

Pediatric Living With Illness Screener and Supplemental Survey Module (LWIM)

Measurement Set Work-Up

DISCUSSION DRAFT

Prepared for the NCQA Technical Advisory Group
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on behalf of the Child and Adolescent Health Measurement Initiative Advisory Committee and
CAHMI Living with Illness Task Force

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Background and Acknowledgements

The pediatric Living with Illness Module has been developed under the rubric of the Child and Adolescent Health Measurement Initiative's (CAHMI) Living with Illness Task Force. The development of the LWIM was 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 CAHMI began in May of 1998. The LWIM has been formally endorsed by the Child and Adolescent Health Measurement Advisory Committee and recommended to NCQA for inclusion in HEDIS. See Attachment A for a list of CAHMAC members.

The Child and Adolescent Health Measurement Initiative is a collaborative effort between FACCT and the National Committee for Quality Assurance (NCQA) to develop strategies and methods for both measuring and communicating the quality of child and adolescent health care provided by organized health care systems, including health plans and provider groups. Three FACCT-led measurement task forces have focused on developing health plan quality measures in consumer relevant quality categories: (1) Staying Healthy (2) Getting Better and (3) Living with Illness. These task forces also considered how measures can be used for quality improvement, community-wide assessment and medical group evaluation. A fourth task force, the Health Plan Task Force, evaluates and refines measures for submission to the CPM for potential inclusion in HEDIS is led by NCQA.

The following individuals have provided substantial and ongoing input regarding the development and testing of the Living with Illness Module screening tool, sampling strategy and supplemental survey items outlined in the measures work-up:

- Charles Homer, MD – Boston Children's Hospital
- Christine Crofton, PhD – Agency for Healthcare Research and Quality
- Debbie Klein Walker, Massachusetts Department of Public Health
- Jack Fowler, PhD – University of Massachusetts
- James Perrin, MD – Massachusetts General Hospital
- Joe Thompson, MD – Arkansas Children's Hospital
- John Hochheimer, PhD – National Committee for Quality Assurance
- Merle McPherson, MD – Maternal and Child Health Bureau
- Nora Wells – Family Voices
- Paul Cleary, MD – Harvard Medical School, Principle Investigator, CAHPS
- Paul Newacheck, DrPH – UCSF Medical Center
- Peggy McManus – Maternal and Child Health Policy Research Center
- Ruth Stein, MD – Albert Einstein College of Medicine
- Shirley Girouard, PhD, RN – NACHRI
- Susan Epstein, – New England SERVE

A full list of the Living with Illness Task Force members and advisors is included in Attachment A.

Christina Bethell, PhD, Director of Research at FACCT-The Foundation for Accountability, has served as Director of the CAHMI and principle investigator for the development of the LWIM. Debra Read, MPH has served as a research associate for the development of the measures. Debbie Levy has provided administrative and research assistance for this effort.

**PEDIATIRC LIVING WITH ILLNESS SCREENER
AND SUPPLEMENTAL SURVEY MODULE
MEASURE WORK-UP**

DEFINITION OF THE MEASURE

A. Description

This measure provides information from parents of children age 12 and under, identified by the survey as having chronic conditions, about their experiences with their child's care. Reported experience of care and levels of satisfaction provide a general indication of how well the MCO meets member needs and expectations. This measure is applicable to the commercial and Medicaid product lines. The CAHPS® 2.0H Child Survey with the LWIM is recommended as a replacement to the CAHPS® 2.0H Child Survey and data collection and reporting is recommended for every two years. Key differences from the CAHPS® 2.0H Child Survey are sampling process (random plus an oversample based on utilization/diagnosis history), survey length and content (add 30 items and 5 new measurement domains), sample size (doubles) and scoring (score CAHPS and other domains separately for children identified as having or not having a chronic condition).¹

B. Measure Specifications

This measure uses enrollment data to identify health plan members who are age 12 years and under at the end of the reporting period. A random sample of children meeting enrollment and age criteria is drawn. In addition, an oversample of children preidentified as having a diagnosis indicative of a chronic condition is also drawn. One child from each household represented in each sample is selected as the "target" or subject child for the survey. The CAHPS® 2.0H Child Survey with the LWIM screener and supplemental survey items for children with chronic conditions is administered using the standardized CAHPS® 2.0H mail protocol with telephone follow up. Only those children who meet the survey-based screener criteria for having a chronic condition are included in the calculation of the chronic condition measures. Health plan-level performance values are scores or rates derived from the survey data and are calculated separately for those with and without a chronic condition. Separate sampling and calculations are recommended for Medicaid and commercial populations.

¹ CAHPS 2.0H Child Health Survey data is currently scored for all sampled enrollees, some of which will have a child with a chronic condition. Therefore, the separate scoring outlined here does represent a departure from 1999 scoring and methods. Scenario analyses to assess the impact of this deviation on trending are underway.

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:	Parent reports at least one health care visit in the past year.

Denominator: The eligible population. Some measures subset to those answering “yes” to filter survey items (e.g. had a need for certain services). See Attachment B for a copy of the survey items recommended for identifying children with chronic conditions.

Numerator: For each performance value, the numerator for the health plan score is the sum of scores for each individual survey respondent on the survey items pertinent to each performance value as outlined in Table 1. See Attachment B for a copy of the survey used during field testing and mapping of survey to each performance value.

Table 1: Summary of performance values derived from the Living with Illness Module

Performance Score	Survey items and content	Scoring
How well doctors communicate {CAHPS composite}	Parent/family report on whether doctors/providers spend enough time, know child's history, show respect and listen, explain things clearly.	-Average score on multi-item scale transformed to 0-100 for ease of interpretation.
Getting care quickly {CAHPS composite}	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 scale transformed to 0-100 for ease of interpretation.
Getting needed care {CAHPS composite}	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 scale transformed to 0-100 for ease of interpretation.
Courteous and helpful office staff (CAHPS composite)	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 scale transformed to 0-100 for ease of interpretation.
Customer service and information {CAHPS composite}	Parent/family report on experience with customer service, written plan materials and paperwork	-Average score on multi-item scale transformed to 0-100 for ease of interpretation.
Access to prescription drugs	Parent/family report on experience getting medication prescribed for their child.	-Proportion reporting no problem or, if a problem, help resolving it.
Access to specialized services	Parent/family report on experience with access to medical equipment, devices, or specialized therapies for child as needed.	-Weighted proportion with no problem across 4 service areas. (Weight by proportion needing each type of special service) or, if problem, help resolving it.
Family Centered Care	Parent/family report on how often/how well primary doctor/providers take time to understand the specific needs of child, discuss child's development and listen to and follows up on questions and concerns	Composite of two multi-item scales
Education and Teamwork	Parent/family report on how often doctor/providers discuss options and involve parents in care decisions, ask how parent is doing (support), give specific information needed and help parent understand what and how to do what they need to do for their child's health.	-Composite of two multi-item scales transformed to 0-100 for ease of interpretation.
Coordination of child's care	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/daycare.	-Proportion reporting no problem.

Sampling and Data Collection Protocol for LWIM:

The sampling for the LWIM builds on existing procedures for CAHPS® 2.0H

The data collection procedures for the LWIM are the same as for the CAHPS® 2.0H Child Survey. The CAHPS® 2.0H Child Survey 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 will use a stratified sample drawn from two sources. As outlined in Table 2, part of the sample will be from a group of children identified by a utilization algorithm and part of the sample will be from children who are randomly sampled from the plan's eligible population. Steps required to conduct sampling are detailed in Attachment C.

Advantages to enriched sampling approach:

- Smaller initial sample size
- Stratified sampling will include children who would be missed by utilization-only sampling

Disadvantages to enriched sampling approach:

Plans vary in their ability to consistently apply utilization algorithms

Table 2: Guidelines for Sampling

Issue	Response	Notes
Definition of approach	A stratified sampling approach consisting of over-sampling children identified via the utilization algorithm in combination with the survey screener and those captured from the general population using only the survey screener might be more efficient than the population-based approach	
Details	<p>1. Enriched sample - Draw a random sample from population of children meeting the age and continuous enrollment criteria and are identified by the following:</p> <p>1. Using claims/encounter data, identify all children with one or more qualifying codes (see Attachment C) at the first or second level of diagnosis for hospitalization, emergency room or outpatient visits.</p> <p>2: Select all children identified in step 1 who have at least one inpatient/ER visit or one outpatient visit for DX requiring one visit or two or more codes for. DX requiring two or more visits (see Attachment C)</p> <p>3: Randomly sample required number of children from the group of children identified in step 2 and ensuring that no more than one child per family is in the sampling frame.</p> <p>4: Assign each child/family a unique identifier which will also appear on the survey administered to the family.</p> <p>2. Population-based sample – Randomly sample 850 (commercial) and 1050 (Medicaid) children who meet the inclusion criteria from health plan member population who are not identified in the enriched algorithm. This sample will be very similar to the existing Child CAHPS™ sample.</p>	<p>1. Staff will check on the ability of small plans to report using this methodology.</p> <p>2. Additional work will identify how to score the results using this sampling methodology.</p>

C. Sample Size

Medicaid Enrollees. The sample size for Medicaid health plans is 2452 (1050 random, 1402 oversample).

Commercial Enrollees. The sample size for commercial health plans is 2186 (850 random, 1336 oversample).

Sample size estimates were based on assumptions regarding statistical power and significance for detecting performance differences, survey response rate, the expected

proportion of children in the population sample who screen positive on the screener, and the number of children identified by the screener in the over-sampled population.

Table 3: 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 measure is 411.
The expected proportion of children in the general population who have at least one practitioner visit and would screen positive for chronic conditions	Data from pilot studies: <ul style="list-style-type: none"> • Average commercial – 16.1% • Average Medicaid – 18.5% 	Population-based sample (number sampled X expected proportion) Commercial – 136 Medicaid – 194
The expected response rate of the survey	Data from pilot studies <ul style="list-style-type: none"> • Average commercial – 43.8% • Average Medicaid – 39.7% 	Population-based sample Commercial – 60 Medicaid – 77 Needed response from over-sample (411-population-based sample) Commercial – 351 Medicaid – 334
The expected catch from the utilization algorithm	Data from pilot studies indicate about 60% (see Attachment D)	Over-sample estimates (response from over-sample/catch/response rate) Commercial – 1336 Medicaid – 1402
Final sample size calculation	Commercial– $850 + 1336 = 2186$ Medicaid – $1050 + 1402 = 2452$	1. Net increase over existing approach is about 500 surveys for commercial and 350 for Medicaid (assuming that the survey is implemented every other year).

E. Type of Measure

This measure is in the Satisfaction with Experience of Care Domain and evaluates several processes for children with chronic conditions. Performance values are appropriate for reporting in the Living with Illness reporting category.

F. Data Requirements

Enrollment data are used to identify eligible plan members, from which a random sample is drawn. Utilization data is used to identify children qualifying for the diagnostic based oversampling algorithm. Parents of sampled eligible members are surveyed to evaluate their experiences with care. The survey uses the CAHPS® 2.0H Child survey as the basis and identifies children with chronic conditions via a screener tool that is administered as a part of the survey.

G. Background

Measures that provide specific information about care for children with 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 and children with chronic conditions. There is high interest and expert consensus around the importance of assessing the LWIM dimensions of quality of care received by this subset of children (Newacheck, Stein, Walker, et al., 1996).

The LWIM incorporates information about the performance of health plans on basic aspects of care parents and families say matter most as well as aspects of care reflected in both condition specific and non-categorical guidelines for the care of children with chronic conditions (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 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 chronic conditions in a reliable manner across multiple settings for the purposes of evaluating the quality of care for this group of children.

The epidemiology of childhood chronic conditions shows that children, unlike adults, face a large number of conditions, 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 Also, single condition monitoring provides an inadequate view of the overall quality and outcomes of care for children with chronic conditions. The relatively low

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.

prevalence of any single childhood chronic condition and the large number of applicable diagnoses, many of which are very rare, also means that disease-specific checklists are inadequate for capturing the full range of chronic childhood diseases. Such an approach is unlikely to lead to sample sizes required for comparative performance measures.

The non-categorical casefinding approach used in the LWIM, responds to both the urgent need for comparative performance measurement for children with chronic conditions and to the technical challenge of identifying sample sizes sufficient to do so. The LWIM casefinding approach reflects state of the art approaches and empirical research regarding non-categorical identification.

The LWIM screener for identifying children with chronic conditions represents intensive collaboration among key researchers and stakeholders in the field. It draws explicitly on a wide body of empirical work regarding methods for identifying children with chronic conditions (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 measurement concepts reflected in the LWIM 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 are 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 valuable for tracking and improvement of performance. The survey items set forth represent a consensus set of minimum survey items agreed upon within the Living with Illness Task Force, which includes lead members of the CAHPS team, NCQA, MCHB, Family Voices and many others.³

RELEVANCE OF MEASURE

A. Meaningfulness of the Measure –

The LWIM measure has been shown to be relevant and meaningful to consumers, purchasers and providers alike. Focus groups conducted as part of the LWIM development as well as by Family Voices and many other organizations verify the relevance of the LWIM measure to families with children with chronic conditions. In addition to verifying the relevance of the LWIM content, families who participated in the focus groups also expressed a strong desire for the information generated by the LWIM to use in guiding their health plan selection. As evidenced by the receptivity of public sector purchasers to the LWIM, this measure 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. The LWIM has the support of members of Child and Adolescent Health Measurement Initiative representing several large

³ As of October 15, 1999 small edits are still expected to some survey items which should not alter the concept, basic formatting or information expected to be derived.

state purchasers, health plans, the American Academy of Pediatrics and the American Academy of Family Physicians.

The Health Care Financing Administration requires states to report on the quality of care provided to children with chronic conditions, making the LWIM especially relevant to states and the Federal government.

B. Clinical Importance -

The LWIM measure represents fundamental aspects of care pertinent to virtually all children with chronic conditions (Newacheck, et al., 1996, Kuhlthau, et al., 1998). Condition specific guidelines emphasize the components of care measured in the LWIM (AAP, 1996). Improvements in functioning and reductions in negative health events associated with chronic conditions such as days lost from school and acute events requiring emergency care for conditions such as asthma and diabetes are expected to result from improvements in aspects of care measured by the LWIM (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 LWIM. 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 LWIM fills unique gaps in HEDIS and represents core aspects of health care quality for the subset of children that use the vast majority of health care resources used by 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 LWIM will allow managed care organizations to demonstrate performance for children with chronic conditions

In addition, the LWIM should be easily applicable to FFS settings as well, making direct comparisons between managed care organizations and FFS models of care possible.

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. In the LWIM field trial, significant within plan differences in care for children with a chronic condition and those without were found for the following performance values:

- Doctors who communicate (one plan sample of four)
- Getting needed care (all four plan samples)
- Getting care quickly (one plan sample of four)
- Access to specialized services (all four plan samples)
- Education and Teamwork (two plan samples of four)
- Coordination of care (applies to children with chronic conditions only)

The CAHMI is working collaboratively with the Maternal and Child Health Bureau and the National Health Interview Survey to ensure that, where possible, survey items used in the NHIS and upcoming National Immunization Survey/SLAITS are the same as those used in the LWIM. We expect several LWIM survey items (and possibly the screener items) to be included in these national survey efforts. This will create national benchmarks and a valuable synergy between health plan assessment and public health monitoring efforts.

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 LWIM. 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 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.

G. Variance among plans –

For all LWIM performance values, significant variations ($p < .0001 - .10$). in performance were detected across the four field trial site health plans for children with chronic conditions, with the exception of the coordination of care performance domain. Notably, however, the coordination of care performance value was uniformly low across all four plan samples. (see Table 4).

Table 4: Discriminant ability of LWIM measures for children with chronic or special health needs

LWIM measures tested in field trial	Population-based sample			Over-sampling approach	F Value from ANOVA, 4 plans
	Site #1 (commercial)	Site #2 (Medicaid)	Site #3 (commercial)	Site #4 (commercial)	
PV1: Doctors Who Communicate CAHPS® composite (Mean score/4 pts maximum)	3.47	3.55	3.32	3.50	2.47 (P= .06)
PV2: Getting Care Quickly CAHPS® composite (Mean score/4 pts maximum)	3.10	3.30	2.89	3.16	5.82 (P= .001)
PV3: Getting Needed Care CAHPS® composite (Mean score/3 pts maximum)	2.78	2.75	2.41	2.71	9.71 (P= .000)
PV6: Access to specialized services [medical equip and/or special therapies] (Mean score/3 pts maximum)	2.47	2.76	1.79	2.24	5.33 (P= .002)
PV7: Education & Teamwork (Components tested in field trials)					
a) Child's personal doctor/provider care scale (mean score/9pts maximum)	7.79	7.89	7.68	8.25	3.56 (P = .015)
b) All child's drs/providers care scale (mean score/9pts maximum)	8.30	8.55	8.02	8.53	3.27 (P = .022)
c) Involvement in decision making (% reporting 'usually/always' involved)	83.0	94.7	91.8	96.4	Chi ² = 9.49 (P = .023)
d) Dr follows-up on parent's concerns (mean score/3pts maximum)	2.76	2.80	2.58	2.76	2.11 (P = .10)
e) Family receives sufficient information about child's condition (mean score/4 pts maximum)	3.26	3.38	2.71	3.33	7.62 (P = .000)
f) Helpfulness of information in caring for child (mean score/4 pts maximum)	3.39	3.58	3.14	3.63	5.98 (P = .001)
PV8: Coordination of child's care (Components tested in field trials)					
a) Dr. help in coordinating care with child's school/daycare (mean score/3 pts maximum)	2.59	2.60	2.42	2.76	1.65 (P = .182)
b) Dr. or health plan assists in coordination of child's care among multiple providers/services (mean score/3 pts maximum))	2.14	2.27	N/A	2.10	.159 (P = .923)

NOTE: See Appendix B for specific survey items used to construct measures. Measures not transformed to 0-100 scores for purposes of statistical testing.

H. Potential for Improvement –

Quantitative and qualitative assessments of health plan performance in meeting the needs and expectations of families with children with chronic conditions show a dramatic need and potential for improvement (Family Voices, 1999, FACCT, 1999, Hill, et al., 1999). This is especially the case in the new measurement concepts reflected in the LWIM – coordination of care, access to specialized services and education and teamwork/family centered care.

Condition specific studies assessing the degree to which health care providers currently use guidelines for common conditions such as asthma, show a dramatic need for improvement. For example, a 1995 study by Crain, Weiss, and Fagan showed that although asthma accounts for 17% of ER visits and that one quarter to one third of children with chronic conditions have asthma, only 2.1% ER room doctors use written protocols and only 24% had read the NHLBI guidelines for pediatric asthma (Crain, Weiss and Fagan, 1995).

SCIENTIFIC STRENGTH OF THE MEASURE

Altogether thirteen managed care organizations have participated in the testing of the LWIM. Results from four plans are summarized here. Results from the additional nine health plans will be referenced to the extent that new information is provided by the fielding of the LWIM in these plans (results available July-August, 2000)

Using a standardized protocol, the LWIM was administered in conjunction with the standard CAHPS 2.OH Child Survey and data to allow for the assessment of the feasibility and the soundness of the proposed measures was collected. See Table 5 below for a summary of participating sites and Table 6 for a summary of the demographic characteristics and response rates for each site. Please note that no significant differences in the age or gender of the sampled and responding population were observed for any of the four sites.

Data analysis conducted by FACCT addressed a number of specific issues, including the adequacy of the sample size and success of the survey administration protocols, validation of the sampling and survey screener approach, the validity and reliability of survey scales and items for use in performance assessment and plan burden and cost were evaluated. A high-level summary of findings are outlined below as appropriate.

Table 5: Brief description of each LWIM field trial site

Name	Location	Type of Plan Sample	Starting Sample Size
Site #1	Hawaii	HMO Commercial	900 Data vendor: HHIC
Site #2	Hawaii	HMO Medicaid	900 Data vendor: HHIC
Site #3	Southern California	HMO Commercial	1600 Data vendor: CSS
Site #4	Washington State	Managed Care (mixed model) Commercial	1200 Data vendor: CSS
Sites #5-13	Washington State	Managed Care (mixed model) SSI FFS	Approx. 20,000 Data Vendor: DataStat

Table 6: Demographic characteristics of populations sampled for the LWIM field trials (Samples 1-4)

	Commercial Site #1 (n=900)	Medicaid Site #2 (n=900)	Commercial Site #3 (n=1600)	Commercial Site #4 (n=1200)
% Female	51	49	50	45
% 0-3 years old	13	30	20	13
% 4-6 years old	19	24	24	21
% 7-9 years old	22	22	27	28
% 10-13 years old	45	24	29	38
Sampling Approach	Random sample of population	Random sample of population	Random sample of population	Oversample for those meeting NACHRI algorithm
Mode of data collection	Mail (modified HEDIS protocol – no CATI)	Mail (modified HEDIS protocol – no CATI)	Mixed (HEDIS protocol)	Mixed (HEDIS protocol)
Response Rate	59.3%	59.5%	42%	51%

A. Reliability

Both the survey items used to identify families with children with chronic conditions and those used to construct the LWIM performance values underwent both cognitive and psychometric testing to evaluate the reliability of these survey items.

Reliability as measured by Cronbach's alpha/internal consistency were well within the acceptable range (average .70) for all survey scales represented in the LWIM.

Some test-retest estimates are available for survey items similar to those included in the LWIM screener and showed Kappa of .90 (Stein, 1999)

While the internal consistency of the LWIM survey scales is high, it should be noted that items included in the LWIM are not highly redundant. 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.

B. Validity

Numerous aspects of validity were examined for both the screener for identifying children with chronic conditions and the survey items used to construct the LWIM performance values.

Face and construct validity was carefully assessed throughout the LWIM development and is demonstrated by the widespread support for the LWIM by multiple consumer and expert stakeholders and by the formal endorsement of the LWIM by the Child and Adolescent Health Measurement Advisory Committee. Concurrent validity was examined by evaluating expected associations among survey items and survey responses and demographic and other variables. Criterion validity was assessed, in part, for the LWIM screening tool by comparing it with another validated instrument – the Questionnaire for Identifying Children with Chronic Conditions-R.

Validity of survey items:

Many hypotheses guided the analysis of the field trial data to assess the concurrent validity of the LWIM survey items. Specifically, the majority of expectations for how families with children with chronic conditions would be expected to answer the survey versus those whose child did not have a chronic condition were confirmed. In cases where hypotheses were not confirmed, survey items were deleted (e.g. written care plan items) or reconstructed and retested (e.g. coordination of care items).

Validity of LWIM screening tool and population-based sampling approach:

Utilization and diagnostic data were collected in two of the four sites (1) to further assess the validity of the chronic condition screener; and (2) to compare a population-based random sample approach to an oversampling approach (pre-identification based on utilization/diagnosis).

To summarize, approximately 65% of children identified by the NACHRI screener⁴ were also identified using the LWIM screening tool. Approximately 18% of those not identified with the NACHRI algorithm were still identified using the LWIM screener. These findings were anticipated. Discrepancies between the NACHRI algorithm and the LWIM screener were evaluated and found to be explained by factors that did not raise concerns about the validity of the LWIM screening tool (quality of utilization/diagnostic data; expected levels of mis-diagnosis and missed diagnoses; lags in utilization/diagnostic data and survey data).

The LWI Task Force carefully considered the use of an oversampling approach, recognizing the potential reduction in starting sample size and, hence, the cost of such an approach (e.g. 40% of children were identified as having a chronic condition in the site using an oversampling

⁴ The NACHRI Classification of Congenital and Chronic Health Conditions is a service use/diagnostic based algorithm developed by the National Association of Children's Hospitals and Related Institutions. It is the most carefully developed and tested algorithm of this kind.

approach compared to 18% with a population-based approach). Even though a population-based approach is preferred, based on NCQA recommendations to use this method, the task force supports the use of an oversampling vs. population-based approach.

Approximately 7-9% of health plan members (14% of those with encounters) are expected to meet the oversampling algorithm (based on Washington State pilot). A full report on the agreement between a utilization and diagnostic case finding method and the survey screener is available. It should be noted, that as with all HEDIS measures relying on utilization data, the outpatient data required may not be available for some plans.

Further assessment of the validity of the LWIM screener took place. Two studies, one based on a health plan sample and another based on a nationally representative sample, showed that the LWIM screener has a 90% agreement with the interviewer administered Questionnaire for Identifying Children with Chronic Conditions—Reduced Version (QulCCC-R). While no “gold standard” exists for identifying children with chronic conditions, the QulCCC-R is a widely adopted, tested, well-respected tool and, therefore, chosen to assess the validity of the LWIM screener (Stein, R, et al., 1997).

The 10% discrepancy between results on the QulCCC-R and the LWIM screener were carefully examined and determined to support the validity of the LWIM screener as a highly specific (.98 specificity estimated to date) and sensitive (.90 sensitivity estimated to date) when compared to the QulCCC-R. Discrepant cases were significantly different from agreement cases and appear to be largely comprised of children with either acute conditions or more mild chronic conditions that do not impact functioning or require higher than routine use of health care services. Similar to other NCQA Measurement Advisory Panels, specificity was identified as the primary measure of agreement used by the LWI Task Force. A larger study conducted by Dr. Ruth Stein (n = 900) confirmed a .93 specificity between the QulCCC and the LWIM screener (Stein, 1999).

C. Power to detect

As outlined earlier, the LWIM specifications recommended here allow for differences of 10 points (or less) to be detected across health plans. Completed sample sizes smaller than 411 will still allow for meaningful comparisons between a health plan and a standard comparison score (e.g. mean of all plans). This is essential, since smaller plans will have a hard time identifying 411 children after applying the HEDIC CAHPS 2.0H eligibility criteria AND the LWIM screener criteria.

D. Risk Adjustable –

No risk adjustment is recommended for the LWIM performance values. Age, gender and incidence of acute conditions were evaluated and rejected as potential risk adjustors as was whether a child was pre-identified using the oversampling algorithm.

E. Comparability of Data Sources –

Data sources across plans are comparable. The additional LWIM questions did not reduce response rates over the CAHPS® 2.0H Child Health Survey (FACCT LWIM field trial reports). Average response rate for field trial sites was 55%.

Feasibility

A. Precisely Specified –

CAHPS® 2.0H Child Survey administration protocol specifications are used with the sampling frame and sample size changes described earlier. All field trial vendors found the LWIM specifications to be clear, easily implemented and precise.

B. Reasonable Cost –

The LWIM is recommended as a replacement for the CAHPS® 2.0H Child Survey. The fielding of the CAHPS® 2.0H Child Survey with the LWIM is recommended every two years. While costs of survey administration will vary, the estimated increase in cost for administering the LWIM is \$4,000 per plan, not including costs associated with drawing the random sample.

Cost estimates are outlined in table 7 below.

Table 7: 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 – LWIM	Commercial <ul style="list-style-type: none">• Low cost, average response - \$10,930• High cost, average response - \$34,976 Medicaid <ul style="list-style-type: none">• Low cost, average response - \$12,260• High cost, average response - \$39,232	Estimates based on Commercial – N=2186 Medicaid – N=2452
Estimate of increased cost	Commercial <ul style="list-style-type: none">• Low cost vendor – \$2,430• High cost vendor – \$7,776 Medicaid <ul style="list-style-type: none">• Low cost vendor - \$1,760• High cost vendor - \$5,632	Adjusted existing estimates for two year cycle.

More detailed work-ups of costs for the LWIM are available upon request.

C. Confidential –

See CAHPS® 2.0H Child Survey specifications. If children are pre-identified and an oversampling approach is used some confidentiality issues will arise (personal communication with OPM and other HEDIS users).

D. Logistically Feasible –

The casefinding and survey administration of the LWIM is straightforward and logistically feasible for health plans. For the LWIM 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 CAHPS™ 2.0H Child Survey specifications

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LIST OF ATTACHMENTS

ATTACHMENT A:

- ❑ LIVING WITH ILLNESS TASK FORCE PARTICIPANTS
- ❑ LIST OF MEMBERS OF THE CHILD AND ADOLESCENT HEALTH MEASUREMENT INITIATIVE ADVISORY COMMITTEE

ATTACHMENT B:

- ❑ COPY OF SURVEY USED IN WASHINGTON STATE PILOT (10 SAMPLES)
- ❑ COPY OF SURVEY ITEMS RECOMMENDED FOR IDENTIFYING CHILDREN WITH CHRONIC CONDITIONS
- ❑ MAPPING OF SUPPLEMENTAL SURVEY ITEMS TO NEW LWIM PERFORMANCE SCORES

ATTACHMENT C:

SAMPLING FOR THE LWIM: OUTLINE OF STEPS AND PROCEDURES

ATTACHMENT D:

DATA TABLES

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LWIM Screener for Children with Chronic Conditions
(HEDIS/NHIS version – mail or telephone)

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
 - Yes ← Go to Question 1a
 - No ← Go to Question 2
 - 1a. Is this because of ANY medical, behavioral or other health condition?
 - Yes ← Go to Question 1b
 - No ← Go to Question 2
 - 1b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

2. Does your child need or use more **medical care , mental health or educational services** than is usual for most children of the same age?
 - Yes ← Go to Question 2a
 - No ← Go to Question 3
 - 2a. Is this because of ANY medical, behavioral or other health condition?
 - Yes ← Go to Question 2b
 - No ← Go to Question 3
 - 2b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
 - Yes ← Go to Question 3a
 - No ← Go to Question 4
 - 3a. Is this because of ANY medical, behavioral or other health condition?
 - Yes ← Go to Question 3b
 - No ← Go to Question 4
 - 3b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
 - Yes ← Go to Question 4a
 - No ← Go to Question 5
 - 4a. Is this because of ANY medical, behavioral or other health condition?
 - Yes ← Go to Question 4b
 - No ← Go to Question 5
 - 4b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
 - Yes ← Go to Question 5a
 - No
 - 5a. Has this problem lasted or is it expected to last for at least 12 months?
 - Yes
 - No

Scoring the LWIM Screener for Children with Chronic Conditions

Conceptual background

The LWIM screener uses consequences-based criteria to screen for children with chronic or special health needs. To qualify as having a chronic condition, the following set of conditions must

be met:

- a) The child currently experiences a specific consequence.
- b) The consequence is due to a medical or other health condition.
- c) The duration or expected duration of the condition is 12 months or longer.

The first part of each screener question asks whether a child experiences one of five different health consequences:

- 1) Use or need of prescription medication
- 2) Above average use or need of medical, mental health or educational services
- 3) Functional limitations compared with others of same age
- 4) Use or need of specialized therapies (OT, PT, speech, etc.)
- 5) Treatment or counseling for emotional, behavioral or developmental problems

The second and third parts* of each screener question ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

**NOTE: LWIM screener question 5 only has 2 parts.*

All three parts of at least one screener question (or in the case of question 5, the two parts) must be answered “yes” in order for a child to meet LWIM screener criteria for having a chronic condition.

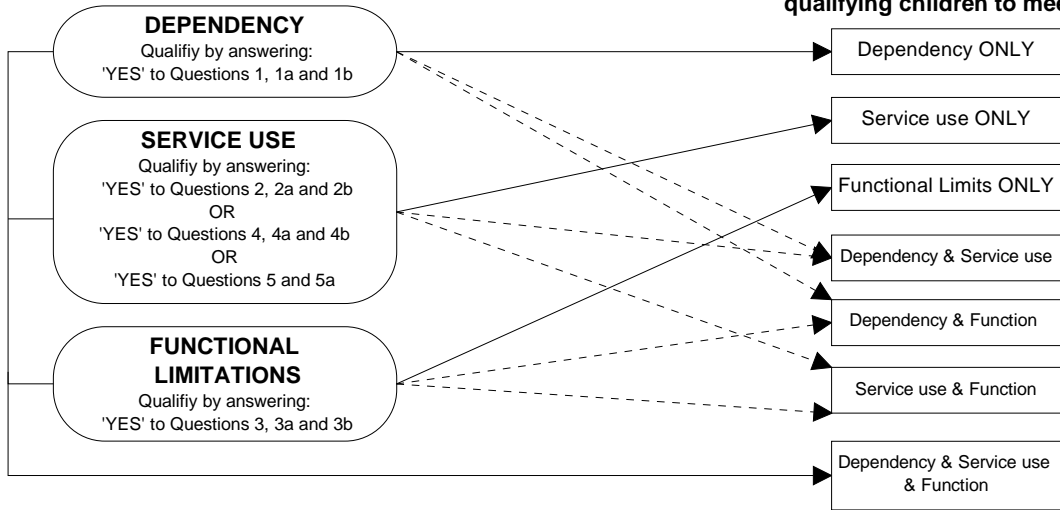
The LWIM screener has three “definitional domains”. These are:

- 1) Dependency on prescription medications
- 2) Service use above that considered usual or routine
- 3) Functional limitations

The definitional domains are not mutually exclusive categories. A child meeting the LWIM screener criteria for having a chronic condition may qualify for one or more definitional domains (see diagram below).

Qualifying questions for meeting a LWIM screener definitional domain

Definitional combinations possible for qualifying children to meet



Percentage of children meeting both diagnostic code and non-categorical screener criteria

	Met LWIM screener criteria
Met NACHRI ¹ diagnosis code criteria	62.4%
Met RCCCC ² diagnosis code criteria	62.5%

1 National Association of Children's Hospitals and Related Institutions.

2 Research Consortium for Children with Chronic Conditions

Performance values for children by LWIM screener status for chronic health conditions

Performance Values	Population-based sampling approach						Over-sampling approach	
	Site 3 (Commercial) N = 613		Site 1 (Commercial) N = 335		Site 2 (Medicaid) N = 275		Site 4 N = 360	
	Chronic (n= 94)	Not chronic (n = 519)	Chronic (n = 61)	Not chronic (n = 274)	Chronic (n = 54)	Not chronic (n = 221)	Chronic (n = 144)	Not chronic (n = 216)
PV1: How well providers communicate (mean score out of 100 points possible)	76.7 points	81.3 points	80.9 points	82.2 points	84.9 points	86.2 points	83.2 points	81.6 points
PV2: Getting care quickly (mean score out of 100 points possible)	66.7 points	75.0 points	71.8 points	75.2 points	79.0 points	80.0 points	73.4 points	76.8 points
PV3: Getting needed care (mean score out of 100 points possible)	68.0 points	85.0 points	87.4 points	92.1 points	87.4 points	94.1 points	84.5 points	94.9 points
PV4: Customer service and information (mean score out of 100 points possible)	64.7 points	70.5 points	n/a	n/a	n/a	n/a	n/a	n/a
PV5: Access to specialized services (composite of a, b, c & d) (weighted % having some kind of problem)	78.5%	33.3%	48.1%	16.7%	12.9%	18.2%	38.4%	33.3%
a. Access to medical equipment (% having problems)	45.5% (n = 11)	20.0% (n = 15)	14.3% (n = 7)	0.0% (n = 2)	8.3% (n = 12)	0.0% (n = 5)	45.5% (n = 22)	16.7% (n = 6)
b. Access to specialized therapies (% having problems)	94.4% (n = 18)	62.5% (n = 8)	66.7% (n = 6)	16.7% (n = 6)	0.0% (n = 5)	100% (n = 1)	43.6% (n = 39)	33.3% (n = 6)
c. Access to home health services (% having problems)	100.0% (n = 1)	0.0% (n = 0)	0.0% (n = 0)	0.0% (n = 2)	100.0% (n = 1)	0.0% (n = 1)	0.0% (n = 1)	0.0% (n = 0)
d. Access to mental health services (% having problems)	81.0% (n = 21)	25.0% (n = 4)	57.1% (n = 14)	25.0% (n = 8)	15.4% (n = 13)	25.0% (n = 4)	32.0% (n = 50)	50.0% (n = 6)
PV6: Access to prescription drugs (% having problems)	26.4% (n = 87)	10.7% (n = 336)	9.8% (n = 51)	8.7% (n = 161)	4.8% (n = 42)	6.0% (n = 117)	11.7% (n = 120)	9.4% (n = 117)
PV7: Family centered care (composite of a, b & c) (weighted % usually/always get family-centered care)	72.3%	81.6%	74.7%	84.0%	80.1%	84.4%	85.9%	90.1%
a. Child's personal dr/nurse scale (% scoring 8 or 9 out of 9 points possible)	56.2% (n = 73)	67.9% (n = 333)	61.4% (n = 44)	73.0% (n = 152)	62.8% (n = 43)	69.3% (n = 114)	77.2% (n = 123)	78.1% (n = 137)
b. All child's dr/other providers scale (% scoring 8 or 9 out of 9 points possible)	73.2% (n = 82)	84.1% (n = 403)	76.9% (n = 52)	85.5% (n = 165)	88.6% (n = 44)	90.1% (n = 111)	89.1% (n = 129)	95.0% (n = 140)
c. Involvement in decisions about child's care (% reporting usually/always)	91.8% (n = 61)	93.1% (n = 189)	79.5% (n = 44)	94.3% (n = 87)	93.3% (n = 30)	95.6% (n = 45)	96.4% (n = 111)	98.8% (n = 83)
d. Dr. follow up on parent's concerns about child's health problems (% reporting no problems)	71.4% (n = 84)	84.9% (n = 417)	79.6% (n = 54)	86.9% (n = 175)	79.5% (n = 44)	89.3% (n = 121)	82.0% (n = 133)	91.7% (n = 144)

	Population-based sampling approach						Over-sampling approach	
	Site 3 (Commercial) N = 613		Site 1 (Commercial) N = 335		Site 2 (Medicaid) N = 275		Site 4 N = 360	
Performance Values (cont..)	Chronic (n= 94)	Not chronic (n = 519)	Chronic (n= 61)	Not chronic (n = 274)	Chronic (n= 54)	Not chronic (n = 221)	Chronic (n= 144)	Not chronic (n = 216)
PV8: Provision of patient education (composite of a & b) (weighted % usually/always get sufficient & helpful info)	70.7%	85.5%	85.7%	89.6%	84.7%	89.0%	92.0%	92.4%
a. Receive sufficient information (% reporting usually/always)	61.6% (n = 52)	81.4% (n = 91)	83.1% (n = 59)	88.4% (n = 190)	78% (n = 50)	87.6% (n = 145)	90.0% (n = 140)	90.9% (n = 143)
b. Helpfulness of education in caring for child's health condition (% reporting somewhat/a great deal))	80.4% (n = 56)	89.5% (n = 95)	88.3% (n = 60)	90.8% (n = 185)	91.7% (n = 48)	90.8% (n = 119)	94% (n = 134)	93.9% (n = 148)
PV9: Coordination of child's care (composite of a, b & c) (weighted % having some kind of problem)	31.6%	15.1%	To-be-determined	To-be-determined	To-be-determined	To-be-determined	To-be-determined	To-be-determined
a. Dr help w/ coor care with child's school or daycare (% having problems)	41.7% (n = 24)	18.2% (n = 2)	31.6% (n = 19)	20.0% (n = 10)	31.8% (n = 22)	0.0% (n = 7)	16.7% (n = 66)	20.0% (n = 10)
b. Dr. or health plan help with coordinating care among multiple providers/services (% sometimes/never)	n/a	n/a	55.6% (n = 18)	42.9% (n = 7)	50.0% (n = 12)	66.7% (n = 3)	56.0% (n = 84)	25.0% (n = 16)
c. Dr. or health plan help identifying community services for child. (% reporting 'No')	n/a	n/a	78.9% (n = 19)	77.8% (n = 9)	58.3% (n = 12)	33.3% (n = 3)	74.1% (n = 85)	80.0% (n = 15)
1. Children with multiple providers ONLY			88.1% (n=59)	91.5% (n=258)	73.1% (n=52)	75.6% (n=213)	79.3% (n=140)	89.4% (n=188)
2. All respondents to question								
PV10: Provision of written care plan (% reporting YES)	18.9% (n = 53)	28.0% (n = 93)	n/a	n/a	n/a	n/a	n/a	n/a
a. Child has written care plan (% reporting YES)	n/a	n/a	19.7% (n = 61)	14.3% (n = 266)	24.1% (n = 54)	11.3% (n = 213)	21.5% (n = 144)	10.8% (n = 213)
b. If child has a care plan, parent was given A copy of the plan by doctor? (% reporting YES)	n/a	n/a	100% (n = 10)	84.2% (n = 38)	100.0% (n = 13)	86.4% (n = 22)	76.7% (n = 30)	95.5% (n = 22)
PV11: Symptom management								
a. % reporting helped 'great deal'	45.1% (n = 51)	64.8% (n = 88)	63.2% (n = 57)	57.6% (n = 170)	62.8% (n = 43)	62.5% (n = 112)	55.5% (n = 128)	63.8% (n = 138)
b. % reporting helped 'somewhat'	33.3% (n = 51)	20.5% (n = 88)	22.8% (n = 57)	25.3% (n = 170)	23.3% (n = 43)	23.2% (n = 112)	36.7% (n = 128)	24.6% (n = 138)

** Composite scores weighted by proportion of those responding to each question or needs component out of the total responding to the performance value composite components.

Results of LWIM case mix adjustment regression analysis

Dependent Variable	Independent Variables			
	Child's Age 5 age categories by 3 year increments	Gender 1 = male	Chronic 1 = have chronic condition	Acute 1 = 1 or more during past 12 mos.
PV 1: Drs who communicate R2 = .008	$\beta = -.075$ $p = .008$	$\beta = .022$ $p = .42$	$\beta = -.026$ $p = .33$	$\beta = -.051$ $p = .06$
PV 2: Getting care quickly R2 = .003	$\beta = -.028$ $p = .31$	$\beta = .015$ $p = .57$	$\beta = -.040$ $p = .131$	$\beta = -.013$ $p = .63$
PV 3: Getting needed care R2 = .038	$\beta = .017$ $p = .53$	$\beta = .019$ $p = .46$	$\beta = -.197$ $p = .000$	$\beta = -.009$ $p = .74$
PV5: Access to specialized services (Medical equip, mental health services, special therapies, home care) R2 = .057	$\beta = -.041$ $p = .52$	$\beta = .020$ $p = .75$	$\beta = -.230$ $p = .000$	$\beta = .037$ $p = .57$
PV 6: Access to Rx medicines R2 = .007	$\beta = .015$ $p = .65$	$\beta = -.031$ $p = .32$	$\beta = -.076$ $p = .018$	$\beta = -.025$ $p = .45$
PV 7: Patient education and teamwork				
<p>A. <u>Care by child's personal dr/nurse</u> PV7a: PCP understands affect of health condition on child's daily life (R2 = .001)</p>	$\beta = -.026$ $p = .42$	$\beta = .003$ $p = .91$	$\beta = .016$ $p = .61$	$\beta = -.034$ $p = .28$
<p>PV7b: PCP understands affect of child's health condition on family (R2 = .005)</p>	$\beta = -.038$ $p = .24$	$\beta = -.026$ $p = .39$	$\beta = -.030$ $p = .35$	$\beta = -.047$ $p = .14$
<p>PV7c: PCP asks how child is feeling, growing, behaving (R2 = .020)</p>	$\beta = -.145$ $p = .000$	$\beta = -.011$ $p = .69$	$\beta = .005$ $p = .87$	$\beta = -.015$ $p = .61$
<p>B. <u>Care by all child's drs and other providers</u> PV7d: Child's drs/providers provide support re: family's care (R2 = .009)</p>	$\beta = -.091$ $p = .001$	$\beta = .007$ $p = .81$	$\beta = .014$ $p = .62$	$\beta = -.066$ $p = .02$
<p>PV7f: Child's drs/providers listen to parent concerns (R2 = .023)</p>	$\beta = -.028$ $p = .35$	$\beta = .002$ $p = .95$	$\beta = -.141$ $p = .000$	$\beta = -.040$ $p = .18$
<p>PV7g: Child's drs/providers make parent feel like a partner in child's care (R2 = .005)</p>	$\beta = -.070$	$\beta = -.008$ $p = .77$	$\beta = .015$ $p = .59$	$\beta = -.036$ $p = .19$

Dependent Variable	Independent Variables			
	Child's Age 5 age categories by 3 year increments	Gender 1 = male	Chronic 1 = have chronic condition	Acute 1 = 1 or more during past 12 mos.
PV7e: Involvement in decision-making (R2 = .007)	p = .013	$\beta = -.033$ p = .38	$\beta = -.068$ p = .08	$\beta = .006$ p = .87
PV7h: Child's drs/providers follow up on parent concerns (R2 = .025)	$\beta = -.024$ p = .55	$\beta = -.035$ p = .22	$\beta = -.134$ p = .000	$\beta = -.061$ p = .04
C) Patient/family education				
PV8a: Receive adequate information about child's health condition (R2 = .018)	$\beta = -.026$ p = .44	$\beta = -.052$ p = .12	$\beta = -.097$ p = .004	$\beta = -.062$ p = .07
PV8b: Helpfulness of information in learning to care for child's condition (R2 = .003)	$\beta = .002$ p = .97	$\beta = -.044$ p = .19	$\beta = -.020$ p = .56	$\beta = .029$ p = .40
PV 9: Coordination of care				
PV9a: Help coord. child's care with school or daycare (R2 = .030)	$\beta = -.065$ p = .40	$\beta = -.013$ p = .86	$\beta = -.108$ p = .16	$\beta = -.139$ p = .07
PV9b: Help coord. child's care among multiple providers (R2 = .042)	$\beta = -.045$ p = .57	$\beta = -.010$ p = .90	$\beta = -.202$ p = .009	$\beta = -.020$ p = .80