, Center for the Study of Children With Special Health Care Needs
- Paul Newacheck, UCSF Medical Center
- James Perrin, Massachusetts General Hospital
- Joe Thompson, Arkansas Children's Hospital
- Ruth Stein, Albert Einstein College of Medicine
- Nora Wells, Family Voices

Christina Bethell, PhD, Senior Vice President at FACCT-The Foundation for Accountability, is Director of the CAHMI and principle investigator for the development and testing of the CSHCN Module. Debra Read, MPH, is the senior research associate for the CSHCN project. Alice Lind, RN, of the Washington State Medical Assistance Administration has played a key role in the Statewide deployment and piloting of the proposed CAHPS 2.5H Child Survey. Ken House, MA, consultant, helped with the application of the CSHCN Module prescreening and sampling approach. Debbie Levy provided administrative and research assistance.

DEFINITION OF THE CAHPS® 2.5H CHILD SURVEY

A. **Description**

The CAHPS® 2.5H Child Survey is recommended as a replacement to the CAHPS® 2.0H Child Survey. The key difference from the CAHPS® 2.0H Child Survey is that the proposed CAHPS® 2.5H Child Survey includes sampling guidelines and survey items that allow the CAHPS® 2.0H Child Survey composites as well as four additional measures to be scored separately for children with chronic or special health care needs. Overall, 36 new survey items and 4 new measurement domains have been added, the sample size is approximately doubled and data collection and reporting are conducted every two years instead of the current annual requirements.

Data collected with the CAHPS® 2.5H Child Survey provides information from two groups of parents of children age 12 and under: 1) the general health plan population of children age 12 and under; 2) children in the health plan, age 12 and under, having ongoing chronic conditions who meet the definition of children with special health care needs (CSHCN) set forth by the Maternal and Child Health Bureau:

> *"Children with special health care needs are those who have…a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[1]*
> *Definition developed by the Maternal and Child Health Bureau, July 1998*

While a "gold standard" definition of children with special health care needs does not exist, the Maternal and Child Health Bureau definition is based on widespread national consensus and was specifically chosen because it is broad enough to include children with a range of ongoing health conditions. The selection of such a broad definition is based on the conclusion that the quality issues addressed in the CAHPS® 2.5H Child Survey are relevant to all families and children, regardless of the specific clinical nature, severity or stability of the condition represented. The screening tool incorporated into the CAHPS® 2.5H Child Survey is specifically based on the Maternal and Child Health Bureau definition of CSHCN.

The proposed CAHPS® 2.5H Child Survey has five components:
1) The core general patient experience of care survey, the CAHPS® Child Survey
2) A screening tool, the CSHCN screener, to identify children with special health care needs according to the Maternal and Child Health Bureau definition.
3) A question supplement including survey items especially relevant to CSHCN
4) A diagnostic code-based algorithm used in an enriched sampling strategy that allows the starting sample size required to identify a cohort of CSHCN to be substantially reduced
5) Guidelines for scoring the new CSHCN measures derived from the CAHPS® 2.5H Child Survey.

Reported experience of care and levels of satisfaction reported through the CAHPS® 2.5H Child Survey provide a general indication of how well the MCO meets member needs and

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[1] McPherson, M, Arango, P, Fox, H, Lauver, C, McManus, M, Newacheck, P, Perrin, J., Shonkoff, J, Strickland, B "A New Definition of Children with Special Health Care Needs" Pediatrics, V102, No. 1, pp137-140, July, 1998.

expectations. The CSHCN measures derived from the survey are applicable to the commercial and Medicaid product lines.

B. **Measure Specifications**

The CAHPS® 2.5H Child Survey measures use enrollment data to identify health plan members who are age 12 years and under at the end of the reporting period. Administrative encounter records are used to prescreen all children eligible for the survey for the presence of a probable chronic or special health need. A random sample of all children meeting enrollment and age criteria is drawn. An additional sample is drawn of children meeting enrollment and age criteria as well as the diagnostic, administrative data based algorithm for having a probable chronic health condition. The CAHPS® 2.5H Child Survey is administered using the standardized HEDIS mail protocol with telephone follow up. Only those children who meet the survey-based CSHCN screening tool criteria for having a chronic or special health care need are included in the calculation of the CSHCN measures. Health plan-level performance scores or rates are derived from the survey data. Separate sampling and calculations are recommended for Medicaid and commercial populations.

Eligible Population

Product Line(s):	Medicaid, commercial (report each population separately).
Age(s):	12 years and under as of December 31 of the measurement year.
Continuous Enrollment:	The measurement year for commercial enrollees and at least 6 months of the measurement year for Medicaid enrollees.
Allowable Gap:	No more than one gap in continuous enrollment of up to 45 days during the measurement year. To determine continuous enrollment for a Medicaid beneficiary for whom enrollment is verified monthly, the member may not have more than a one month gap in coverage (i.e., a member whose coverage lapses for more than two months (60 days) is not considered continuously enrolled).
Anchor Dates:	Enrolled as of December 31 of the measurement year.
Benefits(s):	Medical.
Event/Diagnosis:	Where applicable, parent reports at least one health care visit in the past year; past 6 months for Medicaid.

Denominator: The eligible population for the CAHPS 2.5H Child Survey. The CSHCN measures are subset to the denominator of positively identified by the CSHCN screening tool included in the survey. See Attachment B for a copy of the CSHCN screening tool.

Numerator: The numerators for each of the CSHCN measures are based on qualifying responses to specific CAHPS 2.5H Child Survey questions. See Table 1 for a description of each measure and Attachment D for detailed recommendations on scoring the CSHCN measures.

Table 1: Summary of CSHCN measures derived from the CAHPS® 2.5H Child Survey

CSHCN measures	Survey item content	Scoring
CAHPS® How Well Drs Communicate	Parent/family report on whether doctors/providers spend enough time with child, show respect and listen, explain things clearly.	-Average score on multi-item composite transformed to 0-100 for ease of interpretation.
CAHPS® Getting Care Quickly	Parent/family report on experience on scheduling appointments and wait times and getting phone advice, emergency or urgent care when needed.	-Average score on multi-item composite transformed to 0-100 for ease of interpretation.
CAHPS® Getting Needed Care	Parent/family report on experience with finding a personal dr/nurse and getting referrals to specialists; delays to care by health plan.	-Average score on multi-item composite transformed to 0-100 for ease of interpretation.
CAHPS® Courteous & Helpful Office Staff	Parent/family report on experience with respectfulness and helpfulness of the office staff from their child's doctors/providers offices.	-Average score on multi-item composite transformed to 0-100 for ease of interpretation.
CAHPS® Customer Service	Parent/family report on experience with customer service, written plan materials and paperwork	-Average score on multi-item composite transformed to 0-100 for ease of interpretation.
CSHCN Getting Prescription Medicines	Parent/family report on experience getting medication prescribed for their child.	-Proportion of those getting prescription medicines who report either no problem obtaining the prescribed medication or receiving help with any problem experienced. See Attachment D for details.
CSHCN Getting Specialized Services	Parent/family report on experience with access to medical equipment, devices, or specialized therapies for child as needed.	-Averaged proportion across all specialized services of those needing a service who report either no problem getting services or receiving help with any problem experienced. See Attachment D for details.
CSHCN Family Centered Care • Part A: *Personal Dr / Nurse who Knows Child* • Part B: *Shared Decision making* • Part C: *Getting Needed Information about Child's Health*	Parent/family report on whether child's personal dr or nurse knows child/family and impact of child's condition on the child and family Parent/family report on whether doctors/providers actively involved parents/families in decisions about child's health and health care. Parent/family report on whether they receive sufficient information from doctor/provider about their child's condition and the skills needed to care for child.	-Report each part separately as mean scores on multi-item composites OR -Combine Part B and Part C into a Family Centered Care multi-item composite transformed to 0-100 for ease of interpretation. See Attachment D for details.
CSHCN Coordination of Care & Services	Parent/family report on whether they receive help from child's providers to coordinate child's care among multiple providers and/or the school system.	-Average proportion of YES responses across appropriately answered questions.

The data collection procedures for the CAHPS® 2.5H Child Survey are the same as for the previous CAHPS® 2.0H Child Survey. The data collection protocols are designed to capture accurate and complete information about consumer-reported experiences with health care. Refer to HEDIS® 2000 Volume 3 for specific details. The data collection procedures outlined in HEDIS® 2000 Volume 3 promote both the standardized administration of survey instruments by different survey research firms and the comparability of resulting health plan data.

A. Sample Frame

Medicaid Enrollees. The enrolled Medicaid membership of a health plan comprises the sample frame of the survey. Those eligible for sampling include current Medicaid health plan members at the time the sample is drawn by the survey vendor, age 12 years or younger as of December 31 of the measurement year, and who have been continuously enrolled in the health plan for at least 6 months of the measurement year.

Commercial Enrollees. The enrolled commercial membership of a health plan comprises the sample frame for the survey. Child commercial members include those whose parent or caregiver is covered by an employer or group policy or who have joined the health plan through an individual or family policy. Those eligible for sampling include current commercial health plan members at the time the sample is drawn by the survey vendor, age 12 years or younger as of December 31 of the measurement year, and who have been continuously enrolled in the health plan for the 12 months of the reporting year.

B. Sampling Strategy

An enriched sampling approach in used for the CAHPS® 2.5H Child Survey. Children with chronic or special health care needs represent a relatively small proportion of the total population of children, therefore, administrative data are used to identify a subset of children with a higher probability of meeting the CSHCN screening tool included in the survey. The starting sample for the CAHPS® 2.5H Child Survey is stratified to include both a random sample of all eligible child health plan members and a sample from the group of children identified as having a higher probability of meeting the CSHCN screening criteria. This methodology allows a statistically adequate denominator of CSHCN to be identified while reducing the overall starting sample size required to do so.

To identify a cohort of children more likely to meet the CSHCN screening criteria, administrative encounter records are used to prescreen all children eligible to be surveyed for the presence of a diagnostic code indicative of a chronic or special health need. Administrative data over a 24-month period are examined using a pre-specified list of diagnostic codes (See Attachment C for list of diagnostic codes used in prescreening algorithm). Based upon prescreening results, each child member is assigned one of three statuses: 1) No encounter records found; 2) Encounter records DO NOT MEET criteria for having a probable chronic or special health need; 3) Encounter records MEET criteria for having a probable chronic or special health need.

After prescreening statuses are determined, two samples are drawn. Sample A (Regular CAHPS sample) is a randomly selected population-based sample of 850 (commercial); 1050 (Medicaid) survey eligible child members.

After Sample A is selected, the remaining survey eligible children are subset to ONLY the group of children meeting the prescreening criteria for having a probable chronic or special health need. A second random sample (Sample B: Prescreened Sample) of 1541 (commercial); 1589 (Medicaid) is selected from this group. The purpose of the stratified sample is to increase the number of children with a better than average probability of meeting the survey-based CSHCN screener criteria for currently having a chronic or special health need. The CAHPS® 2.5H Child Survey is administered to both Samples A and B.

Table 2: Issues and Guidelines for Sampling Strategy

Issue	Response	Notes
Description of approach	A stratified sampling approach over-samples for children identified via the diagnostic code-based utilization algorithm as having a higher than average probability of meeting the survey-based CSHCN screening tool. _Sample A_: (Regular CAHPS sample) Random sample from all eligible child members: 850 commercial; 1050 Medicaid _Sample B_: (Prescreened sample) Random sample from child members meeting the prescreen criteria for having a probable chronic or special health need: 1541 commercial);1589 Medicaid CSHCN screening tool administered through the CAHPS 2.5H Child Survey is used to identify those children currently meeting the non-categorical criteria for having a chronic or special health need.	Advantages to enriched sampling approach: • Smaller initial sample size compared with population-based sample alone • Stratifying sample allows CSHCN who may be missed by utilization data to be included through the survey-based screening tool Disadvantages to enriched sampling approach: • Plan may vary in ability to consistently apply utilization algorithms

Details of methodology	**Step 1:** Using claims/encounter data, prescreen all survey eligible child members to identify group with one or more qualifying ICD-9 indicative of a probable chronic or special health need.
	Step 2: Assign prescreening results status to all survey eligible child members:
	  1) No encounters records found
	  2) Encounter records DO NOT meet prescreen criteria for probable chronic or special health need.
	  3) Encounter records MEET prescreen criteria for probable chronic or special health need.
	Step 3: Randomly sample 850 (commercial) ; 1050 (Medicaid) from survey eligible child members (Sample A: Regular CAHPS sample)
	Step 4: Subset remaining survey eligible child members to ONLY the group meeting the prescreening criteria for having a probable chronic or special health need. Randomly sample 1541 (commercial); 1589 (Medicaid) children meeting prescreening criteria (Sample B: Prescreened sample).
	
	Step 5: Administer CAHPS® 2.5H Child Survey to both Sample A and Sample B. Based on results from the CSHCN screening tool used in the survey, identify denominator of children currently qualifying as CSHCN.
		In cases where 1541/1589 children are not identified due to small plan size, Sample B can be supplemented with a random sample of remaining survey eligible child members. This methodology was implemented for several plans in the CAHMI WA State pilot study. Results yielded adequate numbers of CSHCN for plan comparison on nearly all CSHCN measures. Details available on request.

C. Sample Size

Medicaid Enrollees. The sample size for Medicaid health plans is 2639 (1050 Sample A: Regular CAHPS sample; 1589 Sample B: Prescreened sample).

Commercial Enrollees. The sample size for commercial health plans is 2391 (850 Sample A: Regular CAHPS sample; 1541 Sample B: Prescreened sample).

Sample size estimates are based on assumptions regarding statistical power and significance for detecting performance differences, survey response rate, the expected proportions of children who screen positive on the CSHCN screener in the population sample (Sample A: Regular CAHPS sample) and in the group pre-identified as having a probable chronic or special health need (Sample B: Prescreened sample). Table 3 below presents the enriched sampling protocol results from the CAHMI Washington State Medicaid Pilot Study. Details of the size estimates for the CAHPS® 2.5H Child Survey are shown in Table 4.

Table 3: Percentage of children meeting CSHCN screener criteria
CAHMI WA State Medicaid Pilot Study-Interim data / 5 health plans (n = 5225) *
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	SAMPLE A (Regular CAHPS sample)	**SAMPLE B** (Prescreened sample)	**ALL children** (Sample A and Sample B combined)
% children screening 'positive' on CSHCN screening tool	Returned surveys n = 2156	Returned surveys n = 3069	Returned surveys n = 5525
	22.1%	51.4%	39.3 %

* Based on the 5 sites fielding full prescreened samples of n = 1500 / English language surveys ONLY.

Table 4: Issues and Assumptions for Calculating Estimated Sample Size Requirements

Issue	Response	Notes
Final estimate of the number of completed surveys needed, based on the power to detect differences among health plans	Traditionally, HEDIS measure sample sizes are calculated based on a 'worst case' assumption of 50% and use power calculation formulas to detect a 10% difference between two proportions. Using the traditional HEDIS calculations for sample size yield a final returned survey minimum sample size of 411.	In the absence of additional guidance, the desired number of returned surveys needed for the CSHCN measure is 411.
The expected proportion of children in the general population screening positive for chronic conditions	Data from CAMHI field trials and other studies: • Average commercial CSHCN = 16.1% • Average Medicaid CSHCN = 20.0%	Population-based sample CSHCN (number sampled X expected proportion) Commercial = 136 CSHCN (850 X .161) Medicaid = 210 CSHCN (1050 X .20)
The expected response rate of the survey	Data from NCQA HEDIS reporting: • Average commercial RR – 43.8% • Average Medicaid RR – 39.7% NOTE: CAMHI field trials have consistently achieved response rates (based on NCQA definition) of 52% or better for both commercial and Medicaid health plan sites using the CAHPS 2.5H Child Survey.	Population-based sample (using NCQA response rate estimates) Commercial = 60 CSHCN (136 X .438) Medicaid = 83 CSHCN (210 X .397) Additional CSHCN needed for n = 411 Commercial = 351 (411 – 60) Medicaid = 328 (411 – 83)
The expected catch from the diagnostic code-based prescreening algorithm	Data from CAMHI field trial and pilot studies (See Table 3) Approximately 52% children identified as having probable chronic or special health needs can be expected to screen positive in the CSHCN screening tool.	Prescreened sample estimates (response from over-sample/catch/response rate) Commercial = 1541 (Sample B) Medicaid = 1589 (Sample B)
Final sample size calculation for CAHPS® 2.5H Child Survey	Commercial: 850 + 1541 = 2391 Medicaid: 1050 + 1589 = 2639	When changed from current annual requirement to every 2 years implementation, net increase over existing approach is about 691 surveys for commercial and 539 for Medicaid

D. Costs of Sampling and Administration

Cost estimates for the CAHPS® 2.5H Child Survey are outlined in the table below. As can be seen, increases in costs over current CAHPS® 2.0H Child Survey administration are estimated to be $3455-$11,056 for commercial plans and $2695-$8624 for Medicaid plans.

Table 5: Issues and Assumptions Regarding Cost of Sampling and Administration

Issue	Response	Notes
Cost assumptions	Unit cost estimates from prior CAHPS® experience at NCQA show that this will range from $5 to $16 per survey fielded.	
Cost estimates – CAHPS® 2.5H Child Survey	Commercial • Low cost, average response - $11,955 • High cost, average response - $38,256 Medicaid • Low cost, average response - $13,195 • High cost, average response - $42,224	Estimates based on Commercial = 2391 surveys fielded Medicaid = 2639 surveys fielded

E. Type of Measure

This measure is in the Experience of Care Domain and evaluates several processes for children with chronic conditions or special health care needs. Performance scores are appropriate for reporting in the Living with Illness reporting category.

F. Data Requirements

Enrollment data are used to identify eligible child plan members from whom a stratified random sample is drawn. Parents of sampled eligible members are surveyed to evaluate the experiences with their child's care. The survey uses the CAHPS® 2.5H Child Survey as the basis and identifies children with chronic conditions or special health care needs via the CSHCN screener tool administered as a part of the survey.

Measures that provide specific information about care for children with special health care needs, or chronic conditions, fill a unique gap in HEDIS (Kuhlthau, Walker, Perrin, et al., 1998, Pediatric Framework for Accountability, NCQA, 1999). On face value, the health care needs of children with and without chronic conditions differ substantially, especially in terms of the intensity, duration and type of health care services required and the ongoing parent/child needs for health information, education, partnership with providers and coordination of care. There is high interest and expert consensus around the importance of assessing the dimensions of quality of care received by the subset of children identified through the CSHCN screening tool included in the CAHPS® 2.5H Child Survey (Newacheck, Stein, Walker, et al., 1996).

The CSHCN measures incorporate information about the performance of health plans on basic aspects of care that parents and families say matter most, as well as aspects of care reflected in both condition specific and non-condition specific guidelines for the care of children with chronic or special health care needs (Koop, 1987, AAP, 1996, Garwick, Kohrman, 1998., Kihehl, et al., 1991, Newacheck, Stoddard, McManus, 1991, Family Voices, FACCT, 1996 and 1998).

With the onset of the State Children's Health Insurance Program and the growing Congressional requirements for Medicaid performance assessment, there is an urgent need in the field for a simple, straightforward, standard method to identify comparable groups of children with special health care needs in a reliable manner across multiple settings and to evaluate the quality of care for this group of children.

Identifying a comparable denominator of children with special health care needs

Unlike adults, the epidemiology of childhood chronic conditions is characterized by a large number of diagnoses, most with relatively low prevalence (Newacheck and Taylor, 1992, Newacheck and Halfon, 1998). Childhood diabetes, for example, has a prevalence of 1.8 per thousand children. In an average size health plan of 90,000 covered lives with approximately 30,000 children, only fifty-four children would be expected to have diabetes. Most other diagnoses affect even fewer children. Consequently, monitoring any single childhood condition and implementing condition-specific clinical measures is not feasible for HEDIS.[2] Single condition monitoring also provides an inadequate view of the overall quality and outcomes of care for children with chronic or special health care needs and could promote adverse selection.

There is increasing agreement among consumer, expert and policymaker audiences that a non-condition specific approach based on health consequences experienced by children, rather than diagnoses given to children by health care providers, is preferred as a method to identify children with chronic or special health needs. This approach has been demonstrated to produce a more complete and representative cohort of children compared to condition checklists or diagnosis codes recorded in administrative data (Stein, 1997).

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[2] The one exception may be condition specific clinical and self-report measures for children with asthma, which represents one quarter to one third of children with chronic conditions. Even with asthma, however, many sample size concerns still exist for smaller health plans.

Studies of the reliability, accuracy and completeness of condition checklists and diagnostic, administrative data suggest that fewer and different children will be identified than is accurately representative of the cohort of children who have a chronic or special health care need. For instance, administrative diagnostic data can be expected to identify 8-11% of a population of children enrolled in a managed care plan as having a chronic or special health care need, whereas population based studies using a comprehensive screening approach typically identify 16-20% of children.   Moreover, children not identified using diagnostic data consistently cluster within conditions that are mental, emotional, behavioral or developmental in nature. Such identification bias would lead to the exclusion of a group that comprises a substantial proportion of chronic health conditions among children.

Finally, many children assigned a diagnostic code in administrative data are often found to not actually have the indicated condition because of the diagnosis being ruled out or due to coding errors. These and other limitations to administrative and diagnostic data make it insufficient as a source of data for identifying a denominator of children with chronic conditions. Nonetheless, administrative data is useful for finding a cohort of children more likely to be identified using the survey-based screener, thus minimizing the required sample size needed for the CAHPS® 2.5H Child Survey.

The non-condition specific casefinding approach used in the CAHPS® 2.5H Child Survey reflects state of the art approaches and empirical research regarding identification and responds to both the urgent need for comparative performance measurement for children with special health care needs and to the technical challenge of identifying sample sizes sufficient to do so.

The CSHCN screening tool included in the CAHPS® 2.5H Child Survey represents intensive collaboration among key researchers and stakeholders in the field.[3] It draws explicitly on a wide body of conceptual and empirical work (Stein, et al., 1992, Newacheck, et al., 1996, Perrin, E., et al, 1993) and reflects the core concepts set forth in the MCHB consensus definition of children with special health care needs:

"Children with special health care needs are those who have…a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."
Definition developed by the Maternal and Child Health Bureau, July 1998

The CSHCN screening tool includes five items. For children to qualify as having a chronic or special health care need they must experience one or more of five types of consequences due to a medical, behavioral or other health condition lasting or expected to last at least 12 months. The five consequences are (1) child is limited or prevented in any way in ability to do things most children of the same age can do, (2) child needs or uses medications prescribed by a doctor (other than vitamins), (3) child needs or uses specialized therapies such as physical, occupational or speech therapy (4) child has an above routine need or use of medical, mental health or educational services and (5) child needs or gets treatment or counseling for an emotional, behavioral or developmental problem. Parents answering "yes" to any of these consequences or needs are then asked whether the consequence is due to a medical, behavioral or other health condition and whether that

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[3] Since its design and validation, the CSHCN screening tool is being used by the Medical Expenditures Panel Survey (MEPS), the National Immunization Survey/SLAITS survey of CSHCN and in over ten states interested in identifying and measuring quality for CSHCN.

condition has lasted or is expected to last at least 12 months.[4]   A child qualifies as having a chronic or special health care need if parents answer "yes" to one or more of the five core items and all parts of the respective follow up item(s).

Identifying aspects of care for assessment

The concepts reflected in the CSHCN measures represent baseline aspects of care essential for the successful treatment, management and support of children with chronic conditions and for which significant improvements in quality have often been noted as being needed (Hill, et al., 1999, Newacheck, et al., 1996, McManus and Fox, 1996). Information about the performance of health plans and the providers within these plans is invaluable to the tracking and improvement of performance. The survey items set forth represent a consensus set of minimum survey items agreed upon within the CAHMI/FACCT Living with Illness Task Force, a group which has included leading pediatric researchers, members of the CAHPS research team, NCQA, Maternal and Child Health Bureau, Family Voices and many others.

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[4] There is one presence of condition and one duration of condition follow up item for each consequence except question #5: "Child needs or gets treatment or counseling for an emotional, behavioral or developmental problem." Here the presence of condition concept is included in the core item and only the duration of condition follow up item is required.

RELEVANCE OF MEASURE

A. Meaningfulness of the Measure –

1. Consumers

The relevance of the CSHCN measures to families with children with chronic conditions has been verified through focus groups conducted as part of the measure development process. Focus groups conducted by Family Voices, New England SERVE and other organizations and researchers (Krauss, et al., 2000, Garwick et al., 1998) also confirm the saliency of the CSHCN measures, especially those related to access to specialized services, coordination of care and family centered care. In addition to helping develop and confirm the CSHCN measure content, the families who participated in the focus groups also expressed a strong desire for the information generated by the measures to use in guiding their health plan selection (FACCT, 1999).

2. Purchasers

The CAHPS® 2.5H Child Survey meets urgent needs of Medicaid programs looking for ways to measure, report on and improve the quality of care provided to Medicaid beneficiaries enrolled in managed care plans. Guidelines issued by the Health Care Financing Administration suggest that states contracting with managed care organizations identify and measure the quality of care provided to children with chronic or special health care needs enrolled in these health plans, making the CAHPS® 2.5H Child Survey especially relevant for both states and the Federal government. The receptivity of public sector purchasers to the CAHPS® 2.5H Child Survey is evidenced by requests of nearly 20 states for use of the methodology (FACCT CAHMI User's Summary, 2000) and by the fact that the CAHPS® 2.5H Child Survey has the official endorsement of the Child and Adolescent Health Measurement Initiative's National Advisory Committee which includes a number of federal agencies and state purchasers (as well as health plans, provider associations, and consumer groups).

In addition to the clear usefulness of the CAHPS® 2.5H Child Survey measures for State purchasers, the information derived from the survey has relevance for commercial purchasers as well. Approximately 60 percent of American children receive their health insurance through employer-sponsored plans (McManus and Fox, 1999). In a recent national study, employers large and small overwhelmingly indicated that providing employees with health insurance coverage for their dependent children was the "right thing to do" and 90 percent considered such coverage as being importantly linked to employee productivity and satisfaction (McManus and Fox, 1999).

Employers report that employees with dependent children almost unanimously choose to enroll in managed care, with about 40% participating in HMO's (McManus and Fox, 1999). The propensity of employees with dependent children to enroll in managed care in combination with consistent focus group findings that employed parents make the quality of a health plan for their child a priority when selecting a plan supports the relevance of the CAHPS 2.5H® Child Survey measures for commercial purchasers.

The links between employee productivity, well being and the health of their children make the CSHCN measures additionally important for employers. One study found that 54 percent of employed parents of children with special health needs reported they had cut down on their work hours to care for their children (Krauss, et al., 2000). Others have found strong evidence

linking lack of quality care for children with on-going health conditions to parental work absence because of their child's increased health problems (unpublished study findings, Coltin, K., Harvard Pilgrim Health Plan)

Studies suggest that improvements in care for children with chronic conditions can also positively effect parental employment patterns. Asthma is the leading chronic illness among children in the United States and is responsible for the highest number of lost days from school. Studies show providing high quality care for children with asthma resulted in parents reporting significant decreases in time missed from work and significant improvements in the quality of life (Wilson, et al., 1996, Millbank Memorial Fund, 1999). Similar reductions in job absenteeism and productivity-impacting stress through improvements in access, service coordination, and provider-family communication are anticipated to result from improvements in care stimulated by the inclusion of the CSHCN measures into HEDIS.

3. Health Plans

In 1994, an estimated 17 million children or 22% of all US children under the age of 20 were enrolled in HMO's, comprising about one third of the enrollee population (Hughes and Luft, 1998). Since this time, HMO enrollment has increased 91% (AAHP, 1999) among the privately insured and even more dramatically among publicly insured children. The result has been an accompanying rapid increase in the numbers of children with chronic or special health needs served by managed care organizations. As a group, children with chronic or special health care needs are responsible for the vast majority of child health care costs—direct and indirect. The CAHPS 2.5H[®] Child Survey offers a standardized methodology for health plans to use in identifying a robust denominator of children with chronic or special health needs for the purpose of measuring, reporting, and improving care quality for this group.

B. Clinical Importance –

The measures derived from the CAHPS® 2.5H Child Survey represent fundamental aspects of care pertinent to virtually all children with chronic conditions or special health care needs (Newacheck, et al., 1996, Kuhlthau, et al., 1998). Condition specific guidelines emphasize the components of care measured in the CAHPS® 2.5H Child Survey (AAP, 1996). Improvements in functioning, reductions in negative health events associated with chronic conditions such as days lost from school and acute events requiring emergency care for conditions such asthma and diabetes as well as improved adherence to medical advice are expected to result from improvements in aspects of care measured by the CAHPS® 2.5H Child Survey (Clark, et al., 1986, Lewis, et al., 1984, Creer, et al., 1985, Hughs, et al., 1991 Charron-Prochownik, D., et al., 1994 Geller, J., et al., 1985, Sinnock, P., 1984).

C. Financial Importance –

The majority of children's health care dollars are spent on children with chronic conditions. Estimates range from 80-90% of the health care dollars spent on children being for those with chronic conditions (Institute of Medicine, 1998, Neff and Anderson, 1995, Lewit and Monheit, 1992).

D. Cost Effectiveness –

Reductions in health care costs attributable to preventable negative events (e.g. hospitalizations), acute flareups and inefficient use of services such as the emergency room are expected to result from improvements in quality in the areas measured by the CAHPS® 2.5H Child Survey. Randomized trials and other controlled studies assessing the impact of improved communication, education and coordination of care on children with asthma have shown marked reductions in asthma hospitalization and inappropriate emergency room use (Clark, et al., 1986, Lewis, et al., 1984, Creer, et al., 1985, Hughs, et al., 1991). Similar results have been demonstrated for children with diabetes (Charron-Prochownik, D, et al., 1994 Geller, J, et al., 1985, Sinnock, P., 1984).

E. Strategic Importance –

As noted above, the CAHPS® 2.5H Child Survey fills unique gaps in HEDIS and represents core aspects of health care quality for the subset of children who use the vast majority of health care resources compared to children as a whole.

Concerns about the performance of managed care often revolve around the care of people with chronic conditions (Neff and Anderson, 1995). The CAHPS® 2.5H Child Survey will allow managed care organizations to demonstrate performance for children with chronic conditions.

Collection of data specific to children with chronic conditions will yield unique information to assist plans, purchasers and consumers in the assessment and improvement of care. Field trials with the CAHPS® 2.5H Child Survey have consistently demonstrated patterns of differing performance for children with and without chronic or special health needs in both commercial and Medicaid populations. Significant within plan differences in care for CSHCN and non-CSHCN groups were found in the CAHMI Washington State Pilot Study and are summarized below.

Table 6: Number of plans having significant within plan differences between CSHCN and non-CSHCN groups by measure
CAHMI WA State Medicaid Pilot Study 2000-Interim data, 9 health plans

Measure	Number of plans for which significant differences btw CSHCN and non-CSHCN groups were observed
CAHPS® How Well Drs Communicate	2 out of 9 plans
CAHPS® Getting Care Quickly	1 out of 9 plans
CAHPS® Getting Needed Care	9 out of 9 plans
CAHPS® Courteous & Helpful Office Staff	1 out of 9 plans
CAHPS® Customer Service	5 out of 9 plans
CSHCN Getting Prescription Medicine	8 out of 9 plans
CSHCN Getting Specialized Services	N/A*
CSHCN Family Centered Care Part A: *Personal Dr / Nurse who Knows Child*	5 out of 9 plans
CSHCN Family Centered Care Part B: *Support, Info & Decision Making*	2 out of 9 plans
CSHCN Family Centered Care Part C: *Listening &Following up on Concerns*	7 out of 9 plans

CSHCN Communication with School or Daycare	N/A*
CSHCN Coordination of Care & Services	N/A*

*Denominators for non-CSHCN groups are consistently too small to allow within plan comparison with CSHCN groups.

In the CAHMI Washington State Medicaid Pilot Study, the greatest within plan variation in care between the CSHCN and non-CSHCN groups occurred on the following measures: CAHPS® Getting Needed Care, CSHCN Getting Prescription Medicines, and CSHCN Family Centered Care Part 3: Listening to and Following Up on Concerns.

Although within plan performance for children with and without a chronic or special health care needs was often found to vary significantly in both the CAHMI Washington State Medicaid Pilot Study and other CAMHI field trials, a consistent pattern of poorer performance for CSHCN has not been the case. The CSHCN groups in some health plans report significantly better performance for certain measures. In some plans, no significant differences in care between CSHCN and non-CSHCN groups are found on measures for which significant differences are observed in other plans. Tables 7 and 8 provide in more detail within plan performance results for CSHCN and non-CSHCN groups from the CAHMI Washington State Medicaid Pilot Study.

F. Controllability –

Plans and providers are well positioned to design care systems and protocols that will dramatically improve performance in the areas of health care quality included in the CSHCN measures. Specifically, coordination of care, access to specialized services, and patient education and teamwork with providers are directly influenced by health plan rules for accessing care, health plan and provider relationships with families and with other organizations in a community (e.g. schools), and the training, skill and commitment of a wide range of providers in meeting the needs of children with chronic conditions.

The findings that care quality for CSHCN is not uniformly lower and that care for CSHCN actually out performs that for non-CSHCN in some plans suggest a margin of controllability at the plan level. In addition, the relatively small contribution made by demographic and health-related variables to individual variation in performance for the CSHCN group (average adjusted R^2 across all measures = .04; see Tables 11 and 12) lends support to the opportunity plans have for improving performance.

G. Variance among plans –

Significant variations (p < .0001 – .10) in performance for the CSHCN group were detected across the nine health plans in the CAHMI Washington State Medicaid Pilot Study (see Table 9). The only exception was for the Communication with School or Daycare measure. The greatest variations in performance across plans for the CSHCN group were observed for the following measures: CAHPS® Getting Care Quickly, CAHPS® Customer Service, CSHCN Getting Specialized Services, and CSHCN Coordination of Care and Services. The data reported in Table 9 are from Medicaid populations, however, similar patterns of significant variation in care across plans for CSHCN were also found among commercial populations surveyed in earlier CAMHI field trial studies. See Attachment E for summary of earlier findings.

Table 7: CAHPS Mean Composite Scores=
Within plan differences for CSHCN and non-CSHCN groups

	CAHMI Washington State Medicaid Pilot Study 2000 (9 MCO sites) Interim data/mail only									
	CAHPS® How Well Drs Communicate		CAHPS® Getting Care Quickly		CAHPS® Getting Needed Care		CAHPS® Courteous & Helpful Office Staff		CAHPS® Customer Service	
	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN
	mean (n)	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*
Site #1	75.9 (561)	75.4 (418)	65.6 (632)	65.6 (442)	87.4 (646)	83.9* (438)	79.2 (553)	79.1 (413)	72.6 (280)	71.1 (221)
Site #2	76.4 (371)	71.7 (192)	68.4 (420)	65.0 (203)	90.9 (409)	82.2** (210)	80.6 (365)	77.8 (186)	76.6 (211)	66.4* (111)
Site #3	68.2 (535)	68.3 (221)	48.6 (600)	51.8 (244)	85.5 (590)	78.0** (231)	66.3 (516)	68.5 (215)	74.1 (189)	64.7* (92)
Site #4	73.8 (504)	68.3** (388)	70.4 (556)	67.8 (406)	93.6 (572)	87.5** (409)	79.8 (481)	77.7 (378)	81.5 (227)	69.7** (174)
Site #5	71.1 (348)	68.6 (192)	63.9 (409)	58.4* (197)	92.2 (403)	86.5** (200)	76.3 (338)	76.6 (187)	82.1 (171)	75.7 (111)
Site #6	73.2 (319)	67.2* (187)	64.5 (349)	60.2 (202)	83.2 (377)	75.7** (204)	78.9 (309)	73.1* (182)	65.1 (186)	60.5 (129)
Site #7	77.8 (518)	75.9 (430)	70.3 (560)	69.8 (446)	91.3 (558)	84.7** (441)	82.3 (507)	82.3 (420)	75.0 (221)	58.3** (219)
Site #8	76.5 (553)	78.1 (453)	68.0 (596)	70.0 (476)	91.0 (588)	87.6* (471)	81.7 (543)	82.9 (438)	73.1 (183)	69.1 (173)
Site #9	79.0 (450)	77.1 (200)	73.1 (515)	69.3 (213)	93.9 (490)	90.2* (210)	82.8 (440)	83.0 (198)	72.3 (198)	57.0** (99)

Source: Bethell and Read, 2000, FACCT—The Foundation for Accountability

* $p \leq .05$ ** $p \leq .00$

= Mean scores are calculated at the individual level to allow significance testing between CSHCN and non-CSHCN groups. All scores are shown transformed to a 0-100 base using 3 point scales with a maximum score '3' and a minimum score of '1'. Where the items in the CAHPS or CSHCN composites use a 4 point 'Never to Always' response scale, the categories of 'never ' and 'sometimes' are combined to create 3 point scoring scales.

Table 8: CSHCN Mean Composite Scores[=]

Within plan differences for CSHCN and non-CSHCN groups

	CAHMI Washington State Medicaid Pilot Study 2000 (9 MCO sites) Interim data/mail only												
	CSHCN Getting Prescription Medicines		CSHCN Getting Specialized Services		CSHCN Family Centered Care Part A: Personal Dr / Nurse who Knows Child		CSHCN Family Centered Care Part B: Support, Info & Decision making		CSHCN Family Centered Care Part C: Listening &Following up on Concerns		CSHCN Communication with School or Daycare		CSHCN Coordination of Care & Services	
	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN	Non-CSHCN	CSHCN
	mean (n)	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*	*mean (n)*
Site #1	93.8 (352)	87.8** (376)	NA	75.2 (242)	57.6 (553)	65.7** (394)	73.9 (580)	73.9 (426)	92.9 (540)	87.1** (417)	NA	85.8 (194)	NA	44.7 (198)
Site #2	94.6 (221)	86.3** (175)	NA	75.1 (117)	62.1 (373)	59.2 (183)	74.1 (385)	67.9* (195)	91.6 (344)	82.4** (186)	NA	76.1 (67)	NA	37.5 (84)
Site #3	92.0 (293)	87.1** (194)	NA	76.3 (136)	53.4 (413)	61.2* (176)	64.4 (583)	66.8 (234)	88.7 (527)	82.6** (227)	NA	80.8 (99)	NA	44.1 (93)
Site #4	92.9 (317)	85.9** (361)	NA	75.4 (207)	52.1 (519)	56.0 (366)	72.6 (505)	67.0** (397)	92.6 (455)	84.2** (377)	NA	85.8 (179)	NA	41.6 (161)
Site #5	95.7 (185)	89.2** (176)	NA	67.2 (103)	59.3 (306)	59.1 (168)	72.8 (353)	68.5 (196)	91.4 (310)	85.6* (187)	NA	85.9 (71)	NA	35.8 (67)
Site #6	88.1 (189)	81.7* (172)	NA	63.5 (107)	59.4 (309)	54.4 (182)	70.6 (333)	65.8 (191)	88.7 (291)	84.7 (178)	NA	82.9 (76)	NA	29.5 (83)
Site #7	88.1 (349)	77.7** (397)	NA	69.7 (216)	58.9 (524)	66.9** (384)	77.7 (530)	75.2 (436)	92.9 (488)	86.8** (416)	NA	83.6 (168)	NA	46.0 (186)
Site #8	90.9 (339)	83.1** (391)	NA	80.5 (251)	61.7 (518)	68.7** (417)	76.2 (558)	78.1 (465)	92.9 (514)	88.9** (438)	NA	84.2 (203)	NA	49.5 (208)
Site #9	92.9 (282)	88.4 (177)	NA	79.6 (109)	61.2 (514)	67.2* (185)	79.2 (456)	77.5 (201)	93.3 (404)	92.8 (190)	NA	88.1 (59)	NA	45.2 (94)

Source: Bethell and Read, 2000, FACCT—The Foundation for Accountability
* $p \leq .05$ ** $p \leq .00$

[=] Mean scores are calculated at the individual level to allow significance testing between CSHCN and non-CSHCN groups. All scores are shown transformed to a 0-100 base using 3 point scales with a maximum score '3' and a minimum score of '1'. Where the items in the CAHPS or CSHCN composites use a 4 point 'Never to Always' response scale, the categories of 'never ' and 'sometimes' are combined to create 3 point scoring scales.
'NA' indicates cells with too few cases to conduct statistical tests.

Table 9: CAHPS and CSHCN Mean Composite Scores[=]
Across plan differences for Children with Special Health Care Needs (CSHCN) group

CAHMI Washington State Medicaid Pilot Study 2000 (9 MCO sites) Interim data/mail only		
CSHCN groups ONLY	Mean Score Range	ANOVA results (across 9 sites)
	Mean scores	*F ratio (p value)*
CAHPS[®] How Well Drs Communicate (n's range = 187 – 453)	67.2 – 78.1	6.89 (p = .000)
CAHPS[®] Getting Care Quickly (n's range = 197 – 476)	51.8 – 70.0	12.61 (p = .000)
CAHPS[®] Getting Needed Care (n's range = 200 – 471)	75.7 – 90.2	8.53 (p = .000)
CAHPS[®] Courteous & Helpful Office Staff (n's range = 182 – 438)	68.5 – 83.0	6.49 (p = .000)
CAHPS[®] Customer Service (n's range = 92 – 221)	57.0 – 75.7	4.36 (p = .000)
CSHCN Getting Prescription Medicines (n's range = 172 – 397)	77.7 – 89.2	4.73 (p = .000)
CSHCN Getting Specialized Services (n 's range = 103 – 251)	63.5 – 80.5	3.49 (p = .001)
CSHCN Family Centered Care Part A: *Personal Dr / Nurse who Knows Child (n's range = 168 – 417)*	54.4 – 68.7	6.70 (p = .000)
CSHCN Family Centered Care Part B: *Support, Info & Decision making (n's range = 191 – 465)*	65.8 – 78.1	7.30 (p = .000)
CSHCN Family Centered Care Part C: *Listening &Following up on Concerns (n's range = 178 – 438)*	82.4 – 92.8	3.61 (p = .000)
CSHCN Communication with School or Daycare (n's range = 59 – 203)	76.1 – 88.1	0.10 (p = .438)
CSHCN Coordination of Care & Services (n's range = 67 – 208)	29.5 – 49.5	2.15 (p = .029)

Source: Bethell and Read, 2000, FACCT—The Foundation for Accountability

[=] Mean scores are calculated at the individual level to allow significance testing between CSHCN and non-CSHCN groups. All scores are shown transformed to a 0-100 base using 3 point scales with a maximum score '3' and a minimum score of '1'. Where the items in the CAHPS or CSHCN composites use a 4 point 'Never to Always' response scale, the categories of 'never ' and 'sometimes' are combined to create 3 point scoring scales.

SCIENTIFIC STRENGTH OF THE MEASURE

Ten Medicaid health plans, three commercial health plans and one fee-for-service SSI population have been involved in the testing of the CAHPS® 2.5H Child Survey. Nine of the field trial sites implemented the enriched stratified sampling methodology outlined in this measure work-up. As a result of CAHMI field trial studies, over 13,000 cases of CAHPS® 2.5H Child Survey data have been collected by NCQA certified survey vendors using standardized protocols. The data have been used to assess the feasibility and the soundness of the proposed measure. See Table 10 for an overview of the location and type of health plans included in the CAHMI field trials, as well as the sampling and data collection methods used in each site.

Analysis conducted by FACCT/CAHMI staff addressed a number of specific issues. These included the adequacy of the sample size and success of the survey administration protocols, validation of the sampling and case finding approach, the validity and reliability of the supplemental survey scales and items for use in performance assessment, as well as plan burden and cost. High-level summaries of findings are provided in the sections that follow.

In addition to the field trials outlined in Table 10, both cognitive testing and focus groups were conducted with families having children with chronic conditions to assess the CAHPS® 2.5H Child Survey items and measure content.

Table 10: Overview of CAHMI Field Trials of CAHPS 2.5H Child Survey

Testing Phase Description	Number, Location and Type of Health Plans	Sampling Approach	Survey Protocol	Sample Sizes	Response Rate
Phase I: Testing pilot version of the CAHPS 2.5H Child Survey Mar- Oct, 1999	• 2 Commercial HMOs (Hawaii, California) • 1 mixed model MCO (Washington State) • 1 Medicaid HMO (Hawaii)	1 site: Enriched sampling method 3 sites: Population based sampling	2 sites: HEDIS CAHPS 2.5H Protocol 2 sites: HEDIS Protocol without the CATI step	Average starting sample per health plan site = 1150 (range 900-1600)	Average response rate overall = 52.7% (range 42%- 60%)
Phase II: Validation of the CSHCN screening tool Oct, 99 – June, 2000	• 1 commercial mixed model MCO • National sample of families (NIS/SLAITS)	1 site: Enriched sampling method 1 site: Population based sampling	2 sites: Telephone administration (screeners administered only)	Completed surveys per study site (N = 900 and N = 2420)	NA
Phase III: Testing the final version of the CAHPS 2.5H Child Survey Mar - Sept, 2000	• 9 Medicaid HMOs (Washington State) • 1 FFS/SSI population	10 sites: Enriched sampling method	10 sites: HEDIS CAHPS 2.5H Protocol	Average starting sample per health plan site = 2217 (range 1800-2550)	Overall response rate = 57.7% 80% collected by mail 20% collected by telephone

Reliability

The CSHCN screening tool items used to identify families with children with chronic conditions and the CSHCN supplemental survey items underwent both cognitive and psychometric testing to evaluate the reliability. Respondent adherence to skip pattern requirements was also examined.

Reliability as measured by Cronbach's alpha is well within an acceptable range (.65 or above) for all survey scales represented in the CSHCN measure. While the internal consistency of each survey scale is high, it should be noted that items included in the CSHCN question supplement are not highly redundant with each other or with core CAHPS 2.5H survey items. A careful review of the correlation among items within scales and between scales and items across scales informed the final selection of the minimum set of survey items.

The CSHCN screening tool and supplemental survey item skip patterns performed as well or better than the skip patterns currently existing in the CAHPS survey (over 92% appropriately answered or skipped for screening and supplemental items).

The test-retest estimates that are available for survey items similar to those included in the CSHCN screening tool show a Kappa of .90 (Stein, 1999).

A. Validity

Validity was examined for: (1) the survey items used to construct the CSHCN measures; (2) the prescreening, diagnostic-based algorithm used in the enriched sampling strategy for the CAHPS® 2.5H Child Survey; and (3) the survey-based CSHCN screening tool for identifying children with chronic or special health care needs.

Face and content validity were assessed throughout the development of the CAHPS® 2.5H Child Survey and are demonstrated by the widespread support by multiple consumer and expert stakeholders and by the formal endorsement of the survey by the Child and Adolescent Health Measurement Advisory Committee. Quantitative analyses conducted further support the validity of the CSHCN survey items, sampling method and survey-based screening tool.

Validity of survey items:

Several hypotheses guided the analysis of the field trial data to assess the convergent and divergent validity of the CSHCN supplemental survey items. In this analysis, expectations for how families with children with chronic conditions would answer the survey versus those whose child did not have a chronic condition were confirmed along with hypotheses about how parents answering one question a certain way would be expected to answer a different question. Where hypotheses were not confirmed or only weakly supported, survey items were deleted (e.g. written care plan items) or reconstructed and reevaluated (e.g. coordination of care items) and tested during a second round of field testing.

Validity of the stratified and enriched sampling approach:

The enriched stratified sampling approach described in this document was evaluated in nine managed care health plans. Overall, 8.8% of all eligible children in the health plans qualified on the prescreening, diagnostic-based algorithm (range 7.7-11%).[5] As expected, nearly three

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[5] Note that 62% of children qualifying for SSI disability coverage had a qualifying diagnostic code.

times as many children were identified by the CSHCN screening tool if they met the diagnostic-based prescreening criteria for having a probable chronic or special health need compared with those that did not meet the prescreening criteria (19% vs. 52%).

Overall, 82% of those children identified by the CSHCN screening tool had a qualifying diagnostic code and met the prescreening sampling algorithm. However, as expected, many children who met the prescreen criteria <u>were not</u> identified by the survey-based CSHCN screening tool (48%) as currently having a chronic or special health need. Conversely, as also expected, many children who did not meet the prescreening algorithm <u>were</u> identified by the CSHCN screener (19%), supporting the conclusion that diagnostic data is a helpful but not sufficient method for identifying children with chronic or special health care needs.[6] Prescreening status did not appear to influence variations in reported care experiences. Based on regression analyses, meaningful and/or significant differences in reported experience of care were not observed for children meeting the CSHCN screening tool according to whether those children did or did not also meet the prescreening, diagnostic-based algorithm (see Tables 11 and 12).

Overall, the stratified, diagnostic-based prescreening method was found to be an effective and valid method for reducing the required starting sample size for the CSHCN Module while not biasing performance scores. Additional data are available to confirm the superiority of diagnostic data over costs of care or visit frequency data in identifying a prescreened cohort of children.

<u>Validity of the survey-based CSHCN screening tool:</u>

In addition to the extensive and careful review by experts in the field, the CSHCN screening tool has been fielded by mail and telephone in 13 managed care health plan samples, one fee-for-service/SSI population and one random sample of the US population of families (using the Survey of Local Areas Integrated Telephone Survey mechanism). Findings regarding the proportion of children identified as having a chronic or special health care need in commercial (16-17%) or Medicaid (20-22%) health plans are consistent. The proportions identified in the FFS/SSI sample and in the national random sample are 94.6% and 16.6%, respectively.

One of the steps in validating the CSHCN screening tool was to examine and compare the reported care experiences for the denominator of children identified by the tool. Results regarding differences observed are reported earlier in the document and confirm this aspect of the validity for the CSHCN screening tool.

In addition, the validity of the CSHCN screening tool was assessed by comparing results to a more extensive, well-documented and widely used tool—the interviewer-administered Questionnaire for Identifying Children with Chronic Conditions (QuICCC). Although no "gold standard" exists for identifying children with chronic conditions, the QuICCC is a widely adopted, tested, well-respected tool and was therefore chosen for assessing the validity of the CSHCN screener (Stein, R, et al., 1997).

In two studies, one in a health plan and one in a nationally representative sample, the 5 item/14 component CSHCN tool was evaluated in a head to head comparison with the QuICCC-R, a 16 item/41 component version of the QuICCC. In both studies, the CSHCN tool and the QuICCC-R

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[6] Note that the well documented and tested NACHRI Clinical Risk Groups coding system for identifying children with chronic conditions was also evaluated against the survey based CSHCN screening tool.   In the study, 86% of all those identified by the CSHCN screening tool had a qualifying CRG code and approximately 40% with a CRG code were not identified by the screening tool. These findings are similar to findings from the CAHMI field-testing where a different, but similar, set of diagnostic codes were used (82% and 48% respectively). The CRG algorithm can not be used for the CSHCN Module due to both its proprietary and complex nature.

agreed 9 out of 10 times (90 percent agreement) on whether a child did or did not have a chronic health condition.

Discrepancies between results on the QuICCC-R and the CSHCN screener have undergone extensive examination. Using medical chart review data, administrative/diagnostic data, and the survey data, the 10 percent of cases where the screening tools did not agree were determined to be different from the 90 percent of cases where the tools agreed. Specifically, in approximately 56 percent of the 10% discrepant cases, medical chart data and/or administrative data could not support the presence of a chronic condition. In an additional 20 percent of 10% discrepant cases, some indication of health problems were found but could not be confirmed as chronic. In both studies comparing the CSHCN screening tool and the QuICCC-R, approximately 25 percent of the 10% discrepant cases were determined to have a probable chronic condition using information from the medical chart, administrative data and/or survey data variables. In these cases, the health conditions "missed" most frequently were reactive airway disease and ADHD. All "missed" cases were mild or very mild in nature according to the six point NACHRI CRG severity classification system or parent-reported impact of the condition on child's health/functioning/need for services.

As expected, neither screening tool identifies 100 percent of all children whose diagnostic codes may indicate a chronic condition. This is hypothesized to be largely due to the focus of the QuICCC and CSHCN screeners on <u>current</u> consequences, the known errors and/or biases in diagnostic data and the limitations inherent to parent-reported information. Approximately 23 percent of children with a qualifying NACHRI CRG code were not identified by either the QuICCC-R or the CSHCN screening tool. It is expected that at least a portion of these cases do indeed have a chronic health condition.

To ensure that children included in the CSHCN measure denominators do in fact have a chronic condition, the specificity of the CSHCN screening tool was closely examined. Overall, the CSHCN screening tool was found be highly specific using the QuICCC-R as the comparison criteria. In the first study, specificity was .93 (n = 900). In the national sample study, the specificity of the CSHCN screening tool was .98 (n = 2420). Furthermore, a study conducted by Dr. Ruth Stein (n = 900) confirmed a .93 specificity between the QuICCC and the CSHCN screener (Stein, 1999).

B. Power to detect

The CAHPS® 2.5H Child Survey sampling specifications recommended in this document allow for differences of 10 points (or less) to be detected across health plans assuming .80 power and .05 level of significance.

Although meaningful differences may be detected with lower achieved sample sizes, traditionally HEDIS measures have required an achieved sample size of 411. In the CAHMI Washington State Medicaid Pilot Study, interim results for the five health plans with enough members to implement the full enriched diagnostic sampling protocol show an average of 39 percent of children screening positive on the CSHCN screening tool (see Table 3). Proportion of CSHCN identified within each plan ranged from 38.3% to 42.3% with the actual number of CSHCN ranging from 451 to 477.

Four of the health plans in the CAHMI Washington State Medicaid Pilot Study had member populations too small to implement the full Sample B portion of the enriched sampling protocol. Additional random samples of remaining survey-eligible child members were selected in each of these plans to supplement Sample B. Interim results for the four plans fielding partial prescreened samples show an average 30 percent of children meeting the CSHCN screening criteria. Proportion of CSHCN identified within each plan ranged from 26.0% to 33.0% with the actual number of CSHCN ranging from 222 to 231.

The actual numbers of children identified by the CSHCN screening tool are expected to increase once the final data are available. However, based on the interim data results for this statewide pilot of the CAHPS® 2.5H Child Survey, all health plans were able to achieve an adequate sample size to use the data for purposes of comparing performance across health plans.

C. Risk Adjustable –

No risk adjustment is recommended for the CSHCN measures. Multivariate regression was used to evaluate the contributions made by age, gender, incidence of common acute conditions, prescreening status, reported numbers of visits and reported health status to variations in individual level scores on the CAHPS 2.5H and CSHCN measures. As can be seen in Tables 11 and 12, although a number of these variables had significant effects on the CAHPS 2.5H and CSHCN measures, the average adjusted R^2 for all of the variables taken together was less than .05 (CAHPS® 2.0H measures average R^2 = .046; CSHCN measures average R^2 = .037). Given the small explanatory power of these variables as group, they are rejected as potential risk adjusters.

D. Comparability of Data Sources –

The CSHCN screening tool provides a common standard for identifying children with chronic or special health care needs that is not dependent upon plan level data. Random and systematic differences in the administrative data used as a means of identifying a cohort of children having a higher likelihood of meeting the CSHCN screening tool are likely across plans. However, the nature and magnitude of these differences are not expected to bias results in a way that compromises the appropriateness of using the information for comparing performance across plans.

The addition of CSHCN screening tool and supplemental items to the CAHPS® 2.5H Child Survey has not been shown to reduce response rates over the current CAHPS® 2.0H Child Survey. In fact, the response rate for the CAHPS® 2.5H Child Survey has consistently outperformed that of the CAHPS® 2.0H Child Survey in the health plans in which it has been fielded (approximately 52% response rate overall).

TABLE 11: Results of regression analysis: CAHPS® composite measures of quality-CSHCN group only

DEPENDENT VARIABLES: Individual-level mean scores on each composite measure

INDEPENDENT VARIABLES	CAHPS® How Well Drs Communicate ($R^2 = .06$)	CAHPS® Getting Care Quickly ($R^2 = .04$)	CAHPS® Getting Needed Care ($R^2 = .06$)	CAHPS® Courteous & Helpful Office Staff ($R^2 = .04$)	CAHPS® Customer Service ($R^2 = .03$)
Intercept	$\alpha = 47.85$	$\alpha = 44.14$	$\alpha = 65.93$	$\alpha = 55.83$	$\alpha = 51.54$
Child's age (0 to 13 yrs old)	$\beta = .058$ $p = .008$	$\beta = .013$ $p = .55$	$\beta = .019$ $p = .36$	$\beta = .074$ $p = .001$	$\beta = .002$ $p = .94$
Child's gender (Male = 1)	$\beta = -.009$ $p = .67$	$\beta = -.031$ $p = .14$	$\beta = -.040$ $p = .052$	$\beta = -.018$ $p = .39$	$\beta = -.047$ $p = .12$
Child had 1 or more acute conditions, last 12 months (Yes = 1)	$\beta = -.090$ $p = .000$	$\beta = -.043$ $p = .050$	$\beta = -.057$ $p = .009$	$\beta = -.079$ $p = .000$	$\beta = -.075$ $p = .020$
Child's outpatient visits, last 6 months, parent-reported (0 = None; 4 = 10 or more visits)	$\beta = .027$ $p = .22$	$\beta = .026$ $p = .23$	$\beta = .005$ $p = .82$	$\beta = .045$ $p = .046$	$\beta = -.008$ $p = .81$
Child met administrative data pre-screen criteria for probable chronic condition (Yes = 1)	$\beta = .066$ $p = .002$	$\beta = .066$ $p = .002$	$\beta = .013$ $p = .54$	$\beta = .026$ $p = .22$	$\beta = .074$ $p = .02$
Parent's rating of child's health now (1 = Poor; 5 = Excellent)	$\beta = .200$ $p = .000$	$\beta = .186$ $p = .000$	$\beta = .222$ $p = .000$	$\beta = .172$ $p = .000$	$\beta = .135$ $p = .000$

Source: Bethell and Read, 2000, FACCT—The Foundation for Accountability

TABLE 12: Results of regression analysis: CSHCN composite measures of quality-CSHCN group only

	DEPENDENT VARIABLES: Individual-level mean scores on each composite measure						
	CSHCN Getting Prescription Medicines ($R^2 = .02$)	**CSHCN Getting Specialized Services** ($R^2 = .03$)	**CSHCN FFC #1: Personal Dr or Nurse who Knows Child** ($R^2 = .06$)	**CSHCN FFC #2: Support, Info & Decision making** ($R^2 = .05$)	**CSHCN FFC #3: Listening to &Following up on Concerns** ($R^2 = .05$)	**CSHCN Communication with School or Daycare** ($R^2 = .04$)	**CSHCN Coordination of Care & Services** ($R^2 = .008$)
INDEPENDENT VARIABLES							
Intercept	$\alpha = 78.92$	$\alpha = 65.96$	$\alpha = 30.20$	$\alpha = 40.03$	$\alpha = 67.44$	$\alpha = 68.35$	$\alpha = 31.89$
Child's age (0 to 13 yrs old)	$\beta = .026$ p = .26	$\beta = -.072$ p = .016	$\beta = -.005$ p =.81	$\beta = .031$ p =.15	$\beta = .057$ p =.010	$\beta = -.024$ p =.47	$\beta = -.047$ p =.16
Child's gender (Male = 1)	$\beta = -.016$ p = .48	$\beta = -.038$ p = .19	$\beta = .000$ p = .99	$\beta = -.017$ p = .42	$\beta = -.030$ p = .16	$\beta = -.033$ p = .32	$\beta = -.040$ p = .21
Child had 1 or more acute conditions, last 12 months (Yes = 1)	$\beta = -.024$ p = .32	$\beta = -.085$ p = .006	$\beta = -.069$ p = .003	$\beta = -.069$ p = .002	$\beta = -.056$ p = .013	$\beta = -.058$ p = .09	$\beta = -.037$ p = .28
Child's outpatient visits, last 6 months, parent-reported (0 = None; 4 = 10 or more visits)	$\beta = -.048$ p = .041	$\beta = .012$ p = .69	$\beta = .210$ p = .000	$\beta = .084$ p = .000	$\beta = -.020$ p = .36	$\beta = -.020$ p = .55	$\beta = .073$ p = .030
Child met administrative data pre-screen criteria for probable chronic condition (Yes = 1)	$\beta = -.030$ p = .18	$\beta = .014$ p = .62	$\beta = .073$ p = .001	$\beta = .066$ p = .002	$\beta = .042$ p = .049	$\beta = .033$ p = .30	$\beta = .044$ p = .17
Parent's rating of child's health now (1 = Poor; 5 = Excellent)	$\beta = .091$ p =.000	$\beta = .142$ p = .000	$\beta = .158$ p = .000	$\beta = .218$ p = .000	$\beta = .195$ p = .000	$\beta = .191$ p = .000	$\beta = .069$ p = .041

Source: Bethell and Read, 2000, FACCT—The Foundation for Accountability

FEASIBILITY OF THE MEASURE

A. Precisely Specified –

During testing, the HEDIS 1999 Protocol for Administering the CAHPS® 2.0H Survey, Volume 3 specifications were used with the sampling frame and sample size changes described earlier. All field trial vendors found the specifications to be clear, precise and easily implemented. A revised version of the CAHPS 2.0H Survey specifications, reflecting adaptations for the CAHPS® 2.5H Child Survey, has been developed and is attached for review.

B. Reasonable Cost –

The CAHPS® 2.5H Child Survey is recommended as a replacement for the CAHPS® 2.0H Child Survey. The fielding of CAHPS® 2.5H Child Survey is recommended every two years rather than the current annual requirement. While costs of survey administration will vary, the estimated increase in cost for administering the CAHPS® 2.5H Child Survey is $3,455-$11,056 for commercial plans and $2695-$8624 for Medicaid plans.

More detailed work-ups of costs for the CAHPS® 2.5H Child Survey are available upon request.

C. Confidential –

See HEDIS 1999 Protocol for Administering the CAHPS® 2.0H Survey, Volume 3 specifications and the draft CAHPS® 2.5H Child Survey specifications.

D. Logistically Feasible –

The casefinding and survey administration for the CAHPS® 2.5H Child Survey is straightforward and logistically feasible for health plans. In the CAHMI field trials, the only requirement of the health plan was the identification of the sampling frame from member records. This sampling frame was forwarded to the survey vendor who completed all other data collection steps.

E. Auditable –

See the draft CAHPS® 2.5H Child Survey specifications

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