

CHEAT SHEET FOR USING **PARENT REPORT** TO MEASURE THE PERCENT OF CHILDREN SCREENED TO IDENTIFY DEVELOPMENTAL CONCERNS

Overview of Using Parent Report As A Data Source for Measurement:

Surveys of parents can be an invaluable tool for measuring discussion-based aspects of preventive and developmental care for young children, including whether the parent completed standardized tool(s) at their child's visit. Valid and feasible methods for using parent-based surveys have been developed and shown to be useful in guiding and evaluating efforts.

Measure of the Percent of Children Screened Using **PARENT REPORT**

Numerator: Number of children whose parents responded to the survey and indicated their child had been screened through a series of items asking about processes that would indicate that screening had occurred. **X 100**

Denominator: Number of eligible children whose parents responded to the survey and who should have been screened.

Key Clarifying Questions To Ask In Using **PARENT REPORT to Measure % of Children Screened**

Clarifying Questions Related to the Numerator:

- **What survey items accurately assess the standardized screening conducted?**
 - The Child and Adolescent Health Measurement Initiative (CAHMI) developed items assessing whether a parent-completed, standardized developmental and behavioral screening tool was administered. (*For example: Ages and Stages Questionnaire, Parents Evaluation of Developmental Status*)
 - The items are anchored to whether the “child’s doctor or other health provider” had the parent complete the tool.
 - If community-based approaches are being used, it is important to ensure that this wording still is applicable to your project.
- **Periodicity Issues: When and how often should the screening occur?**
 - The survey items need to take the periodicity of the screening into account.
 - The CAHMI items are anchored to screening conducted in the last 12 months.
 - If the survey is being administered after the visit and used to assess care for only that visit, the survey items will need to be modified to be anchored to “*At your child’s visit*”.

Clarifying Questions Related to the Denominator:

- **Who should have been screened and therefore who should get the survey?**
 - Surveys are administered to a “sample” of children. The denominator for the measure will most likely be the parents who receive and respond to the survey. Therefore, the following potential criteria need to be considered when identifying who should receive the survey:

- **Visit:** Should only children who have had a well-child visit receive the survey? When should that well-child visit have occurred? Are there only specific well-child visits for which screening is required?
- **Age of Child:** Should only children of certain ages receive the survey? Should the sampling be specific to age-groups of children for which screening should occur?
 - For example, should age-specific samples be drawn for the age-periods at which a child should be screened based on the American Academy of Pediatrics Statement on Identifying Infants and Young Children with Developmental Disorders in the Medical Home (July, 2006) statement?
 - If so, it is important to consider lags between when a child is supposed to receive care and when they may actually come in. For example, it is important to identify children who may have come in for their “9-month visit” when they were actually 10 months old.
- **Language:** In what language(s) is the standardized screening tool being administered?
 - The CAHMI items are currently available in English and Spanish.
- **Readability:** How is the *screening tool* being administered to illiterate parents?
 - How will the *survey tool* assessing care be administered to illiterate parents.
- **Need criteria:** Should children already identified with developmental concerns be screened?
 - If not, are there feasible methods to identify and remove these children at the time of survey administration?

Other General Issues Related to Longitudinal Measurement Using Parent Report

- **Mode effect:** When, where and how you administer the survey affects the results.
 - Systematic differences in survey responses are obtained when administered by mail vs. telephone vs. in-office (before or after the visit) vs. online.
 - Ideally, the same mode, place and time of survey administration would be used across the measurement project.
 - If not, then these factors need to be assessed and minimized wherever possible.

Tips for Enhancing the Feasibility of Parent Report:

- **Wherever possible, use valid survey items already developed and tested.**
 - The CAHMI developed and tested items assessing whether a parent-completed developmental and behavioral screening tool was administered. These items are also included in the 2007 National Survey of Children’s Health.
 - The *Users Tip Sheet* for these items and additional information about the development and testing of these items is available on www.cahmi.org.
- **If developing new survey items to assess screening or other aspects of care, it is important to conduct cognitive testing on new items.**
 - Developing reliable and valid survey items is more difficult than it may seem.
 - Conduct cognitive testing with socio-demographic characteristics similar to parents who will complete the survey to ensure that your new items measure what is intended.

- **Consider including additional items (beyond screening) that assess other components of the Screening Academy efforts (*This can include the additional required evaluation measure*).**
 - Maximize the opportunity to get parent input.
 - If you are having the parent take the time to complete a survey, include other items of high value.
 - Relative costs between short and medium length surveys can be minimal.
 - This can be especially true when the overall page length remains the same.
 - By including additional items in the survey, you can increase the saliency of the data and therefore the “buy in” needed to administer the survey
 - When considering additional items, consider information that would be valuable to your state-specific Screening Academy stakeholders (*For example: state AAP chapter, Part C, Dept. Of Children with Special Health Care Needs, Dept. of Health*).
- **Consider including items from validated surveys for which national and/or benchmark data is available. Below are a few examples of surveys that could be used:**
 - **National Survey of Children’s Health (NSCH).**
 - A catalog of the items in the 2003 NSCH can be found at: <http://nschdata.org/content/Guide.aspx>
 - **National Survey of Children with Special Health Care Needs (NSCSHCN)**
 - A catalog of the items in the 2001 NSCSHCN can be found at: <http://cshcndata.org/content/Guide.aspx>
 - **National Survey of Early Childhood Health (NSECH)**
 - A catalog of the items in the 2000 NSECH can be found at <http://www.cdc.gov/nchs/about/major/slaits/nsech.htm>
 - **Promoting Healthy Development Survey (PHDS)**
 - An overview and selected implementation manuals for the PHDS can be found at: http://www.commonwealthfund.org/innovations/innovations_show.htm?doc_id=364630
 - **Additional information on the PHDS is available on the CAHMI website at www.cahmi.org including the manual for implementing the reduced-item PHDS in pediatric offices.**
 - Benchmark data based on over 45,000 cases of PHDS data collected at the state-, plan-, community-, office- and provider-level is available.
 - **Survey used to evaluate the Healthy Steps Program (Examples of papers highlighting results from this paper by Cynthia Minkovitz, MD, MPP et al, *Arch Pediatr Adolesc Med.* 2001; 155:470-479; Barry Zuckerman et. al. *Pediatrics* Vol. 114 No. 3 September 2004, pp. 820-826)**
 - A list of additional potential surveys can be found in the report “***Studying and Tracking Early Childhood Development from a Health Perspective: A Review of Available Data Sources***” by Child Trends. This report reviews existing national data sources in terms of their capacity to inform child health policy and practice in

their efforts to promote early child development. Twenty-six national surveys and administrative data sources are assessed and summarized. This report can be found at:

http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=354865

- **Consider adding items about other aspects of preventive and developmental care**
Below are a few examples of topic areas that may be relevant to the Screening Academy efforts:
 - Developmental Surveillance
 - The CAHMI developed items assessing if the parent was asked whether he/she had concerns about their child’s learning, development or behavior and whether these concerns were addressed.
 - These items are included in the 2007 National Survey of Children’s Health and the Promoting Healthy Development Survey.
 - Anticipatory Guidance and Parental Education
 - The PHDS includes items focused on recommended anticipatory guidance and parental education and whether parents’ informational needs are met on these topics. Topics assessed include physical care of the child, development and behavior, and injury prevention.
 - Whether the child’s parent was screened for depression
 - The PHDS has a section focused on assessment of the family, including assessment of depression.
 - Medical home
 - Items assessing components of the American Academy of Pediatrics definition of medical home.
 - A catalog of the items measuring medical home that are in the NSCH can be found at: <http://nschdata.org/content/Guide.aspx#S5>
 - The CAHMI also developed a comprehensive set of survey-based measures addressing medical home. Information about these items can be found at the CAHMI website at: www.cahmi.org.
 - Access to Care, Care Coordination
 - Related items are in the NSCH, NS-CSHCN, NSECH and PHDS.
- **Consider adding items related to parental experiences of care and satisfaction with the screening implemented through the Screening Academy.**
 - Potential concepts to add the survey could be focused on the following:
 - Quality of discussions with their child’s health care provider focused on their child’s social and emotional development.
 - Experiences with completing standardized screening tools.
 - Effect of the standardized development screening tool on discussions with the child’s health care provider and perceived value of the well-child visit
 - Experiences with how their child’s health care providers communicated the results of the screening tool to them.
 - Potential increased knowledge about their child’s social and emotional development. Potential increased knowledge about what they can do to enhance their child’s social and emotional development.

- Suggestions for improvements to the screening, referral and follow-up process.
- **Appendix O** of the paper summarizing the ABCD II Consortium states evaluation measures includes an example of the parent-survey used by **Illinois**. This paper can be found at http://www.nashp.org/Files/Measuring_Dev_Ser_ABCDII.pdf
 - Related items are also in the **Healthy Steps Evaluation Survey**.
- **Items about child and parental health and parenting behavior outcomes**
 - Measures related to child and parental health outcomes are included in the NSCH, NS-CSHCN and PHDS.

Tips for Enhancing the Feasibility Of Survey Administration:

- **Periodically report the findings to the providers of the care being assessed AND to those assisting in the survey administration.**
 - Report the information in a way that is salient and relevant to the user.
 - Reporting information about the findings can guide improvements to the implementation AND increase understanding about the value and relevancy of the data which can enhance support for the survey administration process.
- **Where possible, identify other surveys or direct-to parent communications to which these items could be added.**
 - Is there a state-wide survey to which the items identified could be added?
 - Do care coordinators follow-up with families and could standardized questions be asked at this time?

If implementing a new survey:

- **Build off established protocols/resources for how to administer a survey to parents of young children.**
 - Survey can be administered by mail, telephone, Computer Assisted Personal Interviewing (CAPI), online or in the office.
 - Examples and implementation manuals for using the PHDS by mail and by telephone can be found at: http://www.commonwealthfund.org/innovations/innovations_show.htm?doc_id=364630 . The manual for administering the PHDS in pediatric offices can be found at www.cahmi.org
 - The CAHMI is developing an online version of the PHDS, including modular versions anchored to specific sections of the survey (*For example: Standardized developmental and behavioral screening*). This resource will be available for free thanks to support from the Commonwealth Fund. For more, contact Colleen Reuland at reulandc@ohsu.edu.

If you are implementing the survey in pediatric offices, develop provider, office- and parent-centered approaches to measurement:

- **Build off protocols and methods developed by other projects. (See resources above)**

- **Determine how and when the survey can be administered within the “flow of the practice.”**
 - Pilot test the administration before going to “full scale”.
 - Consider whether the parent is completing a standardized tool at the visit. The survey should not be administered at the same time.
 - If the survey is administered after the visit survey, consider giving the parent the survey (or information about the survey) but having them complete it at home (by paper and mail it back or online).
 - Focus groups and interviews with families found that they do not prefer to fill out a survey at the office after their child has been seen by the doctor or other health provider
 - Consider the length of time of survey administration
 - Set discrete goals and time periods so that the practices know what to expect and when they need to focus on the survey administration.
 - Administering surveys in the office requires time and effort by the staff. Consider “blocks” of time that the survey would be administered.
 - For example: At baseline, the “mid-way” mark, and at the end.
 - The CAHMI does not recommend administering the survey during the entire implementation period in pilot practice(s) of the Screening Academy.
 - Consider methods for reducing the costs of entering the survey data that can be completed in the office or by state staff.
 - Consider developing standardized data entry forms for the survey that can reduce data entry error and for which scoring models can be developed.
 - An example is the ACCESS forms developed in North Carolina to enter in data from the Ages and Stages Questionnaire and the Parents Evaluation of Developmental Status.
 - The CAHMI is developing ACCESS data entry forms and automated feedback reports for the PHDS and for the modular (or topic-specific) versions of the PHDS. This resource will be available for free thanks to support from the Commonwealth Fund. For more, contact Colleen Reuland at reulandc@ohsu.edu.