**Children with Chronic Conditions**
**Prepared by Christina Bethell and Debra Read**
**The Child and Adolescent Health Measurement Initiative**

The reliable identification of children with chronic health problems is challenging for a number reasons. First, a gold standard definition and identification method for children with chronic health conditions does not exist and naturally varies depending upon the specific application of such a definition (e.g., clinical assessment, program enrollment, performance monitoring). Even when the purpose for identifying children is the same, definitions are not standardized and often differ by being more or less inclusive, resulting in a range of estimates of prevalence.

The screening tool developed for testing in the LWIM was designed to reflect consensus definitions of children with chronic conditions and to be both sensitive enough to capture children with a wide range of childhood chronic conditions and specific enough to not include children with non-chronic or very mild health problems. The tool was developed specifically for performance assessment applications and took into account theoretical and empirical findings on the identification of children with chronic conditions.

The LWIM screening tool is adapted from questions and concepts used by several well-tested, widely-administered instruments such as the National Health Interview Survey and the Questionnaire for Identifying Children with Chronic Conditions (QUICCC). The questions have undergone cognitive testing with families with and without children with chronic conditions. A copy of the LWIM screening questions and scoring conventions is included in Table X. Additional background on the development of the LWIM screening tool is included in Attachment 3.

Overall, five options for defining the target population were considered in the LWIM field trial. Two of these options require the use of the LWIM screening tool discussed above. The other three use items developed by the CAHPS team and/or utilization data. The five options considered are listed as Algorithm 1-5 below.

**Algorithm 1**: Population based application of the LWIM screening tool (three sites used this algorithm): A survey including the LWIM screening tool survey items is administered to a random sample of the population. Those screening positively on the tool are included in the denominator for the children with chronic condition specific measures. All sites using this algorithm also collected utilization data.

**Algorithm 2**: Utilization data only (no site is using this algorithm)
Families with children with chronic conditions using a specified set of utilization and diagnostic codes are pre-identified and a survey it sent to these families. Due to concerns about the feasibility and biases inherent in this approach, no site is using this algorithm. Biases include missed diagnoses, mis-diagnoses, errors in coding and data entry. These biases are known to be widespread and are not expected to vary randomly from plan to plan.

**Algorithm 3**: Over-sampling application of the LWIM screening tool (one site is using this algorithm): To reduce the necessary starting sample size required to identify a sufficient number of children with chronic conditions, ½ of the full sample is prescreened as having a child with a chronic condition using a specific utilization algorithm. The LWIM screening tool is administered to a random sample of the resulting cohort of families along with a random sample of families who were not identified as having a child with a chronic condition using the utilization algorithm. All those parent/families screening positively on the LWIM screening tool are included in the denominator for the children with chronic conditions measures whether they met the utilization prescreening criteria or not. This is the approach outlined in Figure 1.

**Algorithm 4:** Population based application of the CAHPS screening items (two of the three sites using Algorithm 1 also included the CAHPS items). A survey including the CAHPS survey items is administered to a random sample of the population. Those screening positively based on these items are included in the denominator for the children with chronic condition specific measures. A copy of the five CAHPS items is included in Table 12.

**Algorithm 5:** Over-sampling application of the CAHPS screening items (the site using Algorithm 3 also used this Algorithm) : To reduce the necessary starting sample size required to identify a sufficient number of children with chronic conditions, ½ of the full sample is prescreened as having a child with a chronic condition using a specific utilization algorithm. The CAHPS screening items are administered to a random sample of the resulting cohort of families along with a random sample of families who were not identified as having a child with a chronic condition using the utilization algorithm. All those parent/families screening positively based on the CAHPS items are included in the denominator for the children with chronic conditions measures whether they met the utilization prescreening criteria or not.

Extensive review and input from the CAHMI/FACCT Living With Illness Task Force advisors and input from the CAHMI/NCQA Health Plan Assessment Task Force led to the preliminary conclusion that Algorithm 3 was most appropriate for potential application of the LWIM in HEDIS. Algorithm 1 is appropriate for other applications. However, comparisons among the approaches outlined above are necessary and possible using data derived through the LWIM field trials.

To assist in selecting an appropriate casefinding and sampling approach, each of the four CAHMI field trial sites administered a survey that included the LWIM screener for identifying children with chronic conditions. Three of the four sites also included the CAHPS survey items for identifying children with chronic conditions. In addition, two sites administered the 39 item Questionnaire for Identifying Children with Chronic Conditions to some or all survey respondents. For this study, the QUICCC is being used as one standard against which to determine the validity of both the LWIM and CAHPS screening approaches. Finally, all sites collected utilization data using ICD-9 and CPT codes indicative of the presence of a chronic condition. Comparisons are made between the proportion that would have been identified using utilization data only and the proportion identified using the LWIM screening items and, in some sites, the CAHPS screening items and the QUICCC.

Specific issues and key findings relevant to the selection of a casefinding and sampling approach are outlined below. Issues to be addressed here are:

> Issue #1: What proportion of survey respondents were identified as having a child with a chronic condition using the LWIM screening tool algorithm? On which components of the LWIM algorithm were children identified? What is the age and gender profile of those identified? See Table 7.
>
> Issue #2: What proportion of survey respondents were identified as having a child with a chronic condition using the CAHPS and NACHRI algorithms and, where possible, the QUICCC? What is the age and gender profile of those identified with alternative algorithms? See Tables 8-11.
>
> Issue #3: How do findings regarding the proportion and characteristics of children screening positively on the LWIM screening tool compare to findings from other research? See Table 12.

Issue #4: How do performance value scores differ for those who do and do not screen positively on the LWIM screening tool? What are performance value differences for other subgroups? See Tables 13-14.

Issue #5: What is the estimated agreement between the LWIM screening tool and alternative methods of identifying children with chronic conditions? See Tables 15-27 and accompanying text.

This discussion guide addresses topics and issues related to the children with chronic conditions screening tool being proposed by the CHMI Living with Illness Task Force as a case finding tool for the Children with Chronic Conditions measurement set . The screening tool was developed by experts on the Living with Illness Task Force and FACCT staff. Context information and a description of the screening tool are included in the meeting binder under Tab 6.

ISSUE #1: Need for robust assessment of children's care quality

On face value, the health care needs of children with and without chronic conditions differ substantially. There is high interest and expert consensus around the importance of assessing the quality of care received by this subset of children, particularly in managed care settings.

Children who have chronic conditions are in the minority, yet this group is the most frequent and intense user of the health care services. Stratifying measures by children with and without chronic conditions allows a more robust assessment of health system performance by providing unique information about care quality for those whose needs for health care are beyond what is considered routine.

ISSUE #2: Need for a non-categorical approach

As the numbers of privately and publicly insured children covered by managed care arrangements steadily increases, there is a heightened need to track the quality of care received by children whose health care needs are beyond that which are considered routine.

The reliable identification of children with chronic health problems is challenging for a number reasons:

- A "gold standard" definition for children with chronic health conditions does not exist and naturally varies depending upon the specific application of such a definition (e.g. clinical assessment, program enrollment, performance monitoring). Even when the purpose for identifying children is the same, definitions are not standardized and often differ by being more or less inclusive, resulting in widely ranging estimates of prevalence.

- The relatively low prevalence of childhood chronic conditions, as well as, the large number of applicable diagnoses, many of which are very rare, mean disease-specific checklists are inadequate in capturing the full range of chronic childhood diseases and conditions.

- Using ICD-9 codes and other diagnoses-specific administrative data for identification have limited usefulness for the same reasons noted above. In addition, administrative data approaches do not identify those children whose condition is managed largely outside of the context of provider visits, whose condition has not yet been diagnosed or has been misdiagnosed, who have not been seen by providers due to access barriers and who may be being underserved by the health system.

In reviewing the above, the CHMI Living with Illness Task Force reached consensus at the June meeting that a non-categorical approach to identifying children with chronic conditions was preferred for assessing health plan and provider performance. During July-October, a core working group of the task force worked closely with FACCT staff to arrive at the screening tool recommended here.

ISSUE #3: Immediate need

While research is underway to test and refine other instruments such as the QuICCC, the results from such testing lag behind the need for a non-categorical screening tool, which is immediate. Both the Maternal and Child Health Bureau and the Association of Maternal and Child Health Programs have tracked the progress of the CHMI Living With Illness Task Force and have indicated support for the recommended approach to meet immediate needs of states.

Considerations:

1. There is a current need in the field by public and private entities is for a simple, straightforward, standard method to identify comparable groups of children with chronic conditions in a reliable manner across multiple settings.

2. The availability of short, easily administered, reliable screening tool would support the following activities:
    - assessment of health plan and provider quality
    - stratification performance measures by children with and without special health care needs
    - estimation of the prevalence of children with special health care needs in health plan or other settings.

ISSUE #4: Need for a parsimonious tool

Screening instruments currently tested and available are too long, difficult or costly to administer to be feasible for purposes of routine performance assessment.

Considerations:

1. Developed in response to this need the short self-administered screening tool proposed by the CHMI Living with Illness Task Force has the following characteristics:
    - it uses non-categorical criteria to identify children with special health care needs.
    - it reflects current approaches and empirical research in non-categorical identification.
    - it is brief and self-administered.
    - it allows the flexibility to screen more broadly or conservatively based upon identification and tracking goals.

The screening questions proposed by the Living with Illness Task Force are adapted from questions and concepts used by several well-tested, widely-administered instruments such as the NHIS, the QuICCC, the CAHPS Child Core Questionnaire, the CAHPS Children with Special Health Care Needs supplement. Further testing of the tool in its current form is planned.

ISSUE #6: Restrictions to the use of the proposed screening tool

If a short, easily administered screening tool is made available, careful parameters for its intended must be well-articulated to reduce the possibility of its use for purposes outside those for which is intended.

Considerations:

1. Without further research, the brief screening tool being proposed:
    - SHOULD NOT serve as a substitute for in-depth, clinical assessment of a child's health needs.
    - SHOULD NOT be expected to have levels of sensitivity and specificity achieved by more lengthy instruments such as the QuICCC and
    - SHOULD NOT be used for purposes and in settings where the application of a population-level screening tool may not be appropriate, such as clinical assessment, program eligibility and highly accurate epidemiologic estimates.

ISSUE #7: Use of tool to stratify CAHPS measures

As part of the Children with Chronic Conditions Measurement Set, it is recommended that the CAHPS Child Core Questionnaire composite measures and sub-scales will be stratified and reported for children with and without chronic or special health care needs.

Considerations:

1. Findings from several of the CAHPS demonstration projects suggest that parents/caregivers of children with chronic health conditions report significantly more problems with basic care across nearly all dimensions and that the impact of chronic conditions on care is dependent on a particular plan. (Dr. Charlie Homer, June 1998 AHSR slide presentation on WA state CAHPS demonstration data. Dr. Charlie Homer, personal communication, October 1998).

2. The version of the CAHPS Core Child Questionnaire endorsed by HEDIS does not currently have questions for identifying children whose health care needs are above what is considered routine. (a decision was made to drop the five items in CAHPS 1.0 which may have served this purpose).

3. The screening questions being proposed are recommended for addition to the CAHPS survey in order that CAHPS data may be stratified for children with and without special health needs

ISSUE #8: Sample size implications

1. In sample size calculations, the expected prevalence of children with chronic conditions needs to be considered to ensure identification of statistically adequate subset of children with special health care needs.

2. Using recently published estimates developed using similar criteria as reflected in the recommended screening tool, a prevalence of approximately 15-25% may be anticipated using the proposed screening questions (expected to be systematically higher for children with lower incomes).

3. Based on HEDIS 1999 specifications for the CAHPS Child Core Questionnaire administration, the recommended sample sizes for commercial and Medicaid populations (685 and 822, respectively) would need roughly to be doubled in order to "catch" a statistically adequate subset of children with special health care needs. This sample size may also allow for other stratification designs (e.g. racial and educational stratification) and can make the CAHPS data more valuable in general terms.

ISSUE #9: Testing and Use History

The screening tool draws almost exclusively from well-tested, validated instruments and approaches to identifying children with chronic conditions. The questions have undergone cognitive testing with families with and without children with chronic conditions. However, it is

important to note that data has not been collected on the proposed screening tool in its current form.

Considerations:

1. The three item screening tool proposed by the CHM Living with Illness Task Force:
    - draws on more than a decade of extensive research on this issue.
    - synthesizes the range of major approaches to defining children with chronic conditions by incorporating both their unique and similar aspects. (see Table 1, Tab 6 in meeting binder for summary comparison of approaches/definitions).
    - adapts questions/concepts from well-researched and tested, widely-administered instruments (see Table 2, Tab 6 in meeting binder for detailed crosswalk) including the NHIS, the QuICCC, the CAHPS Child Core Questionnaire, the CAHPS Children with Special Health Care Needs supplement.
    - has been through several rounds of expert review and input including task force advisors, clinical, policy, epidemiological and consumer experts.
    - has undergone cognitive testing with families with and without children with chronic conditions.
    - have strong face validity.
    - are agreed to by expert consensus to represent a sound, viable approach to the non-categorical identification of children with chronic conditions.

ISSUE #10: Field testing planned

The CHMI Living With Illness Task Force proposed screening items will be tested in three sites during the next five months.

- In all sites, the questions will be appended to either the CAHPS tool or a comparable satisfaction instrument. Prevalence will be estimated and compared among sites. Satisfaction and other aspects of care will be stratified to examine variations in performance for families with and without children with chronic conditions.
- In addition to collecting data on the screening questions, to assess the sensitivity and specificity of the tool, in-depth interviews using the QUICCC and other tools will be conducted with families who screen positive on the screening tool. Interviews will also be conducted with families who do not screen positive on the tool.
- Finally, where possible, clinical and administrative data on individual completing the screening tool will be obtained to examine the relationship between results of the screening tool and information indicated in the clinical records of children.

Dozens of health plans and states have expressed interest in testing this tool (and the other LWITF measures under development). Candidate field trial sites under serious consideration include the State of Florida, the State of Texas, California Cigna Health Plans, Northern California Kaiser Health Plans and Arizona Blue Cross/Blue Shield Health Plans.

## Proposed Case Finding Questions

I. PURPOSE

1) The proposed questions are a response to the growing need for a simple, straightforward, standard method for identifying and tracking children with special health care needs.

2) The questions allow the flexibility to screen more broadly or conservatively based upon identification and tracking goals.

3) The questions are designed to be self administered via caretaker survey to identify children whose health care needs are above those considered routine for the purposes of:
   - health plan and provider quality assessment
   - stratifying performance measures by children with and without special health care needs
   - estimating the prevalence of children with special health care needs in health plans and other settings

4) The questions are designed to be a population-level screener. They are not intended for in-depth, clinical assessment of a child's health needs and should not be used for such. Neither should the screener questions be expected to have the levels of sensitivity or specificity achieved by more lengthy instruments such as the QuICCC[1].

II. DESCRIPTION:

1) A series of three questions addressing:

   - Current health consequences: The 3 questions ask about current consequences or impact on child in the areas of functional limitations, reliance on compensatory mechanisms and/or specialized services, and service use or need beyond that considered routine.
   - Existing condition/duration qualification: Each of the three current consequences questions has a second part which, if the response is YES, asks is this because of a medical, behavioral or other health condition that has lasted or is expected to last for at least 12 months.

2) A scoring algorithm as follows:

   To qualify as a child with special health care needs at least ONE of the following conditions must be met:

* "YES" responses to both Q1 and Q1a
* "YES" responses to both Q2 and Q2a
* "YES" responses to both Q3 and Q3a

III. DEVELOPMENT

1) A set of case finding questions were initially drafted based on a review and synthesis of existing approaches to the non-categorical identification of children with special health care needs, including the QuICCC (Stein, R. et al., 1997), the Maternal and Child Health Bureau's definition of children with special health care needs (MacPherson, M. et al., 1998) and recommendations made by the Research Consortium on Chronic Illness in Childhood (Perrin E. et al., 1993).

[1] Stein, R. et al. (1997). The questionnaire for identifying children with chronic conditions: a measure based on a non-categorical approach. *Pediatrics* Vol. 99 (4); 513-521.

2) The draft questions were circulated to a working group of experts which included clinicians, epidemiologists, policy makers, and consumer representatives.

3) Several rounds of review, input, and revision of the draft questions were conducted with working group members via conference call discussions and individual interviews.

4) The resulting three questions:
   - are conceptually aligned with the major approaches to non-categorical identification of children with special health care needs
   - incorporate available empirical research
   - draw upon several well-tested instruments such the QuICCC and the CAHPS Child Core Questionnaire.
   - reflect approaches and questions currently under use in different settings
   - have strong face validity

5) On the basis of the above, the three questions are agreed by the expert working group to represent a sound, viable approach for use by organizations for the purpose of identifying children with special health care needs.

1. Clairfying some issues regarding the screener -- only one version, minimal changes expected

On our last call, toward the end of the time, Paul Newacheck shared that for the NHIS it would be preferrable to use the two part QuICCC-like follow up item as depicted in the telephone administration version of the screener I sent out after our call. Since that time I've heard concern that we should go as far as we can to have whatever we recommend for HEDIS be the same as what might be viable for the NHIS, etc. As you know the reason we reformatted the follow up items to begin with was due to readability concerns.

<<HEDIS NHIS Screener Nov. 17.doc

Here are my questions:

QUESTION for everyone: Do you agree that we should not recommend a slightly different version for HEDIS (even though it is a bit shorter) than is likely to be a contender for NHIS? If you agree, please re-review the attached tool and indicate to me your support -- go ahead and include any caveats or concerns but please be clear about where you are in terms of support. The attached is the tool we are using in the QuICCC-R comparison and the one we will share as the CAHMI/CAHPS convergence tool at this moment unless I hear otherwise.

QUESTION for Paul C./Jack/Trish: For the CAHPS North Carolina study are you using the telephone version (which is appropriate for mail as well)? Is the NC survey mail and telephone (Trish sent the telephone version and we were not sure if you also sent it out by mail)? What research questions/analysis do you have planned regarding the screener? What specifically, if anything, from the NC study might you advocate changing in the attached tool depending upon your findings? How can we (meaning

me and Deb) help?

QUESTION for Joe: Are you using the attached screener in the DOD study? If so, on what portion of the sample (by the way, can you briefly describe the sampling approach). What other "versions" are using and what specific questions are you hoping to answer with these alternatives? What specifically, if anything, might you advocate/hope to change in the attached tool depending on your findings? How can we help?

QUESTION for everyone: As agreed, I am stating publicly that we are working on a complete CAHMI/FACCT - CAHPS convergence for purposes of HEDIS application. I think that we have agreed on a screener and a set of items with the caveat that we need to rework the access to specialized service items to include the concept of getting help from plans to get services that are not in the benefits package. We also need to begin focusing on the specific of scoring the items. If there are specific changes some still hope for in the screener for purposes of HEDIS we should outline them now. We can not afford to leave this vague if we want to maximize the small window of opportunity we have to introduce a children's measure inot HEDIS. Are you comfortable with what I have said here?

2. Feedback from NCQA -- need to keep collaboration tight and revisit sampling strategy

The LWIM was favorably reviewed by NCQA's TAG and CPM. If we make more than the smallish changes to the screener or items we've talked about without retesting I think we will be endangered. Also, the collaboration between CAHPS and the CAHMI is key as well. I think we are okay in this regard as long as we continue on the path we are on to edit the few items we need to, etc.

The biggest issue is regarding sample size. We need to provide an oversampling alternative for them to review. They understand the issue of there not being a robust algorithm for identifying CCC that most plans could employ and that the lowest common denominator data is inpatient data or simple level of use or costs data. Still, we need to provide an option and let them decide whether the tradeoffs we worry about are worth it for the HEDIS context.

Without a population based method we may compromise using NHIS and other surveys that use the screener and some of the items as a benchmark. Also, we know that since so many items are about access that prescreening for access may confound performance values.

It is my sense that there may be interest in using a use only or code based inpatient/outpatient algorithm to preidentify children more likely to have a chronic condition (still using the screener in the survey as the final determination of this as many will simply have acute conditions, etc). As long as the bias created is toward making plans with only inpatient data look worse on the performance scores NCQA might advocate for this approach as a way to encourage improvement in data systems for plans without the requisite outpatient data. In this case at least 680 or so of the total sample would be truely random (replicating existing CAHPS 2.0H method) and an additional cohort would be randomly selected from the utilization/code screened group (deduplicating those

identified in the random population catch first, ofcourse). I'd say we would identify about 30-40% of the preidentified group with the screener if we used the RCCCC codes (not just use rates).

To begin to evaluate whether to even consider a use only algorithm (vs. code-based), we looked at reported number of doctor visits for children that had were (1) chronic only (2) acute only (3) chronic and acute or (4) neither chronic or acute. The upshot is that unless we get into very high use rates (over 4 visits), we are just as likely to be preidentifying a child with an acute as a chronic condition. If we used high use rates, then I think we introduce a bias that we have to think hard about (e.g. high use may reflect poor quality or good access -- who knows which). I think we should stick with oversampling based on codes and not just use. (RESULTS: Kids with neither chronic or acute had about 2 visits in a year, chronic only or acute only about the same at 3.2 or so and chronic and acute about 4.2 visits).

We are just finishing a three way comparison using the NWMB data to see whether performance scores within one plan vary depending upon wether a child met the NACHRI algorithm AND the screener, the screener ONLY, or NACHRI only. We are also doing across plan comparisons. This will begin to help evaluate expected changes in performance scores that might be attributable to oversampling. If we don't find a huge effect, this will support the oversampling approach since the sample size issue may very well be a make or break deal for the CPM.

As you know, we have use/code data from Cigna and NWMB and are preparing analyses to demonstrate the issues and tradeoffs. For the Cigna sample, only 7.8% of kids 0-12 in the population met the RCCCC definition using a one inpatient or outpatient visit criteria (4% for one IP and two or more OP). Recent analysis on NWMB show about a 7.5% catch with the NACHRI codes if you subset to those with at least one IP or two or more OP visits. With such small numbers, for smaller plans is may require sampling ALL FAMILIES with children who meet the definition.

Overall, if we assume a 50% response rate and an 18% catch on the random group and 30% catch on the prescreened group (and a minimum final sample of 250 or so) we can reduce the starting sample to about 2000 (vs. 3200). That's still high and I might be low on the catch for the prescreened group but want to be conservative.

QUESTION for everyone: While you may abhor a use/code based oversampling method altogether, do you prefer recommending an algorithm at simply screens for use (say any inpatient or 4 or more outpatient visits) or for codes (say one hospitalization or ER and two or more outpatient for the set of codes recommended by the Research Consortium on Children with Chronic Conditions -- we used this algorithm in the CIGNA study)?

QUESTION for Paul C/Jack/Trish: What are your utilization data anlaysis plans for NC? Will you use the codes and algorithm we shared with Trish earlier (e.g. RCCCC codes and at least one IP/ER and/or two or more OP at first level of DX to qualify)? How can we help to make sure your work corresponds with or supplements analyses conducted to date gets integrated ASAP into the decisions at hand?

QUESTION for Joe: What are your utilization data anlaysis plans for DOD? Will you use the codes and algorithm we shared with Trish earlier (e.g. RCCCC codes and at least one IP/ER and/or two or more OP at first level of DX to qualify)? How can we help to make sure your work corresponds with or supplements analyses conducted to date gets integrated ASAP into the decisions at hand?

3. OTHER issues

QUESTION: What do youwant to call the screener/survey module for purposes of HEDIS. We've called it the CAHMI LWI Moduel, CAHMI/FACCT LWIM, CAHMI/CAHPS Module. Clearly we need to get more formal about this as we begin to lay the way for making the convergence we will reach explicit to the outside world -- please give me your candidate names.

QUESTION: We'll need a response SWAT team as we move this through to public review if we make it through the CPM review in January. Please let me know if you are willing to stay involved in this capacity to the end -- we'll have to add a couple of others too (like Nora Wells and Debbie Klein Walker...).

We have a conference call with other task force members invited on the 29th to continue the process.

Thanks for time to review this and respond. I am sorry the message is so long! I hope you are well and not stricken with one of the many viruses that have made way through our office of late! Be well!