

# Promoting Healthy Development Survey

## Implementation Guidelines



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## INTRODUCTION

### Well-child care is the heart of health care for young children.

- The American Academy of Pediatrics recommends that children have 10 well-child visits in the first three years of life.<sup>1</sup>
- Front-line health care providers report that a cornerstone of their partnerships with their patients is the discussions they have during well-child visits.<sup>2</sup>
- Parents view the well-child visit as an important time to have their child's growth and development assessed, to ask questions and address their concerns, and to receive advice and guidance.<sup>3</sup>
- Health systems affect the settings and providers of well-child care. Health systems also provide parents of young children with a wealth of information. Parents of young children are important health care consumers and invaluable members of a health system.<sup>4</sup>

Recent national and regional studies find that recommended preventive and developmental services are not routinely provided and that parents have unmet informational needs.<sup>5</sup>

The question for you then is: **What is the quality of preventive and developmental services in your health system?**

The Promoting Healthy Development Survey (PHDS) is a survey for parents of young children (3 years old and younger) that assesses whether recommended preventive and developmental services are provided, and the degree to which parents' informational needs are met.<sup>6</sup> The PHDS also collects baseline descriptive information about the child, parent, and family that is useful for targeting improvement efforts. Since 1997, the **Child and Adolescent Health Measurement Initiative (CAHMI)** has developed, tested, and implemented the PHDS. The PHDS has been used at the national, state, health plan, practice, and provider-level. To date, more than 45,000 surveys have been collected by 10 Medicaid agencies, four health plans, 38 pediatric practices, and nationally through the **National Survey of Early Childhood Health (NSECH)**.

#### Evidence of the Quality Chasm in Developmental Services

- ✓ **Nine of 10** young children have one or more unmet developmental service need.
- ✓ **Six of 10** young children's parents did NOT get needed guidance and information on promoting their child's health and development.
- ✓ **Half of young children** with significant risks to their development did NOT receive follow-up.
- ✓ **Half of young children's parents** are NOT asked about smoking, alcohol, and drug use in the home.
- ✓ **Less than half of children whose parents have symptoms of depression** were screened for depression by their child's provider.

**Source: Data from the National Survey of Early Childhood Health and the CAHMI Promoting Healthy Development Survey (PHDS) benchmark database,**

Components of the PHDS are also included in the [National Survey of Children's Health](#).

[Appendix 1](#) provides a summary of the PHDS and why health systems should use this tool.

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<sup>1</sup> American Academy of Pediatrics, Committee on Practice and Ambulatory Medicine. *Recommendations for Preventive Pediatric Health Care*. Elk Grove Village, IL: American Academy of Pediatrics; 2000

<sup>2</sup> Markel H. For the welfare of children. In: Stern AM, Markel H, eds. *Formative Years: Children's Health in the United States, 1880-2000*. Ann Arbor, MI: University of Michigan Press; 2000:47–65

<sup>3</sup> Schuster MA, Regalado M, Duan N, Klein DJ. Anticipatory guidance: what information do parents receive? What information do they want? In: Halfon N, McLearn KT, Schuster MA, eds. *Child Rearing in America*. New York, NY: Cambridge University Press; 2002:320–344

<sup>4</sup> Bergman, D., P. Plsek, and M. Saunders, A High-Performing System for Well-Child Care: A Vision for the Future, The Commonwealth Fund, October 2006

<sup>5</sup> Olson, Lynn, Moira Inkelas, Neal Halfon, Mark A. Schuster, Karen G. O'Connor, and Ritesh Mistry Overview of the Content of Health Supervision for Young Children: Reports From Parents and Pediatricians, *Pediatrics*, Jun 2004; 113: 1907 - 1916.

<sup>6</sup> Bethell, C., Colleen Peck, and Edward Schor, Assessing Health System Provision of Well-Child Care: The Promoting Healthy Development Survey, *Pediatrics*, May 2001; 107: 1084 - 1094.

## **Step 1: Learn About the PHDS**

Step 1 contains an overview of the PHDS: what it measures, how it was developed, and how it has been used, as well as a list of PHDS resources. This section of the manual is useful for people who want a high-level overview of the PHDS and a sense of what implementation involves.

Step 1 answers eight common questions about the PHDS:

1.1: What is the PHDS?

1.2: How does the PHDS compare with currently used quality measures?

1.3: How has the PHDS been used by health systems?

1.4: How has the PHDS been used for practice-level assessment?

1.5: How does the PHDS complement and enhance improvement and measurement activities?

1.6: How was the PHDS developed?

1.7 What is required to implement the PHDS?

1.8 What PHDS tools and resources are available?



## Step 1.1: What is the PHDS?

The Promoting Healthy Development Survey is a parent survey that assesses whether young children age 0–3 (under 48 months of age) receive nationally recommended preventive and developmental services.

This survey-based tool captures information about the provision of preventive and developmental services recommended by the American Academy of Pediatrics and the Maternal and Child Health Bureau's Bright Futures. Specifically, the survey assesses recommendations provided in the context of discussions between parents and their children's pediatric clinicians. The PHDS also collects descriptive information about child health, parent health, and family behaviors.

The PHDS was designed to measure these communication-dependent aspects of care because studies have shown that medical chart reviews and claims or billing data do not reliably or validly measure clinical recommendations that providers discuss with their patients. A second goal of the PHDS is not only to assess whether recommended care was provided, but also to measure the degree to which the parent have their informational needs met and whether the care provided is family-centered. Again, these important characteristics of a high-quality health system are best measured by asking the parent(s) directly.

This manual provides the implementation guidelines for administration of the PHDS by mail. There are two versions of the PHDS that can be administered by mail:

- The full-length PHDS (Appendix 3)
- The reduced-item version of the PHDS, named the Pro-PHDS. There are three age-specific versions of the ProPHDS (Appendices 4–6).

The PHDS tools are summarized in the "Fast Facts" table that follows.

Table 1.1 Promoting Healthy Development Survey (PHDS) Fast Facts

<p><b>Overview of the PHDS</b></p>	<p>The Promoting Healthy Development Survey (PHDS) assesses whether young children age 0–3 receive nationally recommended preventive and developmental services. The full-length PHDS takes approximately 15–18 minutes to complete and the reduced-item PHDS takes approximately 5 minutes to complete. The PHDS includes additional items related to the child's health, parents' health, and family behaviors. An additional version of the PHDS for telephone administration (PHDS-PLUS). To date, over 45,000 surveys have been collected by 10 Medicaid agencies, four health plans, 38 pediatric practices, and nationally through the National Survey of Early Childhood Health. Components of the PHDS have also been included in the National Survey of Children's Health.</p>
<p><b>Quality of Care Topics Assessed in the PHDS</b></p>	<p>The PHDS collects data on 10 health care quality topics related to clinical and patient-centered care preventive and developmental services for young children:</p> <p><i>Appropriate Clinical Care</i></p> <ol style="list-style-type: none"> <li>1. Anticipatory guidance and parental education provided by doctors or other health care providers.</li> <li>2. Assessment of parental concerns about their child's learning, development, and behavior.</li> <li>3. Provision of specific information to address parental concerns.</li> <li>4. Follow-up for children at risk for developmental, behavioral, or social delays.</li> <li>5. Administration of a standardized, parent-completed developmental and behavioral screening tool.</li> <li>6. Assessment of psychosocial issues in the family.</li> <li>7. Assessment of smoking, substance abuse and safety in the family.</li> <li>8. Coordination of care for children requiring multiple types of health care services or seeing more than one health care provider. (Items not included in the ProPHDS.)</li> </ol> <p><i>Patient-Centered Care</i></p> <ol style="list-style-type: none"> <li>9. Provision of family-centered care that respects and partners with parents.</li> <li>10. Helpfulness of care provided to parents. (Items included in the PHDS only.)</li> <li>11. Effect of care provided on parental confidence. (Items included in the PHDS only.)</li> </ol> <p><i>Health Information</i></p> <ol style="list-style-type: none"> <li>12. Provision of written or other types of health information to parents on caring for their child, preventing injuries, and ensuring optimal development. (Items included in the PHDS only.)</li> <li>13. Provision of information about resources in the community for parents.</li> </ol> <p><i>Minimum Comprehensive-Care Composite – "Got All Care Measure"</i></p> <ol style="list-style-type: none"> <li>14. Provision of comprehensive care, meaning patients were provided a minimum threshold of care for the components of care listed above.</li> </ol>

Table 1.1 PHDS Fast Facts (Continued)

<p>Additional Information Collected by the PHDS</p>	<p>The PHDS also gathers information useful for quality improvement and community assessment:</p> <ol style="list-style-type: none"><li>1. Child health and descriptive characteristics (risk for developmental, behavioral or social delays, special health care need, overall health status, premature birth, birth order).</li><li>2. Parental health and socio-demographic characteristics (risk for depression, problems paying for child's basic health and medical needs, relationship to child, education level, marital status).</li><li>3. Parenting behaviors (breastfeeding, reading, screen time, actions parents take to protect their child from injury).</li><li>4. Child's health care utilization (number of regular or routine care visits, ER visits).</li><li>5. Access issues (problems getting necessary care, use of health care).</li></ol>
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## 1.2: How does the PHDS compare with currently used quality measures?

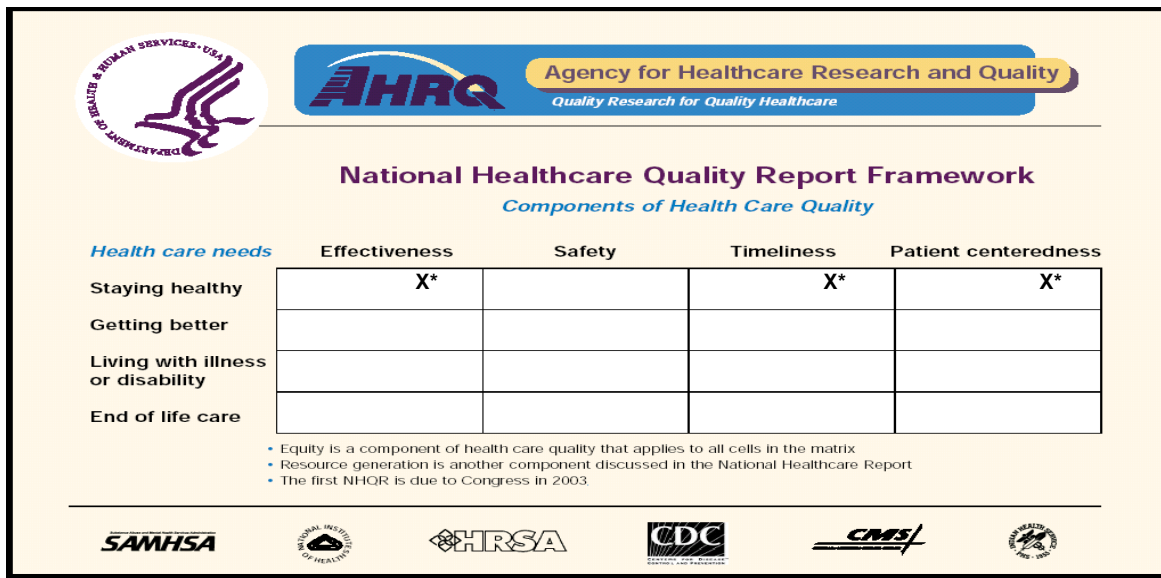
The PHDS assesses the quality of recommended preventive and developmental care that children receive. Given that the PHDS is anchored to national recommendations about well-child care, it focuses on topics of national interest and compliments existing quality measures on access to well-child care.

### How does the PHDS relate to national quality measurement frameworks?

The National Healthcare Quality Report has a useful framework for identifying components of health care quality that is a combination of the Consumer Information Framework (CIF) and the Institute of Medicine priority areas for improving health care quality.

The PHDS focuses on recommended preventive and developmental care, so the quality measures derived from the PHDS are within the Staying Healthy domain of the CIF. The PHDS quality measures focus on clinical recommendations and whether parents have their informational needs met (effectiveness), access to care (timeliness), and family-centered care (patient centeredness). In Figure 1.1 we have noted the components of the Quality Report Framework that the PHDS quality measures address.

**Figure 1.1: Components of the National Healthcare Quality Report Framework Addressed by the PHDS Quality Measures**



\* Selected PHDS measures address this component of the framework.



## **How does the PHDS compare with commonly used quality measures?**

The PHDS compliments information obtained from commonly used quality measures but is also quantitatively unique in the aspects of care it measures. The points below compare the PHDS with commonly used measures related to preventive care for young children.

### ***Health Plan Employer Data and Information Set (HEDIS<sup>®</sup>) Measures by the National Committee for Quality Assurance (NCQA)***

#### *HEDIS<sup>®</sup> Well-Child Visit Measures (15 months, 3 year)*

- These measures provide valuable information about whether children are accessing well-child visits.
- The PHDS is only administered to children who have had one or more HEDIS<sup>®</sup> defined well-child visits (See Step 2 for detailed information).
- Therefore, the HEDIS<sup>®</sup> well-child visit measure tells you whether kids are coming in for well-child visits, while the PHDS tells you about the quality of preventive and developmental care children receive during the well-child visit(s).

#### *HEDIS<sup>®</sup> Immunization Measure*

- This measure tells you whether children are up-to-date on their immunizations.
- The PHDS does not assess whether immunizations are provided.
- It should be noted that past users of the PHDS have not observed that practices with the highest immunization rates are necessarily the practices with the highest PHDS quality measures. Again, it is important to remember that the PHDS measures recommendations that are provided in the context of discussions and/or parent-completed assessments given by the child's health care provider. Therefore, one should not assume that by measuring immunizations that they are measuring all of the preventive care recommendations.
- Therefore, the HEDIS<sup>®</sup> immunization measure and the PHDS provide different information about preventive care recommendations for young children.

#### *HEDIS<sup>®</sup> Access to Primary Care Provider Measures*

- This measure tells you whether children are able to access their primary care provider.
- The PHDS includes information about the degree to which the parent reports problems accessing care. It is important to remember that the PHDS is only sent to children who have accessed the health system for a well-child visit. (See Step 2 for detailed information.) Secondly, the PHDS asks the parent to report whether their child has a personal doctor or nurse who knows their child's health and history well. Therefore, the HEDIS<sup>®</sup> Access to Primary Care Provider measure and the PHDS provide different, complementary information.

### *Satisfaction and/or Experience of Care Surveys*

- Many systems use the Consumer Assessment of Healthcare Providers and Systems (CAHPS®), the CAHPS for Children with Chronic Conditions (CAHPS-CCC), or other surveys that measure the patient's satisfaction with and experience of care.
- The PHDS is not a satisfaction survey. The primary purpose of the PHDS is to measure whether clinically recommended preventive and developmental services are provided. However, a small set of items in the PHDS are similar to these surveys, specifically the items related to access to care, care coordination, and family-centered care. The items that identify children with special health care needs (CSHCN) in the CAHPS-CCC were developed by the CAHMI team and are included in the PHDS.
- A recent study comparing data from the PHDS and a satisfaction and experience of care survey used by a health plan found less than a 45 percent agreement between the providers and/or offices that scored the highest on the PHDS quality measures and those that scored the highest on a satisfaction measure.

### *Medical Chart Reviews*

- Some health systems review the content of the medical chart to determine whether recommended care is provided.
- The PHDS was designed to measure recommended aspects of care for which the parent, not the medical chart, is the most valid and reliable source of information. Specifically, the PHDS was designed to measure communication-dependent aspects of care (i.e., what the provider discussed with the parent). Another goal of the PHDS is to assess the degree to which parents have their informational needs met and whether the care provided is family-centered. These important characteristics of a high quality health system are best measured by asking the parent directly.
- The medical chart is the best source of data for measuring items that are consistently documented in the chart and for which the parent is not the most valid reporter of (e.g., lead screening, immunizations, diagnoses, referral). The PHDS, on the other hand, is the best source of data for measuring discussions the parent can validly report on and for gathering information about the degree to which the care provided met the parent's needs and was provided in a family-centered manner. An enhanced value of the PHDS is that it can capture information about the child, parent, and family behaviors.



## 1.3: How has the PHDS been used by health systems?

Since 1997, CAHMI has developed, tested, and implemented the PHDS. The PHDS has been used at the national, state, health plan, practice, and provider-level. To date, more than 45,000 surveys have been collected by 10 Medicaid agencies, four health plans, 38 pediatric practices, and nationally through the National Survey of Early Childhood Health (NSECH). Components of the PHDS are also in the National Survey of Children's Health.

The primary reason the PHDS has been used by health systems is to address the following goals:

### 1. Quality Measurement and Improvement

- Assess performance.
- Compare performance across different plans, offices/medical groups, pediatric providers, or service areas.
- Learn about differences in quality within and across many groups of children.
- Fulfill quality measurement and improvement project requirements by Medicaid.

### 2. Program and Policy Planning and Evaluation

- Identify unmet needs of parents across aspects of care and specific care topics.
- Target quality improvement efforts.
- Assess whether quality improvement efforts have resulted in improved performance based on the parent's perspective.
- Stimulate partnerships and coordinate efforts to improve care.
- Determine health risks and health care service needs of children and their families.
- Compare policies for organizing and paying for health care services for children.

### 3. Educate and Empower Families, Providers, and Other Partners

- Inform and activate providers, families, health care leaders, and others as partners.

### Future applications of the PHDS by health systems may focus on:

- Recognize providers who have shown a commitment to measure and improve care for young children.
- Implement pay-for-performance (P4P).
- Demonstrate to purchasers and consumers a commitment to being a child-friendly health plan focused on aspects of care that are highly valued by parents of young children.
- Serve as a pre-visit assessment tool that can identify specific child and parent health needs that should be addressed in well-child visit.

Appendix 1 provides an overview of the reasons health systems should use the PHDS. This overview could help you describe the PHDS to various stakeholders in your system. Table 1.2 provides specific examples of how the PHDS has been used in the field.

**Table 1.2: Examples of PHDS Applications in the Field**

<p>Medicaid</p>	<p>Ten Medicaid agencies have used the PHDS tools. These include Florida, Louisiana, Maine, Massachusetts*, Minnesota, Mississippi, North Carolina, Ohio, Vermont, and Washington. For example:</p> <ul style="list-style-type: none"> <li>• Washington Medicaid used the PHDS-PLUS to complement their Early and Periodic Screening, Diagnostic and Treatment (EPSDT) measures. It compared differences in the prevalence of parents of young children being counseled on various topics by type of well-visit (EPSDT well-visit rates, chart review, or any type of well-visit).</li> <li>• Maine Medicaid used the PHDS-PLUS to evaluate the quality of care provided by health care providers enrolled in the Primary Care Case Management (PCCM) program. Findings were inserted into the PCCM newsletter and were used to inform quality improvement priorities for PCCM providers. Secondly, Maine Medicaid used the PHDS-PLUS to evaluate their chart-based encounter forms to guide health care providers and guide future improvement efforts.</li> <li>• Vermont Medicaid used the PHDS-PLUS and ProPHDS as part of their External Quality Review work focused on measuring and improving preventive and developmental services for young children. Medicaid allowed the Vermont Department of Children with Special Health Care Needs to further analyze the PHDS-PLUS-by special health care need status to evaluate the need for targeted outreach efforts.</li> </ul> <p>* Massachusetts used items from the PHDS-PLUS in their survey.</p>
<p>Health Plans</p>	<p>Four health plans have used the PHDS to collect baseline information to guide quality improvement efforts. For example:</p> <ul style="list-style-type: none"> <li>• Three health plans (Kaiser Permanente-Oakland, Alliance, and United) used the PHDS for baseline measurement.</li> <li>• Kaiser Permanente Northwest (KPNW) collaborated with their pediatric providers to implement the PHDS to collect baseline information and to identify system-level strategies for improvement care.</li> </ul>

**Table 1.2: Examples of PHDS Applications in the Field (Continued)**

<p>Providers</p>	<p>Thirty-eight pediatric offices have used the PHDS to gather baseline information and/or to evaluate their improvement efforts. For example:</p> <ul style="list-style-type: none"> <li>• Two pediatric practices in North Carolina used the ProPHDS to guide an improvement effort focused on developmental services.</li> <li>• Pediatric health care providers in Vermont implemented the reduced-item PHDS in their pediatric practices to inform their quality improvement efforts. Analyses were conducted at the medical group-, office-, and provider-level.</li> <li>• The Healthy Development Collaborative used the ProPHDS to collect baseline information and to assess whether the improvement efforts resulted in parent-perceived increases in the level and quality of care provided. The Healthy Development Collaborative was a Commonwealth Fund–supported initiative designed to help primary care practices in Vermont and North Carolina engage families in a partnership to promote positive developmental outcomes for the families' children through the development of improved office systems.</li> <li>• The pediatrics department of Northwest Permanente Medical Group led the implementation of the PHDS in Kaiser Permanente Northwest. Ten office-level reports and 56 provider-level reports were disseminated within the pediatrics department. The department used the findings to identify improvement strategies focused on: (1) addressing topics for which parents have unmet information needs; (2) incorporating standardized developmental screening; and (3) enhancing parental depression screening in pediatric offices.</li> </ul>
<p>Consumers</p>	<p>The PHDS findings can be reported to consumers (parents of young children in this case).</p> <ul style="list-style-type: none"> <li>• A pilot study was conducted in pediatric practices in Vermont to develop and test feedback templates to parents displaying the findings from the PHDS tools. Overall, the templates were very well received and parents expressed high interest in receiving this type of information.</li> </ul>

### **Example 1.1: Implementation of the PHDS in Kaiser Permanente Northwest**

Kaiser Permanente Northwest (KPNW) implemented the PHDS to assess health care quality and identify improvement opportunities across the health plan within pediatric offices and across pediatric providers.

This was a collaborative effort between the pediatrics department and the health plan.

- The sampling allowed for office- and provider-level analysis so that individualized reports could be disseminated.
- Assessment of the pediatric office systems and the standardized templates providers use in their electronic health records were conducted in order to identify system-level factors associated with higher quality.
- Strategic meetings were held with senior staff in the health plan that addressed quality measurement, quality improvement, information technology (including the electronic health record) and member education and Web site services to ensure that the PHDS findings would be used to guide system improvements.

Based on the PHDS findings three primary "change concepts," or improvement strategies were identified:

- **Change Concept:** Enhance and focus parent education and activation materials on areas where PHDS shows parent needs are least likely to be met.
- **Change Concept:** Prompt providers to focus on areas where parent needs are not met using EPIC.
- **Change Concept:** Advance the pre-visit use of parent-completed standardized developmental screening tools and parental depression screening tools, and report findings to pediatric providers for use during the child's well-visit.

The providers who scored the highest on the PHDS quality measures related to the three change concepts noted above were identified as "champions" and leaders for the improvement efforts. Working groups of key stakeholders with a role in implementing the change concept were then identified.



## 1.4: How has the PHDS been used for practice-level assessment?

Since 2001, CAHMI has focused on the validation and implementation of the PHDS for practice-level assessment.

### *What is a "practice-level" assessment?*

The goal of practice-level assessment is to examine the quality of care by (1) specific health care providers or (2) by the place (e.g., office) where care was received.

Practice-level assessments of care may include analysis of the following:

- An individual health care provider.
- The office where care is received. One health care provider or multiple health care providers can be located in an office.
- The medical group responsible for the child's health care. This examines care across two or more individual offices comprising one medical group.

### *How can the PHDS be used for "practice-level" assessment?*

There are two primary ways that the PHDS can be used for practice-level assessment:

1. Practice-level sampling and analysis of PHDS data.
2. In-office administration of the PHDS.

Because this manual is about implementing the PHDS via a mail mode of administration, it addresses the first application.

- **Step 2** provides detailed information about how practice-level sampling is conducted.
- **Step 5** provides detailed information for how the PHDS can be analyzed at the practice-level.
- **Step 6** provides detailed information for reporting the practice-level findings to front-line health care providers.

Tools and resources for how to administer the PHDS in pediatric offices are listed in **Step 1.9** and **Appendix 2**.

*How has the PHDS been used for practice-level assessment?*

Many health systems or providers implementing the PHDS have used it for practice-level assessment. Given that a primary goal for the PHDS is to motivate and guide improvements, users have found that analyzing the data at the level where care is provided is most valuable. Secondly, most providers find information that is specific to their patients more useful than information summarizing quality-of-care findings across an entire health system. Below is a brief description of how the PHDS has been used for practice-level assessments.

**Table 1.3: Examples of How the PHDS Has Been Used for Practice-Level Assessment**

<p><b>Practice-Level Analysis of PHDS Data: Medicaid</b></p>	<p><b>Three Medicaid agencies</b> have administered the PHDS by mail or telephone and then analyzed the PHDS data at a practice-level. For example:</p> <ul style="list-style-type: none"> <li>• <i>Maine Medicaid</i> analyzed their PHDS-PLUS by health care providers enrolled in the Primary Care Case Management (PCCM) program. Findings were inserted into the PCCM newsletter and were used to inform quality improvement priorities for PCCM providers. They also analyzed the quality-of-care findings by the type of health care provider (e.g., family practice, pediatrician) and tailored improvement methods accordingly.</li> <li>• <i>Vermont Medicaid</i> analyzed their PHDS-PLUS data at the practice level and disseminated practice-level reports. This work was done in collaboration with the Vermont Child Health Improvement Program (VCHIP) and CAHMI.</li> <li>• <i>Washington Medicaid</i> analyzed their PHDS-PLUS data at the practice level and disseminated practice-level reports as part of an improvement effort focused on EPSDT services. This work was done in collaboration with the Oregon Medical Professional Review Organization (OMPRO) and CAHMI. The practice-level reports incorporated data from the PHDS-PLUS and quality-of-care data obtained from medical chart reviews conducted by OMPRO via their External Quality Review activities.</li> </ul>
<p><b>Practice-Level Analysis of PHDS Data: Health Plans</b></p>	<p><i>Kaiser Permanente Northwest</i> collaborated with its pediatrics department to use the PHDS for office- and provider-level assessments of care.</p> <ul style="list-style-type: none"> <li>• 10 office-level reports were disseminated.</li> <li>• 56 provider-level reports were disseminated.</li> <li>• Office- and provider-level characteristics were examined for attributes associated with the provision of higher quality care. The findings were used to identify improvement opportunities.</li> <li>• Higher performers for each PHDS measure of care were identified as champions for the topic-specific improvement teams.</li> </ul>



**Table 1.3: How the PHDS Has Been Used for Practice-Level Assessment (Continued)**

<p><b>In-Office Implementation of the PHDS</b></p>	<p>Thirty-eight pediatric offices have implemented the PHDS in their pediatric offices in order to gather baseline information and/or to evaluate their improvement efforts. For example:</p> <ul style="list-style-type: none"><li>• <i>Two pediatric practices</i> in North Carolina used the ProPHDS to guide an improvement effort focused on developmental services.</li><li>• <i>Pediatric health care providers</i> in Vermont implemented the reduced-item PHDS in their pediatric practices to inform their quality improvement efforts. Analyses were conducted at the medical group-, office-, and provider-level.</li><li>• The <i>Healthy Development Collaborative</i> used the ProPHDS to collect baseline information and to assess whether the improvement efforts resulted in parent-perceived increases in the level and quality of care provided.</li></ul>
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## 1.5 How does the PHDS complement and enhance measurement and improvement activities?

Leading methodologies in effective quality improvement put performance measurement at the center of their efforts to inform, shape, and track improvements in care.

Donald Berwick, M.D., president and CEO of the Institute for Healthcare Improvement, asserts that patients, in this case parents and children, are the most underutilized resource in informing and ensuring that improvements in health care quality occur.

The PHDS complements and enhances measurement and improvement activities by achieving the following:

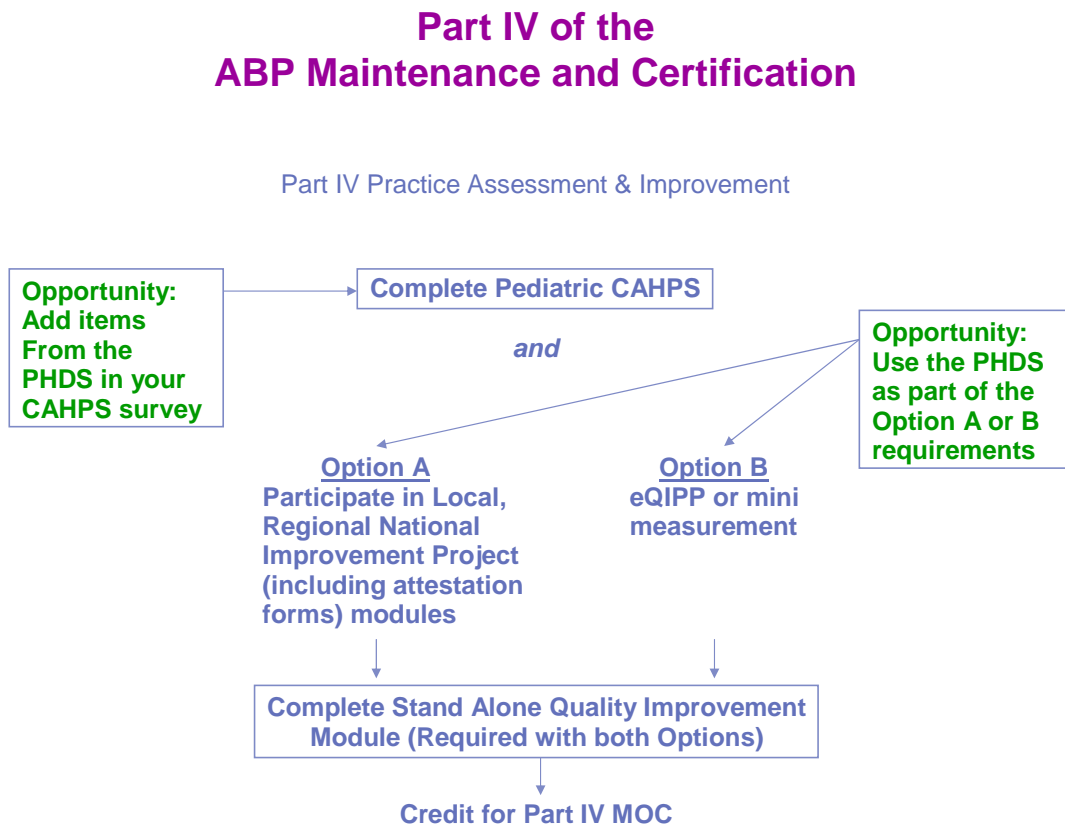
- **Content focus on aspects of care that matter to the consumer.** A key component of the development of the PHDS was focus groups and interviews with consumers about what clinically recommended aspects of care matter the most to them. Using the PHDS helps ensure that measurement and improvement efforts are focused on areas of care that matter to consumers.
- **An involved consumer.** By completing the PHDS, the parent is part of the measurement process. This provides users with an opportunity to partner with parents not only to measure quality of care, but also to help improve the care provided. Step 6 provides examples of how the PHDS findings can be reported back to parents in a way that informs them about questions and issues they can raise during their child's well-child visit so that recommended topics are discussed.

As the focus and emphasis on quality measurement and improvement increases, it is valuable to consider how a consumer-centered approach such as the PHDS can enhance and maximize such efforts.

### Example 1.2: Potential for the PHDS to Be Used in Maintenance of Provider Certification

The American Board of Pediatrics (ABP) recently enhanced their certification process with a section on measurement and improvement in the practice. Part IV of the ABP certification requires providers to report CAHPS or other peer survey data and to demonstrate participation in quality improvement efforts. The PHDS can enhance and complement providers' efforts related to Part IV of the certification. Figure 1.2 below highlights opportunities for using the PHDS for this purpose.

Figure 1.2: Opportunities for Using the PHDS for Maintenance of Provider Certification





## 1.6: How was the PHDS developed?

The PHDS was designed and tested by CAHMI with a peer-reviewed measurement development process. It was developed to fill important gaps in available methods to evaluate quality in the many areas of recommended preventive and developmental services that require parent-reported information as well as program-wide assessments.

The following selection criteria were used to select topics assessed in the PHDS survey:

- Appropriateness for all children in the specific age group.
- Strength of scientific evidence.
- Professional consensus.
- No existing reliable, valid, or efficient way to measure the topic.
- Topic is important to parents (according to cognitive interviews and focus groups).
- The topic can be validly and reliably reported by parents.
- Parsimony (e.g., topic is not already largely represented by another, related topic in the PHDS).

A rigorous six-stage process was used to develop the PHDS, beginning with focus groups with families to identify the aspects of health care quality that are important to parents in the area of preventive care for their children. A review of literature identified through MedLine and through key interviews was conducted. The materials reviewed included more than a dozen parent surveys on early childhood development, family-centered care, and other topics, as well as encounter forms and checklists used by clinicians to help with the provision of anticipatory guidance and the assessment of young children and their families.

The six stages were:

- Stage 1:** Develop conceptual framework and investigate the relevance of each measure.
- Stage 2:** Develop starting point measurement proposal, including initial feasibility studies.
- Stage 3:** Develop draft instrument and implementation methodology.
- Stage 4:** Conduct field-testing.
- Stage 5:** Revise and refine as necessary.
- Stage 6:** Develop scientific and technical documentation to support larger scale implementation and dissemination.

In the early stages of developing the PHDS, many existing surveys and tools were reviewed, particularly those designed to evaluate the Healthy Steps project or survey-based tools, such as Parental Evaluation of Development Status (PEDS). Although many of the PHDS survey concepts reflect those in existing surveys and tools, nearly all of the PHDS items were new, due to a lack of available, tested candidate items appropriate for performance assessment in a self-administered survey.

Three advisory groups within CAHMI—comprised of pediatricians, family practitioners, consumer representatives, public health experts, and researchers—regularly reviewed and provided input on the identification of quality measurement topics and the development of the PHDS.

### *Special Note About Cognitive Testing and Reading Grade Level:*

An important component of the development of the PHDS-PLUS was to ensure that the survey was written at a low reading-grade and cognitive-ease levels. Computer programs were used to determine reading-grade level estimates, using algorithms that take into account the length of the words used, etc. However, a very common word used in a cognitive interview may be considered easy to read, but may have a high reading-grade level because its length. The cognitive ease of a survey can be assessed by conducting formal cognitive interviews with subjects on the survey items.

Reading-grade-level experts, such as Mark Hochauser, Ph.D., recommend conducting a formal reading grade level assessment with standard computer programs coupled with cognitive interviews.

In accordance with these recommendations, the CAHMI team conducted the following steps to ensure that the PHDS is at an appropriate reading-grade level and cognitive level for parents of Medicaid clients:

1. Formal readability assessments were conducted that indicated that the PHDS is written at the eight to ninth grade reading level using various reading-grade level computer programs.
2. In-depth cognitive testing was conducted with 15 families representing a range of racial, income, and education groups, as well as different types of health insurance coverage, age of child, age, and sex of parent, and number of children in family. Parents were uniformly able to complete the self-administered survey in 10–15 minutes and the readability of the survey was confirmed.
3. A second round of cognitive testing was conducted in 2001 to ensure that the PHDS-PLUS survey, when administered over the telephone, was feasible to administer to parents of children enrolled in Medicaid. The CAHMI team conducted cognitive interviews with 20 parents of children 3–48 months old who were enrolled in Medicaid. Five of these interviews were conducted in-person, while the remaining 15 were

conducted over the telephone to assess the response burden and cognitive ease of the PHDS-PLUS when using a telephone administration.

For each item, instances where the respondent required clarification or did not appropriately answer an item were noted. Also, items where the interviewer had difficulty asking the question without edits to the wording were noted. Survey modifications were made based on these findings to improve the reliability, validity, and cognitive ease of the PHDS-PLUS items.

### **Development of the Reduced-Item PHDS**

The reduced-item PHDS (ProPHDS) was developed so that it could be feasibly implemented in health care provider offices. The manual for implementing the ProPHDS in office settings is listed in Step 1.8.

The ProPHDS is different from the full-length PHDS in the following ways:

- 1) Length of the Survey.** The in-office PHDS is a reduced-item version of the PHDS. Research with health care providers demonstrated that for the in-office survey administration to be feasible, the survey must take no longer than five minutes for parents to complete.

Three criteria were used to determine which items to include in the reduced-item version of the survey:

- Preference was given to PHDS items focused on preventive and developmental care over items related to child health, parenting behaviors, and parent ratings of the health care provided.
- CAHMI kept a majority of the items within measures of care that health care providers and parents found to be the most valuable for improving quality of care.
- Preference was given to items for which national data was available or where a national objective, such as Healthy People 2010, was measured.

Using these criteria, the item-reduction process was informed by the following:

- Two focus groups with the health care providers in the participating practices.
- Two focus groups with parents whose child receives care in these practices.
- Review of national surveys focused on preventive and developmental care for young children, such as the National Survey of Early Childhood Health.
- Review of key national health objectives.

The result of this work was the creation of the four-page, reduced-item version of the PHDS provided in this toolkit. This reduced-item version of the PHDS collects some descriptive information about parenting behaviors and issues in the family, and captures information about six PHDS measures of care:

- Anticipatory guidance and parental education.\*
- Family-centered care.\*
- Ask about and address parental concerns.\*
- Follow-up for children at risk for developmental/behavioral delays.
- Assessment of the family.

\* Because research with health care providers and parents demonstrated that these three measures of care are the most valuable in gathering information for quality improvement purposes, all items within this measure of care were included in the reduced-item version of the PHDS.

2) **Age-Specific Surveys.** The anticipatory guidance and parental education section has three age-specific sections to ensure that the questions asked are age appropriate. To increase the feasibility of administering the PHDS in the office, three distinct age-specific surveys are recommended as opposed to one survey with age-specific skip patterns provided for a mail or telephone administration. The three surveys are for the following age groups:

- 3–9.99 months old
- 10–18.99 months old
- 19–47.99 months old



## 1.7 What is required to implement the PHDS?

This section offers a summary of the strategic and technical requirements for the successful use of the PHDS.

### Summary of Strategic and Technical PHDS Requirements

1. Determine the primary uses of PHDS Quality Data.
2. Identify and engage key partners.
3. Identify an analyst or data programmer within your organization who can identify the starting sample for the survey and collect analytic variables for the starting sample. If you do not have one internally, hire a survey vendor.
4. Estimate of analyst/programmer time for sample: 10–24 hours. You ideally want someone with experience sampling for a survey and in calculating HEDIS measures from enrollment and utilization data.
5. Estimate of costs per completed survey: \$8.00–\$18.00 per completed survey. This cost includes a mailing, follow-up post card reminder, second mailing, and a telephone reminder phone call. It also includes the data entry.
6. Estimate range of observed response rates for the PHDS: 39 percent to 60 percent.

**Strategic Requirements.** The PHDS requires users to: (1) clearly define how this tool fits into their overall quality measurement and improvement strategy, and (2) to identify key partners.

1. **Priority Application(s).** You need to determine the priority application for the PHDS data. For example, will results be used to (1) assess and compare performance across providers, (2) compare quality of care across specific subgroups of children, and/or (3) determine health risks and unmet needs of children living in different geographic areas



2. **Key Partners.** You need to consider who to involve upfront to ensure that information derived from the PHDS is used to inform, shape, and stimulate improvements in care. Consider the: (1) quality measurement department, (2) quality improvement department, (3) health education department, (4) providers responsible for developmental services, and (5) parents who can be key allies in stimulating improvements in care.

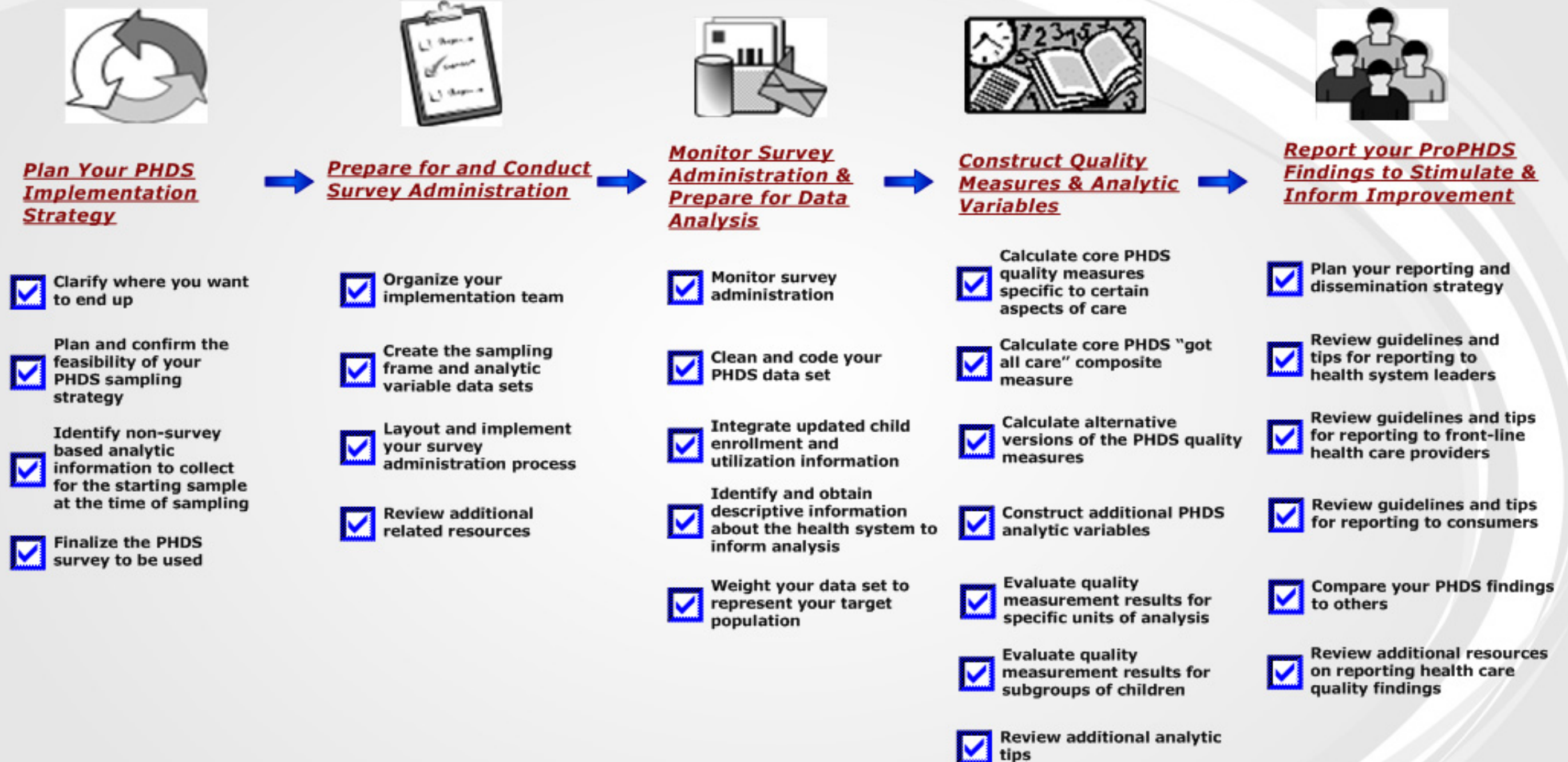
**Technical Requirements.** You will need to: (1) obtain or supply sampling and analytic information to a vendor child/parent contact, and (2) ensure internal or external survey vendor conducts sampling, administration, and scoring in a high-quality manner.

1. **Contact and Eligibility Information.** You will need to construct a sampling data set that includes contact and eligibility information for children who meet criteria to be included in the PHDS sample (See Step 2). This will include providing: (1) mailing information, (2) length of continuous enrollment in the health plan, with a provider, or in a specific office, (3) information about whether the child received a well-visit in the past year, (4) number of visits in the past year, (5) child's age, and (6) other variables, such as the provider who is designated as the child's primary care provider.
2. **Internal or External Survey Vendor Supervision and Guidance.** To get the most out of the PHDS survey, you will need to ensure that the survey vendor has adequate guidance and supervision regarding: (1) sampling to ensure sufficient completed sample sizes for different subgroups of children, (2) administering the survey to ensure the highest response rate possible, (3) coding and constructing quality scores and analytic variables based on survey data, and (4) scoring and presenting the data in different ways.

**Requirements for Parents of Young Children.** Parents of young children: (1) need to be able to be contacted, and (2) need to respond to the PHDS.

1. **Keep Contact Information Up-To-Date.** Updated contact information is ideal.
2. **Respond When Contacted.** Parents of young children should be encouraged to respond to surveys to provide feedback and guide improvements aimed at ensuring their child receives the highest quality of care possible. The PHDS takes about 12–15 minutes to complete and the ProPHDS takes 5 minutes. Response rates have ranged from 39 percent to 60 percent.

# Figure 1.3 Checklist for Planning, Implementing and Reporting the PHDS





## 1.8 What PHDS tools and resources are available?

**Appendix 2** provides a detailed list of the PHDS tools and resources available. An abbreviated summary can be found below.

CAHMI Contact Information:

- [www.cahmi.org](http://www.cahmi.org)
- 503-494-1930
- [cahmi@ohsu.edu](mailto:cahmi@ohsu.edu)

For more information on the development of the PHDS and quality measures included in the PHDS, review the CAHMI Web site ([www.cahmi.org](http://www.cahmi.org)), contact CAHMI or refer to the following publications:

- Bethell C, Reuland C, Schor E. Assessing health system provision of well-child care: The Promoting Healthy Development Survey. *Pediatrics*. 2001 May; 107(5):1084-94.
- Bethell C, et al. Partnering with Parents to Promote the Healthy Development of Young Children Enrolled in Medicaid. September 2002. Available at: [http://www.cmwf.org/publications/publications\\_show.htm?doc\\_id=221310](http://www.cmwf.org/publications/publications_show.htm?doc_id=221310)
- Bethell, C, et al, Measuring the quality of preventive and developmental services for young children: National estimates and patterns of clinicians' performance. *Pediatrics*. 2004 Jun;113(6 Suppl):1973–83.
- Reuland C, Bethell C. Key Measurement in Screening, Referral, and Follow-Up for Care for Young Children's for Children's Social and Emotional. [www.nashp.org/Files/measurement\\_paper\\_for\\_web\\_final\\_4.7.05.pdf](http://www.nashp.org/Files/measurement_paper_for_web_final_4.7.05.pdf)
- Blumberg SJ, Halfon N, Olson LM. The National Survey of Early Childhood Health *Pediatrics*. 2004 Jun;113(6 Suppl):1899-906. Available at: [www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list\\_uids=15173460&query\\_hl=5&itool=pubmed\\_docsum](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=15173460&query_hl=5&itool=pubmed_docsum)
- Kogan MD et al. Routine assessment of family and community health risks: parent views and what they receive. *Pediatrics*. 2004 Jun;113(6 Suppl):1934-43. Erratum in: *Pediatrics*. 2005 Sep;116(3):802. Available at: [www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list\\_uids=15173464&query\\_hl=1&itool=pubmed\\_docsum](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=15173464&query_hl=1&itool=pubmed_docsum)

- Halfon N et al. Assessing development in the pediatric office. *Pediatrics*. 2004 Jun;113(6 Suppl):1926-33. Available at: [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list\\_uids=15173463&query\\_hl=4&itool=pubmed\\_docsum](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=15173463&query_hl=4&itool=pubmed_docsum)
- Zuckerman B et. al. Prevalence and correlates of high-quality basic pediatric preventive care. *Pediatrics*. 2004 Dec;114(6):1522-9. Available at: [www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list\\_uids=15574610&query\\_hl=5&itool=pubmed\\_docsum](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=15574610&query_hl=5&itool=pubmed_docsum)

**For more information about the Promoting Healthy Development Tools and Implementation Guidelines, visit the CAHMI Web site ([www.cahmi.org](http://www.cahmi.org)) for the following documents:**

- [Promoting Healthy Development Survey Toolkit](#)
- [In-Office Administration of the Reduced-Item Promoting Healthy Development Survey \(ProPHDS\) Manual](#)
- [Promoting Healthy Development Survey-PLUS \(PHDS-PLUS\) Implementation Guidelines](#)
- [Measure of Standardized Developmental and Behavioral Screening: Users Tip Sheet](#)

In addition, there are number of reports and presentations highlighting how the PHDS has been used and key findings. A listing of these resources can be found in Appendix A.

**For more information on national guidelines and recommendations measures by the PHDS visit the following Web sites:**

***Federal Maternal and Child Health Bureau's Bright Futures***

[www.brightfutures.org/bf2/about.html](http://www.brightfutures.org/bf2/about.html)

- Green M, ed. *Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents*. Arlington, VA: National Center for Education in Maternal and Child Health; 1994.
- Important Note: The Bright Futures recommendations are currently being revised by the American Academy of Pediatrics. For information about the update recommendations, please review the following resource: <http://brightfutures.aap.org>

***American Academy of Pediatrics Health Supervision Guidelines***

[www.aap.org](http://www.aap.org)

- American Academy of Pediatrics. *Guidelines for health supervision III*. Chicago, IL: American Academy of Pediatrics; 1997.

***U.S. Preventive Services Task Force***

[www.ahrq.gov/clinic/uspstfix.htm](http://www.ahrq.gov/clinic/uspstfix.htm)

- U.S. Preventive Services Task Force. *Guide to Clinical Preventive Services, 2nd ed.* Washington, DC: Office of Disease Prevention and Health Promotion, U.S. Government Printing Office, 1996.

**For more information about national surveys that have incorporated items from the PHDS visit the following organizations:**

***National Survey on Early Childhood Health (NSECH)***

[www.cdc.gov/nchs/about/major/slaits/nsech.htm](http://www.cdc.gov/nchs/about/major/slaits/nsech.htm)

***National Survey of Children's Health***

[www.cdc.gov/nchs/about/major/slaits/nsch.htm](http://www.cdc.gov/nchs/about/major/slaits/nsch.htm)

[www.nschdata.org/Content/Default.aspx](http://www.nschdata.org/Content/Default.aspx)

For more information about improvement efforts focused on preventive and developmental services, check out the following organizations:

*Note: The list below only represents those organizations that the CAHMI has worked with to consider how the PHDS fits within their models for improvement. It is not a full listing of quality improvement resources related to preventive and developmental health care.*

***Center for Health Care Quality***

[www.cincinnatichildrens.org/svc/alpha/h/health-policy/](http://www.cincinnatichildrens.org/svc/alpha/h/health-policy/)

- Established at Cincinnati Children's Hospital Medical Center, the center is a resource for health care providers throughout the world to make the highest-quality care a reality for children and their families. The Center for Health Care Quality is the result of a merger of the Center for Children's Healthcare Improvement, formerly based at the University of North Carolina at Chapel Hill, and the Center for Health Policy and Clinical Effectiveness ([www.cincinnatichildrens.org/svc/alpha/h/health-policy/](http://www.cincinnatichildrens.org/svc/alpha/h/health-policy/)) at Cincinnati Children's, which not only does improvement work but also conducts research into interventions that improve health outcomes in the community and the home.

***UCLA Center for Healthier Children, Families and Communities (CHCFC)***

[www.healthychild.ucla.edu/](http://www.healthychild.ucla.edu/)

- The center is a multi-disciplinary program in the UCLA School of Medicine, Department of Pediatrics and the UCLA School of Public Health dedicated to improving society's ability to provide children with the best opportunities for health and well-being—and the chance to assume productive roles within families and communities.
- **Report of Interest:** Quality of Preventive Health Care for Young Children: Strategies for Improvement, Neal Halfon, M.D., M.P.H., Moira Inkelas, Ph.D., M.P.H., Melinda Abrams,



M.S., and Gregory Stevens, Ph.D., M.H.S., The Commonwealth Fund, May 2005. Available at:  
[www.cmwf.org/publications/publications\\_show.htm?doc\\_id=275484](http://www.cmwf.org/publications/publications_show.htm?doc_id=275484)

### ***Healthy Development Collaborative***

- A Practical Guide for Improving Child Developmental Services.  
[www.cmwf.org/tools/tools\\_show.htm?doc\\_id=372065](http://www.cmwf.org/tools/tools_show.htm?doc_id=372065)

### ***Healthy Steps Model***

[www.cmwf.org/general/general\\_show.htm?doc\\_id=246567](http://www.cmwf.org/general/general_show.htm?doc_id=246567)  
[www.healthysteps.org](http://www.healthysteps.org)

- Healthy Steps for Young Children is a national initiative aimed at enhancing the quality of preventive health care for infants and toddlers. Established with Commonwealth Fund support, the program emphasizes a close relationship between health care professionals and parents in addressing the physical, emotional, and intellectual development of children from birth to age 3.

### ***Help Me Grow***

[www.cmwf.org/publications/publications\\_show.htm?doc\\_id=379780](http://www.cmwf.org/publications/publications_show.htm?doc_id=379780)

- Help Me Grow Roundtable: Promoting Development through Child Health Services Supplement to the Journal of Developmental and Behavioral Pediatrics.

### ***National Initiative for Children's Health Care Quality***

[www.nichq.org](http://www.nichq.org)

- The National Initiative for Children's Healthcare Quality (NICHQ) is an education and research organization dedicated solely to improving the quality of health care provided to children. Founded in 1999, NICHQ aims to eliminate the gap between what is and what can be in health care for all children.

### ***Vermont Child Health Improvement Program***

[www.med.uvm.edu/vchip/HP-DEPT.asp?SiteAreaID=513](http://www.med.uvm.edu/vchip/HP-DEPT.asp?SiteAreaID=513)

- The Vermont Child Health Improvement Program (VCHIP) is a population-based child and adolescent health services research and quality improvement program of the University of Vermont. VCHIP's mission is to optimize the health of Vermont's children by initiating and supporting measurement-based efforts to enhance private and public child health practice

## **Step 2: Planning for the PHDS Implementation**

Step 2 provides the information and guidance you will need to plan your PHDS project. This step is intended for project managers and vendors who will conduct the sampling and/or survey administration.

There are four sections in Step 2:

2.1: Clarify where you want to end up

2.2: Plan and confirm the feasibility of your PHDS sampling strategy

2.3: Identify non-survey-based analytic information to collect for the starting sample at the time of sampling

2.4: Finalize the PHDS survey to be used



## STEP 2.1: Clarify where you want to end up

### ➡ What is the purpose of this step?

The purpose of this step is to maximize the value of your PHDS project by making sure that you meet your specific project goals and reporting requirements. It is easy to miss opportunities for collaboration, data collection, and dissemination of your PHDS findings if time is not spent up front clarifying where you want to be at the end of the project.

#### In this step you will:

- Clarify the purpose(s) for collecting PHDS data.
- Set overall goals for what you want to accomplish by using the PHDS.
- Identify overall measures you will use to determine if you have achieved your goals.
- Clarify internal or external audiences that will evaluate your project's success.
- Specify evaluation measures for each "evaluation" audience.
- Confirm audiences for reporting PHDS results (e.g., providers, families).
- Specify key messages for each "reporting" audience.





## Guidelines and Issues to Consider

**Be as specific as possible about your PHDS implementation goal(s).** As with any project, you need to set the goal(s) you wish to accomplish. And these goals need to be specific. For example, administering the PHDS because you want to implement a quality measurement project is not specific enough.

It is imperative that—at the beginning of the project—you think about the ideal "ending" of the project.

You need to answer two primary questions:

- Who will use the results?
- What do you want them to do with the results?

### WHO



- **Who** do you want to use the results?
- **Who** in your health system is focused on health care quality measurement and improvement efforts?
- **Who** is focused on the components of care measured in the PHDS (anticipatory guidance and parental education, assessment of families for risk factors, identifying and treating children at risk for delay)?

Examples of key potential users of the PHDS findings in your health systems include: Pediatric providers (physicians, nurses), other office staff, parents of enrolled children, health system leaders focused on quality measurement and improvement, health education departments, health system leaders focused on electronic medical record prompting systems and/or patient education materials in the electronic medical chart.

## WHAT



➔ **What** will you want them to do with the results?

The data could be used to:

1. Guide and inform improvement efforts at the system-, office- and/or provider-level. (Each level requires consideration at the time of sampling.)
2. Compare performance across offices and/or providers. Identify high and low performers that can be rewarded and/or penalized based on the PHDS findings.
3. Compare the PHDS findings to currently used quality measures such as the HEDIS well-visit or survey-based satisfaction measures.
4. Design parent education and activation tools and strategies. The results could be used to encourage parents to ask their providers about key topics not routinely addressed during a well-child visit.

**Involve each evaluation and reporting audience member in specifying goals, measures of success, and key messages.** You can do this through in-person meetings, e-mail, or phone calls. Past CAHMI experiences have found that the first meeting should occur in person and that subsequent discussions can take place electronically.

This important step can lead to small but critical changes to the design of your project that will enhance its relevance and value, as well as improve "buy-in" by essential stakeholders. Like you, many stakeholders use information to guide their efforts. Additionally, they are likely to have unique and valuable information about the health and health care of the children you are trying to reach. Past users have found that because the PHDS captures more than just health care quality improvement information (e.g. child health and health care characteristics, parental health and behaviors), they have been able to partner with organizations that they do not normally collaborate with on quality measurement projects the quality measurement department working with the patient education and information department.

Therefore, before deciding on contacting the reporting and audience member, make sure you:

1. Identify specific benefits for potential partners.
2. Specify information and resources these partners can bring.
3. Identify how these partners can ease data collection and analysis and/or the dissemination of the results.
4. Clarify the best time to include these partners.
5. Specify how these partnerships will affect the timeline, staffing, and budget of the project.

**Example Worksheet 2.1: Specifying Evaluation and Reporting Audience Members**

<b>Reporting and Audience Member</b>	<b>Value of the PHDS to them</b>	<b>How you want them to use the PHDS findings</b>	<b>Information/resources partner can bring</b>	<b>How partner can ease administration, analysis, and/or dissemination</b>	<b>Best time to include partner</b>	<b>Impact on timeline, staffing, budget</b>
#1:						
#2:						
#3:						

**Decide whether you want to be able to compare PHDS findings across groups, such as providers' offices, provider types, and geographic areas.** If so, this will have many implications for your PHDS project sampling, administration, and scoring steps.

**Confirm whether you intend to repeat the PHDS in the future or if this is a "one-time" effort.** If you will repeat it, when will you do so? Repetition will allow for trending of PHDS measures and could affect your project's initial design.



## **STEP 2.2: Plan and confirm the feasibility of your PHDS sampling strategy**

### **➔ What is the purpose of this step?**

The purpose of this step is to ensure you will identify a starting sample that will allow you to analyze the PHDS data in a way that meets your project goals.

#### **In this step you will:**

- Verify all units of analysis for which you would like to construct PHDS measures.
- Identify eligible children for sampling.
- Specify the minimum completed and starting sample sizes needed for each unit of analysis.
- Specify age-stratifications required for each specific unit of analysis.
- Finalize and implement your sampling strategy.



## Guidelines and Issues to Consider

### Verify your unit(s) of analysis

This may seem like an obvious step, and you may have already done this while conceptualizing your project. However, it is critical that you are clear about your unit(s) of analysis. In other words, what entities, areas, or groups of children are you measuring? Each of these units of analysis has different specifications for sampling, so you need to decide upon them first.

Units of analysis past users of the PHDS have sampled for include:

#### 1. Health System

*For example: Across the entire pediatrics department in a health plan.*

#### 2. Office or Provider-Group

*For example: An office located at a specific location that is comprised of multiple providers.*

#### 3. Individual Health Care Providers

*For example: Dr. Jones and Dr. Smith*

#### 4. Specific Populations of Children

*For example: Children within specific race-ethnicity groups. Children who reside in specific locations (i.e., rural vs. urban).*

Secondly, you need to ensure that there are valid data to allow you to analyze the desired unit of analysis. **Table 2.1** located on the next page provides highlights of common units of analysis for the PHDS and issues to consider when sampling for these specific groups. The bottom line is to think about what unit of analysis is most relevant to your priority audiences for the PHDS findings. Health care systems vary across markets, so who is accountable and who will use the information will differ depending on your health care system.

**Table 2.1 Units of Analysis and Sampling Issues to Consider**

Potential Unit of Analysis	Issues to Consider at the Time of Sampling
<b>Health System</b>	<ul style="list-style-type: none"> <li>➤ Variations in the "microsystems" within the health system in how preventive and developmental health care is provided: Consider the characteristics within the "microsystems" that influence how well-child care is provided. Consider the various groups within a health system that may want to analyze the findings.</li> </ul>
<b>Office or Provider Groups</b>	<ul style="list-style-type: none"> <li>➤ Number of providers: When doing office-level sampling, it is imperative to consider the number of providers and the (full-time employees) of the providers in each office. Bigger offices will need a bigger starting sample size than smaller offices.</li> <li>➤ Provider team: Think about the health care provider team that will be measured. How is well-child care provided? Who gives the care that is measured in the PHDS? Do the nurse and physician divide up the well-child visit? The more people who provide care measured in the PHDS, the more variation there will be, and the greater the sample size will need to be.</li> </ul>
<b>Individual Health Care Providers</b>	<ul style="list-style-type: none"> <li>➤ Provider team (see above)</li> <li>➤ Provider-level variables: What variables will you use to identify the provider to whom the child should be assigned at the time of sampling? There are two options:               <ol style="list-style-type: none"> <li>1) Provider with whom the child is enrolled or "paneled" as a primary care provider.</li> <li>2) Provider with whom the child had the most well-child visits in the last 12 months or since birth.</li> </ol> </li> </ul> <p><b>Tip from the Field:</b> Although you may want to analyze the data at the health care provider level, you may not have valid information at that level. Specifically, the CAHMI team has found that while many systems note the provider with whom the child is enrolled, this provider is not necessarily the person that the parent is most likely to think about when responding to the survey. This could be due to a variety of factors: A) The provider variable is based on the claims/bills database (this allows for one centralized billing code for a medical group) or B) The child may receive well-child care from providers with whom they are not enrolled (e.g. they see a provider in the same office, therefore the claim is still paid, etc.).</p> <p>To address this issue, <b>CAHMI recommends</b> that systems use available enrollment and utilization information for sampling and then ask parents/survey respondents to indicate their child's personal doctor or nurse in the survey and use this data for provider-level reporting.</p>

**Table 2.1 Units of Analysis and Sampling Issues to Consider (Continued)**

Potential Unit of Analysis	Issues to Consider at the Time of Sampling
<p><b>Specific Populations of Children</b></p>	<p>➤ Child-level variables: What variables will you use to identify specific children? Are these variables valid?</p> <p><b>Tip from the Field:</b> Many health systems have variables related to a child's race/ethnicity in their data systems, but these variables are not reliable (e.g., they are not consistently used or they are only valid for some children). To address this issue, <b>CAHMI recommends</b> that systems use available enrollment and utilization information for sampling and then ask parents/survey respondents to indicate their child's race/ethnicity and use this data for reporting purposes.</p>

☑ Identify **eligible children** for sampling

Sampling is the process used to identify children whose parents will be asked to complete the PHDS. There are five criteria that a child must meet in order to be eligible for inclusion in the PHDS sample:

1. **Age criterion:** Select children 3–45 months of age (allows for time lag in sampling administration).

**Purpose:** The PHDS measures care recommended in the first three years life. This includes care provided through the three-year-old well-child visit.

2. **Enrollment criterion:** Select children continuously enrolled in the health system for 12 months or since birth.

**Purpose:** The PHDS is a measure of health care quality. You want to include in the sample children who have been in the system for the time period referenced in the survey.

3. **Well-child visit criterion:** Select children who have had one or more well-child visits (as defined by the HEDIS well-child visit specifications) in the last 12 months or since birth.

**Purpose:** The PHDS is a measure of health care quality. The care provided in the PHDS should have been provided during well-child appointments. You want to include in the sample children who have received well-child care in the time period that is referenced in the survey.

4. **One-child per family/target child criterion:** Randomly select only one eligible child per family.

**Purpose:** You want the PHDS administration process to be as family-centered as possible. **CAHMI recommends** that only one child be sampled for the survey, as many families could have more than one eligible child and may be overwhelmed by multiple surveys.

5. **Give survey in language spoken in the home (if available):** Select families that speak the language in which the survey is administered.

**Purpose:** The current version of the PHDS is available in English and Spanish and the ProPHDS is available only in English at this time (translation will occur in Fall 2006).



### Tip from the Field

Before going on to the next step, **CAHMI recommends** that you examine the number of children that meet the eligibility criterion described above for each unit of analysis. For example, if you are sampling for individual providers, we recommend that you first examine how many children are eligible for each of the providers. This will raise issues early on in the process that may otherwise arise once the sampling strategy is implemented.

**Additional PHDS Resources:** Keep in mind that if you are planning to administer the survey in the pediatric office (not by mail) or via the telephone, a different sampling methodology will need to be used (see guide for *In-Office Administration of the PHDS, Reduced Item Version* or the *PHDS-PLUS Implementation Guidelines* listed in the resources section).

- Specify the minimum completed and starting sample sizes needed for each unit of analysis

Now that you have identified eligible children, you need to specify the following:

- 1) The minimum number of completed surveys that you will need for each unit of analysis.
- 2) You can then determine the starting sample size needed, taking into account the following:
  - a) The response rate you think you will be able to achieve,
  - b) The number of surveys that will not reach the parent for completion due to bad addresses, and
  - c) The data error rate for the specific unit of analysis.

#### Figure 2.1: Determining starting sample size

$$\text{Minimum sample} = \frac{\text{target completed surveys}}{\text{response rate} - \text{bad address rate}} * (1 - \text{data error rate})$$

The sampling strategy that you implement is dependent on how you will be using the results. For example, if you plan on using the results to compare health care providers, then you will need more completed surveys than if you were using the results to examine the quality of preventive care at the population level.

**Tip from the Field**

If you are planning multiple uses for your results, choose the sampling strategy with the largest minimum sample required.

**Table 2.2** provides recommended sampling strategies based on different units of analysis. Definitions of each of the variables in this table are located on the next page.

**Table 2.2: Determining the Starting Sample Size Required for Each Unit of Analysis**

	<b>Comparison of individual providers<sup>a</sup></b>	<b>Comparison of offices or provider groups</b>	<b>Health-system level reporting</b>	<b>Comparison of health plans<sup>e</sup></b>
Target number completed surveys	30 per health care provider <sup>b</sup>	30 per health care provider in each office	100 <sup>d</sup>	250 per health plan
Estimated data error rate	1%	1%	1%	1%
Estimated response rate	40%	40%	40%	40%
Bad address rate	Depends on the setting	Depends on the setting	Depends on the setting	Depends on the setting
Minimum starting sample, assuming no bad addresses <sup>c</sup>	78 per health care provider	78 per health care provider in each office	253	632 per health plan

<sup>a</sup> Although a smaller sample could be drawn if you are not planning on using the results for comparison, we recommend that you assume comparisons will be made if you are reporting results at the provider or health plan levels. If 30 surveys are not feasible, the minimum number CAHMI recommends per provider is 15. See Table 2.1 for other issues to consider in provider-level sampling. Lastly, one of the PHDS measures (follow-up for children at risk) is only calculated for a portion of children (approximately 25% of the sample). Therefore, if this is a primary measure to be used in comparisons, then the sample size should be adjusted accordingly.

<sup>b</sup> Providers who are very consistent in the care they provide across patients will need fewer surveys, as compared to providers who target certain discussions to certain patients. Secondly, if the provider and nurse each provide components of the well-child visit, then more surveys may be needed as the provision of care by two individuals increases the level of variation in this communication-dependent measure.

<sup>c</sup> CAHMI recommends that each sample contain members enrolled in the same type of health insurance coverage. Therefore, different samples should be drawn if you wish to assess quality of care for Medicaid beneficiaries and commercial enrollees.

<sup>d</sup> As is described in Table 2.1, the more providers there are, the more variation there is. Therefore, CAHMI recommends that you base the sample size on the number of providers. An alternate approach is to base the sample size on the number of FTE in each office.

<sup>e</sup> This is the minimum number of surveys recommended. However, to date, all of the Medicaid agencies and recent health plans that have implemented the PHDS have set their completed survey goal at N=2000. This sample size has allowed the state to do a number of analyses that met their strategic and political goals, and allowed stratified analysis for specific groups of children and program and policy areas.

## Definition of Terms in Table 2.2

**Targeted Number of Completed Surveys:** The minimum number of completed surveys necessary for analysis. A completed survey is defined as a survey in which at least 80 percent of the items were answered; it will be discussed in greater detail later in this section.

**Estimated Response Rate:** The percentage of parents who responded to the survey. You can never know for sure what the response rate for your survey will be. However, you can estimate this rate based on your own previous survey experience. If you do not have previous experience, we recommend using 40 percent. This represents a conservative estimate for a response rate based on field-testing and the implementation of similar surveys. It should ensure that you have enough completed surveys for analysis. Field test and previous implementation results of the PHDS have yielded response rates from 20 to 70 percent. Any response rate estimate that you have from previous survey experience in your area should be substituted for the estimated response rate when determining the minimum sample size. Many factors that can influence the response rate of your survey, and suggestions will be provided throughout this section to help you to maximize your response rate.

**Bad Address Rate:** The rate of addresses in your database that will be incorrect. As is noted later in the chapter, Address Service Correction should be part of your survey administration. However, there still will be a number of addresses that will be incorrect. The rate of bad addresses has varied significantly across past users of the PHDS (2%–38%). CAHMI recommends that you examine other surveys used within the health system to determine an estimated bad address rate.

**Estimated Data Error Rate:** The rate of data errors that you expect within your sample or sampling frame. Data errors are incorrect or bad contact information, enrollment information, eligibility information, or any other type of information necessary for the administration of the survey. You may not know what the data error rate is for your sampling frame; however, you are likely to find some data errors. We recommend using a rate of 1 to 2 percent if you do not know your rate. If you do know the data error rate, this number can be substituted in the chart above and will increase or decrease your minimum sample size.

**Minimum Starting Sample:** The minimum number of children who should be sampled for the administration of the survey given the intended use of the results.

### EXAMPLE 2.2: Determining Minimum Sample Size

The Health Plan A chose to administer the PHDS across the entire system. The plan primarily contracts directly with 10 medical groups comprised of 25 individual providers and would like to use the PHDS results primarily for quality improvement at the system-, office- and provider level. However, they will also be publishing the results in a consumer guide. Two years ago, the plan administered the CAHPS and had a 52 percent response rate and a 3 percent bad address rate. They conducted an audit of their provider records just last year and expect their data error rate to be less than 0.05 percent.

Minimum starting sample size=

$$\frac{25 (\# \text{ of providers}) * 30 (\# \text{ of completed surveys per provider})}{(.52 (\text{response rate}) - .03 (\text{bad address rate})) * [1 - (.05) (\text{data error rate})]}$$

Minimum starting sample = 1611

#### Specify age stratifications required for each specific unit of analysis

The last step in identifying the starting sample of children whose parents will be sent the PHDS survey is to stratify the sample for three age groups of children.

- Children **3–9.99** months old at the time of survey administration
- Children **10–18.99** months old at the time of survey administration
- Children **19–45.99** months old at the time of survey administration

This stratification is to ensure that sufficient samples are obtained for the three groups listed above. The reason you want sufficient samples for each of these age groups is because the PHDS items focused on anticipatory guidance and parental education are different for each of these groups.

At the time of sampling, it is important to specify the date when the surveys will be sent out to the parent and to conduct the age-stratification based on how old the child will be when the parent receives the first mailing of the survey.

There are two options for stratifying the sample by age that have been used:

**Option 1:**

- One-fourth of the starting sample is children **3–9.99** months old
- One-fourth of the starting sample is children **10–18.99** months old
- One-half of the starting sample is children **19–45.99** months old

**Option 2:**

- Examine the proportion of eligible children (the children who met the five eligibility criterion described earlier) in each of the groups in your health system for the units of analysis of interest and base the stratification on your own population.

It is important that each sample is stratified for each unit of analysis. For example, if you are sampling for 10 offices. The sample **for each office should be stratified by age.**

**Tip from the Field**

In order to reduce burden and administrative time, users of the PHDS for office- and provider-level analysis have stratified the sample at the office level only. However, if you are using the PHDS for incentive-based payments, then the starting sample should be stratified for each unit of analysis examined.

**Important Note for Users of the ProPHDS:**

If you are using the ProPHDS, you will administer three, age-specific versions of the survey that map to these three age-specific groups. The age of the child for the starting sample needs to be adjusted to allow for the time of survey administration. CAHMI recommends that you assume that the survey administration will take two months. Therefore, the starting sample for the ProPHDS should be stratified by the following age groups.

- One-fourth of the starting sample is children **3–7.99** months old
- One-fourth of the starting sample is children **10–16.99** months old
- One-half of the starting sample is children **19–43.99** months old

Finalize and implement sampling strategy

Once you have:

- 1) Identified eligible children for sampling
- 2) Determined the minimum starting sample for each unit of analysis
- 3) Stratified the starting sample by age

You are then ready to randomly identify the number of children in each group in each of the units of analysis.

**Tip from the Field**

Again, we recommend confirming the feasibility of obtaining all needed data before finalizing your plan. It is not uncommon for data elements or contact information needed to administer the PHDS to be lacking for key subgroups of children who you would like to include in your sampling.



## STEP 2.3: Identify non-survey based analytic information to collect for the starting sample at the time of sampling

### ► What is the purpose of this step?

The purpose of this step is to identify data that can be linked to PHDS results to enhance the value of the data collection. Supplemental data, in this case, refers to any data that is not directly needed for the administration of the survey, but is obtained from the survey and used for analytic and dissemination purposes.

For example, you may want to add an indication of whether the child had a **HEDIS-defined well-child visit**, or you may even want to have the child's claims history for more detailed analyses.

Due to new federal regulations on data privacy (HIPAA), it is best to collect any child-level information prior to administering the survey, since obtaining information retroactive to receipt of completed surveys is often not acceptable. The confidential survey administration process recommended in this manual does not allow any person-identifying information, such as the enrollee ID, to be linked with completed survey data.

### In this step you will:

- ☑ Identify data elements to collect at the same time as survey sampling, such as those outlined in Figure 2.2 (e.g. child enrollment and utilization). These data file elements will be used for analytic purposes.
- ☑ Obtain and link data elements to the sampling data file before pulling the starting sample.





## Guidelines and Issues to Consider

For each child in the starting sample, create a unique identifier that will link the starting sample with the completed survey data and with this supplemental data.

- ☑ **Identify elements for the supplemental data.** It is important to specify the data elements that will be collected for each of the following:
  1. Each child in the starting sample. Collect descriptive variables about the child that you can use to stratify the PHDS data. Supplemental variables created by past users of the PHDS have been based on the following data systems:
    - **Administrative and/or enrollment data:** Information that can be derived from this data includes the payor (e.g. public or private); the provider the child is enrolled with; and how long the child has been enrolled with that provider.
    - **Utilization data:** In the PHDS data collected to date, over 95 percent of families who complete the survey say that their child has seen a doctor or other health care provider in the last 12 months or since the child's birth. Such a detail can be valuable when analyzing PHDS results. Other examples of information that can be derived from this data include the number of visits over the past year and indications of certain health problems.
  2. Each unit of analysis that you will use to analyze the PHDS findings (e.g. individual pediatric offices, individual pediatric provider). Information that can be collected includes the gender and FTE (full time equivalency) of the individual provider and the number of providers in an office.

Figure 2.3 in the next step provides examples of supplemental items collected by past users of the PHDS.

- ☑ Create a data dictionary that clearly describes the supplemental variables that will be created based on this data. **Appendix 7** provides an example of a data dictionary for a supplemental data collected by a past user of the PHDS.

**Figure 2.2: Examples of Data Elements to Collect at the Time of Sampling**

***Child  
Characteristics***

- Race/ethnicity
- Date of birth
- Gender
- Geographic region (e.g. urban, suburban, rural)

***Child Enrollment  
Characteristics***

- Payor for child's insurance (public vs. private)
- Months of continuous enrollment
- Provider and/or office the child is currently enrolled
- All Providers and/or offices the child has been enrolled with in the last 12 months
- Where applicable, specialty of child's primary care provider (e.g. pediatrics, family medicine).

***Child Health Care Utilization  
Characteristics***

- Number of office visits (non-ER, urgent care)
  - Number of well-child visits
  - Number of sick visits
  - Number of urgent care visits
  - Number of hospital visits
  - Number of referrals, categorical variables related to type of referred services
- (For each of the above, the provider who delivered the care and the setting in which the care was provided [e.g. specific office])



## STEP 2.4: Finalize the PHDS survey to be used

### ➡ What is the purpose of this step?

The purpose of this step is to finalize the PHDS tool (the full-length PHDS **or** the reduced-item PHDS) and to consider whether there are a small number of items (3–5) you can add that will enrich your PHDS data for you and your strategic partners.

#### In this step you will:

- Finalize the PHDS tool you would like to administer (The full-length PHDS **or** the reduced-item PHDS).
- Identify any important topics to add to the PHDS that would enrich the PHDS data.
- Identify existing and tested survey items for topics of interest or develop and test new items.
- Double check the impact of new items included in your sampling strategy to ensure your completed sample will allow you to meaningfully evaluate responses to the new items.



## Guidelines and Issues to Consider

- Finalize the PHDS tool you would like to administer (the full-length PHDS or the reduced-item PHDS).

A copy of the PHDS and the age-specific versions of the ProPHDS can be found in **Appendices 3–6**.

The primary difference between the PHDS and the ProPHDS is the length of the survey and therefore the depth and breadth of the information obtained in the survey. (More information about the development of the ProPHDS can be found in the *In-Office Administration of the PHDS Manual* located on the CAHMI Web site.)

Where feasible (given the difference in length and costs) CAHMI recommends the PHDS if you are using a mail mode of administration. The additional items provide valuable information and more specificity about the care provided and key child- and parental-health characteristics.

**Table 2.3** on the following page provides an overview of the PHDS and ProPHDS to assist you in deciding which tool best meets your needs and in setting information goals for the project.

**Table 2.3: Comparison of the PHDS and the ProPHDS Tools**

	<b>PHDS</b>	<b>ProPHDS</b>	<b>Difference Between the Tools?</b>
<b><u>General Characteristics</u></b>			
Length of Survey	10 pages	5 pages	Yes
Time for Parent to Complete the Survey	10-15 minutes	5-10 minutes	Yes
<b><u>Survey Content</u></b>			
<b><u>Number of Items</u></b>			
<b><i>Rec. aspects of prev. and dev. care</i></b>			
Anticipatory Guidance and Parental Education	15-18	15-18	No
Family-Centered Care	10	5	Yes
Ask About and Address Parental Concerns	2	2	No
Follow-Up for Children at Risk for Delays	4	4	No
Assess Family for Psychosocial Well-Being	4	3	Yes
Assess Family for Smoking, Substance Abuse, and Safety	4	2	Yes
Standardized Developmental Screening <sup>a</sup>	1 stem, 2 follow-up items	1	No
Presence of a Personal Doctor or Nurse	1	1	No
Care Coordination	1 stem, 1 follow-up item	0	Yes
Helpfulness and Effect of Care Provided	8	0	Yes
Health Information	4	0	Yes
<b><i>Child Health Care Characteristics</i></b>			
Access to Care, Use of Health Care	7	0	Yes
<b><i>Target Child Characteristics</i></b>			
Health Status, Premature Birth	2	0	No
Risk for Dev., Behav., Social Delays (Items from the PEDS©)	10	6	Yes
Children with Special Health Care Needs	5 stem, 2 follow-up items	0	Yes
Whether Breastfed	1	1	No
Child Demographic Characteristics	3	2	

**Table 2.3: Comparison of the PHDS and the ProPHDS Tools (Continued)**

	<b>PHDS</b>	<b>ProPHDS</b>	<b>Difference Between the Tools?</b>
<i>Family Characteristics</i>			
Birth Order of Target Child	1	1	No
Family Behaviors (e.g., reading, safety behaviors)	11	1	Yes
Education Level of Parent	1	1	No
Parental Health (e.g., symptoms of depression)	5	2	Yes
Problems Paying for Basic Health and Medical Expenses	5	3	Yes
Relationship of Respondent to Child	1	0	Yes
Respondent's Socio-demographic Characteristics (e.g., marital status)	4	0	Yes

<sup>a</sup> These items are recommended for inclusion only if one or more health care providers in your system use a parent-completed standardized developmental screening tool.

- Identify any important topics to add to the PHDS that would enrich the PHDS data

It can be valuable to add items that capture information about a specific topic of interest in your health system. This can increase buy-in and perceived value of the project.

However, it is important to consider the following:

- The survey should not significantly increase in length. Consider adding only 3–5 new items.
- Only include new survey items that can not be found more reliably using another data source, such as the medical records or administrative data.

***Important Note for Those Using the PHDS for Provider-Level Analysis:***

If you are using the PHDS for provider-level analysis, **CAHMI recommends** you add an item asking the parent to indicate their child’s personal doctor(s) or nurse(s). This question can be a follow-up question to the PHDS item asking the parent whether or not their child has one or more personal doctors or nurses (PHDS Q 38, ProPHDS Q11).

**EXAMPLE 2.3: PHDS Item Asking the Parent to Identify the Child’s Personal Doctor or Nurse**

**PHDS Q38:** A personal doctor or nurse is a health professional who knows your child well and is familiar with your child’s health history. This can be a general doctor, a pediatrician, a specialist, a nurse practitioner or physician assistant. Do you have one more person(s) you think of as your child’s personal doctor or nurse?

Yes (Go to 38a)      No (Go to 39)

**PHDS Q38a:** Which of these people do you think of as your child’s personal doctor or nurse? (Please check one or more)

**Office X**

- Dr. Jones
- Dr. Smith
- Dr. Murray
- Other:

**Office Y**

- Dr. Reinbold
- Dr. Peck
- Dr. Rutenberg
- Other:

Further specifications about how to use parent-report in combination with other data sources (administrative and utilization data) is provided in **Step 5.5**.

- ☑ Identify existing and tested survey items for topics of interest or develop and test new items.

If you do decide to add items to the PHDS, CAHMI recommends that, wherever possible, you try to use items that have been validated and tested with parents of young children.

#### **Tips from the Field**

- Make sure the items you add are **age-appropriate** for children under age four.
- Only include new survey items that can not be found **more reliably using another data source**, such as the medical records or administrative data.
- Do not develop new survey items if there are **already reliable and valid items** about the topic of interest. In many instances, existing survey items have already been tested and implemented.



You may wish to examine the following surveys for supplemental items:

1. National Survey of Early Childhood Health (NSECH). Visit <http://www.cdc.gov/nchs/about/major/slaits/nsech.htm> for more information.
2. National Health Interview Survey (NHIS). Visit <http://www.cdc.gov/nchs/nhis.htm> for more information.
3. National Survey of Children with Special Health Care Needs (NS-CSCHN). Visit <http://www.cshcndata.org> for more information.
4. National Survey of Children's Health (NSCH). Visit <http://www.nschdata.org> for more information.
5. Behavioral Risk Factor Surveillance Survey (BRFSS). Visit <http://www.cdc.gov/brfss/> for more information.

Figure 2.3 on the next page provides an example of supplemental survey items that have been added to the PHDS.

### **Figure 2. 3: Examples of Supplemental Survey Item**

Tailoring the PHDS by adding 3–5 questions has valuable for past users. Below are examples of items that have been added to the PHDS.

#### ***Topic: Parent Perception about Well-Child Care (items derived from the NSECH)***

Well-child care visits are visits that are made to a doctor or healthcare provider who takes care of your child when (he/she) is not sick but needs a check-up or a shot. (In the last 12 months/Since CHILD'S birth), how many times has (he/she) had a well-child visit for a check-up or shot?

Let's talk about the well-child care (CHILD) has received (in the last 12 months/since [his/her] birth). Think about the last time you took (CHILD) for a check-up. How long was the doctor or health care provider who examined (CHILD) in the room with you?

How would you rate (CHILD)'s check-ups (during the last 12 months/since [his/her] birth)? Please include all the doctors, nurses, and other health providers that (CHILD) may have seen (Scale of 0-10).

#### ***Topic: Care Coordination (items derived from the NSCH)***

In the last 12 months (or since your child's birth), did your child need any special services, equipment, or other care for his/her health?

- 1a. How much of a problem, if any, did you have obtaining the special services, equipment, or other care that (he/she) needed? Would you say you had a big problem, moderate problem, small problem, or no problem at all?

#### ***Topic: Day Care (items derived from the NSECH)***

In a typical week, how many hours does your child spend in the care of someone other than a parent or guardian?

- 1a. Is the person who usually cares for child a relative or non-relative?
- 1b. Is your child mostly cared for in your home, in someone else's home, or in a day care center?

#### ***Topic: Obesity***

How much does your currently weigh? \* What is your child's current height? \*\**Items used to calculate the child's body mass index. Only applicable to children 2 years or older.*

### **Before adding any items to the PHDS survey, be sure to do the following:**

- ⇒ Double check the impact of new items included in your sampling strategy to ensure you will have a completed sample that will allow you to meaningfully evaluate responses to the new items.
- ⇒ Test any new items you design yourself to make sure the wording is interpreted in the way you intended. Do this "cognitive testing" even if you only have access to a small group of parents of young children.
- ⇒ Think about the placement of any new survey items. The survey should flow from topic to topic with similar items grouped together, rather than jump between different topics. Discontinuity complicates the cognitive task of completing the survey and can frustrate the respondent. All items that collect demographic information should be in the last section of the survey. Also, adding an item in a certain place in the survey can lead to unintended "order effects." This occurs when the answer to a previous question "primes" or influences how a person responds to a following question in an undesirable way.
- ⇒ Minimize the number of different time frames and response options included in a survey. Wherever possible, ensure that added items have similar framing and response option language to what is used in the PHDS. For example, when asking about discussions with a child's doctor, the PHDS uses the following anchoring text; "In the last 12 months did your child's doctor or other health provider talk with you about..."

### ***Removing items from the core survey***

CAHMI **strongly** recommends using the PHDS in its entirety, but recognizes that you may need to remove items in some cases to accommodate your needs. Before you remove any items from the core survey, consider the following:

- ⇒ Start with the non-quality of care items, such as general information on parenting behaviors, parent health, child's health, and the child's use of health care. Do any of these items fail to provide you with information that you can use for this project? Can you get valid information about this same topic from enrollment, member, or claims databases?
- ⇒ The only quality measure that CAHMI would suggest omitting, as a last resort, would be the "Helpfulness of Care" quality measure. The other quality measures all measure whether specific aspects of recommended care were received, whereas "Helpfulness of Care" asks whether the care that was received helped respondents with their parenting.

#### **Important Note about CAHMI Copyright of the PHDS**

The PHDS tools and implementation strategies are copyrighted by the Child and Adolescent Health Measurement Initiative (CAHMI) and should therefore be cited properly. If modifications are made to the PHDS items or sampling strategy described in this manual, the citations should note an adaptation from the CAHMI copyright.

## **Step 3: Prepare for and Conduct Survey Administration**

Step 3 provides detailed technical assistance to develop, prepare for, and conduct survey administration. This step is intended for project managers and vendors who will conduct the sampling and/or survey administration.

There are four sections in Step 3:

- 3.1: Organize your implementation team
- 3.2: Create the sampling frame and analytic variable data sets
- 3.3: Lay out and implement your survey administration process
- 3.4: Review additional related resources



## **STEP 3.1: Organize your implementation team**

### **➔ What is the purpose of this step?**

The purpose of this step is to develop a specific working team, work plan, and timeline for your PHDS project, and to assemble the data needed to conduct your PHDS sampling and administration.

#### **In this step you will:**

- Build an internal and external team to implement the PHDS project.
- Assign specific roles to each team member.
- If Applicable: Hire a survey vendor.



### **Guidelines and Issues to Consider**

- Determine which tasks will be completed internally and which will require external partners or vendors.

When building your internal and external PHDS teams to administer the survey, consider the following:

- Which parts of the process can you handle internally? Which parts will require hiring an external vendor?
- Do internal staff members have the skills/expertise as well as the time needed to complete the tasks that will be assigned to them?
- Do you have the resources to pay external vendors, if you need them? How will you do so?
- What is the status of the data systems you will use for sampling and gathering information? Will you need to contract with an external organization to gather population files?

- ☑ Immediately involve all leaders whose approval is needed to implement your PHDS project activities or to disseminate PHDS findings.

Obtaining the full support of senior leadership is essential to the success of your PHDS project. While it is possible to conduct the PHDS without the early involvement and support of senior leadership, they may key to community-wide distribution of the results. They also may help explain the value of the project to others, such as the chief of pediatrics, or approve contracts with external vendors.

- ☑ If you hire an external vendor, be sure to carefully craft a survey vendor request for proposal (RFP).

Now that you have determined which parts of the project will be contracted out, you will likely need to find a suitable survey vendor. Your organization may have specific rules and requirements for hiring a vendor. Depending on these requirements, hiring a vendor can be a lengthy process.

The process begins by writing an RFP (which may go by a different name in your health system). This is the document that informs potential bidders of exactly what work needs to be done, how it should be done, and when it needs to be finished. This document should be as detailed and specific as possible. Be sure to review the technical specifications before you write the RFP so that all necessary details are included. Also include management tasks such as regular progress meetings and/or interim reports, decision-making processes, and conflict resolution procedures. Make sure bidders understand exactly which costs they are responsible for, such as survey printing and mailing costs or report development and testing costs.

All deliverables that you expect from the vendor should be specified in the RFP. This includes interim deliverables, such as progress reports and interim completed PHDS survey data sets, as well as final deliverables, such as the data set and all documentation about the project. If you make changes later on, it will most likely cost you more than if they were included in the original RFP.

The RFP should provide potential bidders with information on the processes for bidding, evaluating, and selecting a vendor. It is important to include the following information in your RFP:

- The deadlines and format for proposals.
- Information about how bidders can ask questions or get clarification when preparing the proposals.
- The criteria used to score the proposals and select the vendor.
- Provisions for data security and confidentiality. Person-identifiable data is necessary only for the administration of the survey. Include provisions for the return or destruction of any data files with identifying information that were needed for the sampling and administration of the survey.

- ☑ If you hire an external vendor, carefully evaluate candidate survey vendors who respond to your RFP.

When evaluating survey vendors who respond to your RFP, the minimum scoring criteria should evaluate applicants on how well they demonstrate they have the following:

### **General characteristics**

- An understanding of the overall project and the goal of the PHDS.
- A comprehensive response to all tasks described in the RFP.
- Sufficient and qualified staff to do the work.
- Sufficient facilities and resources.

### **PHDS-specific characteristics**

- Experience and expertise in sampling, specifically:
  - Experience in obtaining population files from health systems and pulling samples for survey administration based on enrollment and health care utilization. Vendors with experience in calculating child-focused HEDIS measures should be preferred.
  - Experience in creating weighted, stratified sampling files based on information about the child's enrollment in a health system and child's age.
  - Experience pulling survey samples at the level or unit of analysis desired, such as health care provider or office.
- Experience in conducting parent-based surveys about the quality of care received, specifically:
  - Demonstrated ability to maximize response rates and produce acceptable telephone response rates. The telephone response rate is calculated by dividing the total number of completed phone interviews by all possible phone respondents. An acceptable response rate is 40 percent or higher.

The contract will be based on the project detailed in the RFP. Remember that the contracting process will be easier if your RFP contains specific details on the scope of the work, deliverables, and timelines. Consult your legal department to make sure all necessary legal language and requirements are included. This is most likely standardized for all contracts with external vendors.

In addition, ensure that the data collection and sharing are compliant with the Health Insurance Portability and Accountability Act (HIPAA), so that any public health information shared between organizations is strictly protected. Include provisions for the return or destruction of personal health information once the project is completed. Create a HIPAA Business Associate agreement between all parties who will have access to the data.



## STEP 3.2: Create the sampling frame and analytic variable data sets



### What is the purpose of this step?

#### In this step you will:

- Create the child-level sampling frame data set (specified in Step 2).
- Create the child-level analytic variable data set (specified in Step 2).
- If Applicable: Deliver the data sets to your survey vendor.
- If Applicable: Have the survey vendor pull your PHDS sample.



### Guidelines and Issues to Consider

- Create the child-level sampling frame data set and analytic variable data set.

**Step 2.2** provided a detailed description of the guidelines that should be used in identifying and selecting the sample.

To review, you (or your hired vendor) will do the following:

- 1) Identify eligible children for sampling.
- 2) Determine the minimum starting sample for each unit of analysis.
- 3) Stratify the starting sample by age and determine the minimum starting sample for each age group in each unit of analysis.

Once these steps have been completed, you are ready to randomly select the starting sample for the PHDS.

Additionally, for each child and unit of analysis represented in the starting sample you will identify the analytic information not based on the survey, as described in **Step 2.3**.



- ☑ If Applicable: Provide survey vendor with a sampling and analytic data set data dictionary (**Appendix 7**).

If you are providing a data set to a survey vendor to conduct the sampling, outline the specific variables you want to include in the child-level sampling and analytic data sets (e.g., utilization, enrollment, etc.), and/or obtain a data dictionary from your survey vendor before the PHDS sample is pulled. This ensures that all variables that need to be linked to the survey data set will be available to you. Once the sample is pulled, you may not be able to go back to get additional variables. In particular, be sure your vendor makes clear which stratified sampling groups each child belongs to (e.g., age, continuous enrollment, age group, and any state-specific sampling strategies).

### **Tip from the Field**

You want to use the most updated information possible for sampling because a key eligibility criterion is whether the child had a visit or not. Children have seven well-child visits in their first year of life alone. Therefore, you want to make sure that your sampling is done as close as possible to when the survey is administered. Past users of the PHDS have conducted a “dry run” of the sampling to ensure that their sampling data specifications work and then have re-run the sampling at the latest time possible.



## **STEP 3.3: Plan and implement your survey administration process**



### **What is the purpose of this step?**

Establishing a specific work plan and realistic timeline is essential to the success of your PHDS project. Many expect instant results with a quality measurement initiative. However, it takes time to collect, analyze, and report the quality measurement data—and to have those data used in ways that lead to improvements in care. So make sure you set a reasonable timeline for the overall project. It is very important to allow enough time for the administration of the survey, analysis of the results, and reporting of development, testing and production.

This section provides detailed information about the technical requirements for implementing the PHDS. The timelines listed in the technical specifications below have been tested in the field to ensure the best response rates and highest-quality data. Compressing the timeline can compromise data quality and reliability.

### **In this step you will:**

- Understand the key steps and timeline for administering the PHDS.
- Verify your work plan and delegation of tasks within your implementation team.
- Prepare to specify in a contract with an internal or external vendor/department how you would like the PHDS to be administered.



## Guidelines and Issues to Consider

Important note: This manual is specific to the administration of the PHDS or ProPHDS by mail. Refer to Step 1: PHDS Tool and Resources for other manuals describing the implementation guidelines for administering the PHDS over the telephone or in a pediatric office.

### Survey administration process

This section contains a framework for a survey administration process that has been used by CAHMI and achieved acceptable response rates.

However, it is important to review survey administration processes used in your own health system with your own patients, and to identify strategies that have yielded the highest response rates.

The timing of the administration is also critical. Please consider the following:

1. **Holidays:** It is not recommended that you administer the survey during November and December as many parents are busy with the holidays.
2. **Seasons:** Summer can be a difficult time for survey administration as families are often on vacation. Higher response rates are often observed in the early fall and in late winter. However, avoid survey administration during the first week of school or during school holiday weeks.
3. **Other surveys in your health system:** Check to see if there are other surveys that may be sent to parents and try not to coincide with other survey mailings, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS).

There are six stages to administering the PHDS by mail:

- Stage # 1: Pre-notification letter
- Stage # 2: Toll-free number for parents
- Stage # 3: First mailing of cover letter and survey

- Stage # 4: Reminder postcard
- Stage # 5: Second mailing of cover letter and survey
- Stage # 6 (Optional): Second reminder postcard and/or telephone call

### **Stage #1: Pre-notification letter**

For each selected child with a viable address, a pre-notification letter should be mailed. This letter should be available in all languages in which the survey will be administered. Pre-notification letters should be customized at the respondent level (e.g., "To the parent/guardian of [Child Name]") and should include the logo of your health system and the signature of the appropriate agency's executive or the leader of the units of analysis for which you are focused (e.g., the chief of pediatrics).

The pre-notification letter should:

- Provide the name of the target child for whom the survey should be completed.
- Explain that they were randomly chosen to assist you in providing information that would be useful in improving the health care of children.
- Explain that the parent or guardian who takes the child to the doctor most often should complete the survey.
- Specify how long the survey will take (See Table 2.3).
- Provide the toll-free number parents can use to call the vendor to ask questions about the study, verify the study's legitimacy, or request no further contact pertaining to the study.

**Appendix 8** provides an example of a pre-notification letter.

Similar to the protocols developed for External Quality Review, the pre-notification letter is a strategy to maximize response rates, ensure confidentiality, describe how the results will benefit the respondent, and provide instructions on how to complete the survey.

#### **Tip from the Field**

Make sure that the United States Postal Service's "**Address Correction Service**" is utilized for all mailings. This will assure that you get accurate and complete information about the number of pre-notification letters that were not received by parents due to a bad address.

### **Stage #2: Toll-free number for parents to call with questions or to schedule an interview**

Throughout the field phase, a live toll-free number should be maintained from 10:00 a.m. to 11:30 p.m. (local time) Monday through Saturday and 3:00 p.m. to 11:30 p.m. (local time) on Sunday for respondents. Calls outside these hours should be referred to voicemail.

### **Stage # 3: First mailing of cover letter and survey**

The survey should be sent one week after the pre-notification letter is mailed. It should be accompanied by a cover letter that explains the project and includes the other details from the pre-notification letter. **Appendix 8** provides an example of a cover letter.

It is important the letterhead used includes a name/logo that parents recognize/value that parents recognize and value (e.g., the health system name).

### **Stage # 4: Reminder postcard**

A reminder postcard should be sent to the entire starting sample. There are two options for the timing of the postcard reminder:

1. **One week** after the survey mailing. With this option, the postcard goes to the entire starting sample and thanks those who have already responded. This option saves the data analyst the time it would take to remove respondents from the data file used for the survey mailing. On the other hand, printing and mailing costs are higher because you are mailing to the entire starting sample.
2. **Two weeks** after the survey mailing. This allows parents more time to complete the survey, but may increase the chance that they have thrown it out. If you go with this option, remove the known respondents' names from the mailing, but still thank those who may have responded after you mailed the postcards. Also, provide parents with a toll-free number to use to request another survey.

### **Stage # 5: Second mailing of cover letter and survey**

A second mailing of the cover letter and survey should be sent to the non-respondents at least one month after mailing the first survey.

### Stage # 6 (Optional): Reminder Postcard and/or telephone call

If the response rate is low, then CAHMI recommends that you send another reminder to the parent.

You can use either a postcard OR you call the parent.

The telephone call should be used ONLY to remind the parent to send the completed survey back and find out if they need another one. CAHMI does not recommend that you administer the survey over the phone if you have conducted a majority of the survey administration by mail.<sup>1</sup> The telephone reminder is more costly than the postcard reminder; however, it can reach parents who might not have responded to the postcard.

**Appendix 8** provides an example of the telephone script that can be used to remind parents to complete the survey.

### Example 3.1: Survey Administration Timeline

Task	Date
<b>Mail pre-notification letter</b>	<b>Day 1</b>
<b>Toll-free number for parents</b> <ul style="list-style-type: none"><li>• Live toll-free number maintained from 10:00 a.m. to 11:30 p.m. (local time), Monday–Friday, and 11:00 a.m. to 11:30 p.m. on Saturday.</li><li>• Calls outside these hours referred to voicemail.</li></ul>	<b>Day 1</b>
<b>First mailing of cover letter and survey</b>	<b>Day 8</b>
<b>Reminder postcard</b>  Option 1: To the entire starting sample  Option 2: To the non-respondents	<b>Day 15</b>  <b>Day 22</b>
<b>Second mailing of cover letter and survey</b>	<b>Day 36</b>
<b>Reminder postcard or telephone call</b>	<b>Day 50</b>

<sup>1</sup> As with all surveys, there is a mode effect on the survey results depending on whether it is completed by mail or telephone. Telephone-based surveys tend to systematically higher quality of care findings.

## **Data Confidentiality**

The recommended protocol for implementing the PHDS ensures the confidentiality of the data. If you contract the administration of the survey to an external vendor, make sure to include data confidentiality provisions in the RFP and the contract.

Be sure that the organization conducting the survey administration signs a HIPAA Business Associate agreement. Check with your legal department about HIPAA compliance. The HIPAA privacy provisions establish how covered entities must safeguard the confidentiality of patients' protected health information. Your legal department can help you determine whether you are a covered entity under HIPAA and whether your project adequately safeguards the confidentiality of patients' protected health information as specified in the HIPAA regulations.

## **Institutional Review Board (IRB) Approval**

You may be wondering if you need approval from an Institutional Review Board (IRB), especially if you do not have an IRB within your organization. While many people think that IRB reviews are only for research projects, IRB approval should be obtained before conducting the PHDS or any survey. IRBs ensure that consumer/patient rights are protected. The technical specifications in this manual are meant to address legal issues and allow for IRB approval. These specifications are based on past pilots of the PHDS that have undergone IRB review and been approved.

If your organization does not have an IRB, you can still have a review. Independent IRBs often review projects on a contractual basis; nearly every educational institution has an IRB.



### **STEP 3.4: Review additional related resources**

As mentioned earlier, there are additional versions of the PHDS that can be administered via mail and/or in-office. For more information about how items from the PHDS have been administered, visit the CAHMI Web site at [www.cahmi.org](http://www.cahmi.org).

The Spanish version of the PHDS is also available at [www.cahmi.org](http://www.cahmi.org).

For more information on HIPAA privacy provisions or for a copy of the final law, go the Department of Health and Human Service's Web site at [www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa).



## **Step 4: Monitor Survey Administration and Prepare for Data Analysis**

Step 4 provides detailed technical assistance on the five steps needed to ensure the proper administration of the PHDS and to prepare data files for analysis. This step is intended for project managers and vendors who will conduct the sampling and/or survey administration.

There are four sections in Step 4:

4.1: Monitor survey administration

4.2: Clean and code your PHDS data set

4.3: Integrate updated enrollment and utilization information

4.4: Identify and obtain descriptive information about the health system to inform analysis

4.5: Weight your data set to represent your target population



## STEP 4.1: Monitor survey administration

### ➔ What is the purpose of this step?

The purpose of this step is to closely track the quality of your survey administration process, and to monitor and troubleshoot any problems with securing an optimal response rate and accurate data entry.

#### In this step you will:

- Receive and review weekly tracking reports from your survey vendor.
- Assess and troubleshoot problems with response rates.



### Guidelines and Issues to Consider

- Specify and obtain weekly survey tracking report.

Survey responses should be tracked throughout the administration process. At a minimum, a variable indicating the survey disposition should be maintained by your survey vendor and reported on a weekly basis throughout the administration process. Values for this variable can include:

- *Survey received* – Survey was sent back.
- *Complete* – At least 80 percent of the survey items parents should answer were completed.
- *Incomplete* – Less than 80 percent of the survey items were completed.
- *Refused* – Parent refused to complete survey, sent it back blank, OR called the toll-free line and asked to be removed from list.
- *Bad Address*
- *Ineligible* – Parent returned the survey saying that their child was not in the age group, has not had a well-child visit, or child is no longer enrolled in the health system.
- *Deceased* – Child has passed away.
- *Language barrier* – Respondent cannot read and understand the survey.

Calculate interim response rates and troubleshoot response problems.

Your *raw response rate* is simply the number of questionnaires returned divided by the number of children in your starting sample. However, this rate is often misleading and not representative of the true response rate. Therefore, an *adjusted response rate* should be calculated on an interim basis throughout survey administration to track whether you are meeting response rate targets.

For the adjusted response rate, both the numerator (number of respondents) and the denominator (number sampled) are adjusted based on certain factors:

- First, the numerator (number of respondents) is adjusted from the total number of questionnaires returned to the number of completed questionnaires returned. A survey is defined as “completed” if the parent answered at least 80 percent of the items that they should have answered. You should not include items that were skipped appropriately in your count. You can adjust this algorithm if you want to allow responses to be considered even if less than 80 percent of items are completed.

Second, the denominator (number sampled) is adjusted to include only those children who are eligible for the survey, for whom you have a valid address, and whose parents do not have a language barrier. The formula to adjust your response rate is:

$$\text{Response Rate} = \frac{\text{Number of 80\% or more completed surveys}}{\text{Number of children sampled} - (\text{deceased} + \text{ineligible} + \text{language Barrier} + \text{bad address})}$$

If your response rate falls short of projections, you may need to troubleshoot with your survey vendor and consider adding and/or altering administration steps. For instance, you may decide to add an additional phone call, send a postcard, alter your introductory message left on voicemail systems, or introduce a small incentive for participation in the survey.



## STEP 4.2: Clean and code your PHDS data set

### ➡ What is the purpose of this step?

The purpose of this step is to obtain an accurate data set from your survey vendor. This step includes consistent and accurate cleaning and coding of the data set in preparation for constructing PHDS quality measures and the analytic variables needed to report your PHDS project findings.

#### In this step you will:

- Specify data files to be created.
- Obtain and check interim data sets for accurate data labeling and entry.
- Prepare data files for analysis.



### Guidelines and Issues to Consider

While data preparation is often considered part of the analysis, this task is included in the data collection section because it may be completed by the vendor while administering the survey. Additional data preparation and cleaning steps are described in Step 5.

- Specify data files to be created.

If you are using a vendor to administer the survey, the vendor should submit a data file that contains the following:

1. Coded responses for all PHDS items, including blank, do not know, refused to answer, and item skipped.
2. Survey disposition, such as if the survey was completed and the reasons for incomplete surveys (see variables noted in Step 4.1).
3. Other descriptive variables identified and collected for the starting sample (e.g., related to enrollment, health care utilization, etc.) that were identified in Steps 2 and 3.
4. Administrative data used for generating the sampling frame.
5. Age of child in months.
6. Any supplemental data linked prior to the removal of identifying information used for survey administration.
7. A data dictionary for the file. An example data dictionary for the ProPHDS survey data file can be found in **Appendix 9**.

You also may choose to have your vendor conduct some initial data preparations, such as:

- ⇒ Verifying ineligible cases
- ⇒ Checking for duplicate data records
- ⇒ Running frequencies on all variables to check for values that are out of range
- ⇒ Identifying problems with skip patterns

If errors are found, you should have the vendor verify them with the original surveys to ensure that the errors stem from the respondent and not from the administration process. Once these are identified, you will need to make decisions on how they will be handled for the analysis. Refer to Section 5 for more detail on analyzing the results.

- ☑ Obtain and check "test" and interim data sets for accuracy of data entry and survey administration.

The vendor administering your survey (either internally or externally) should provide you with a test and interim PHDS survey data sets according to a predetermined schedule.

**CAHMI recommends** that you ask your survey vendor to send a test data set that is based on a handful of mock completed surveys. This data set will test the data entry processes and ensure that the data set you receive matches the data dictionary your vendor is using.

#### **Tips from the Field**

- Always label data variables.
- Update your data dictionary with any changes made to data labels or response codes. Good documentation is essential!
- Create a backup of your data set in case of emergency. Also, create temporary and permanent data sets wisely. Think about what you would need to do if you lost the data.
- Always keep a copy of your original data set.

When you receive the test data set you should make sure that your vendor is using the data variable labels agreed upon and that responses to survey items are assigned the agreed-upon values (e.g., 1 = "no"; 2 = "yes", etc.). If errors are found, request that they be corrected immediately.

CAHMI recommends that you request at least two interim data sets. The first should include the first 100 surveys entered and the second should include half of your expected final completed survey data set (e.g., if your final complete survey goal is N=2,000, then the second interim data set should be N=1,000). These interim data sets allow you to develop the syntax that you will use to clean and analyze your PHDS data. Therefore, when the final data set is received, you will have already done a significant amount of preparatory work.

Preparing the PHDS data files for analysis.

Valid PHDS findings require careful preparation of your data prior to starting your analysis. The following are necessary steps to prepare the data for analysis. They do not necessarily need to be conducted in the order presented.

**Data Prep Step #1:** Verify survey completeness.

You should receive the data from the vendor for all of the interviews conducted. However, for your analysis you should limit the data to surveys with at least 80 percent of the items completed.

**Data Prep Step #2:** Check for ineligible cases.

Make sure parents who responded have children who meet the sampling criteria for age and continuous enrollment. (a) Run a frequency on the age variable from the survey responses. Here you should ensure that the age the parent reports in the survey and the age-specific section of the PHDS that the parent completes match the age of child that you have in your administrative data files. Use the parent report as the "gold standard" and exclude cases where the child was erroneously included in the sampling frame. (b) Remove records where the child was found not to be in the health plan, provider, or unit you are sampling.

**Data Prep Step #3:** Check for duplicate data records.

Make sure every record has a unique identifier.

**Data Prep Step #4:** Check for out-of-range values.

Run frequencies on all of your variables to check for out-of-range values or odd-looking distributions. At this point, you may not be able to go back and correct the data error. If the error is random and affects only a few cases, then you may want to exclude those cases. However, if the error seems to be systematic and affects a large number of responses, it may be worth finding the source of the error and correcting it.

**Data Step #5:** Identify problems with skip patterns.

Run frequencies and cross-tabulations to verify that skip patterns were followed correctly. If errors seem random and affect only a small number of records (less than 2%), assume the item stem (the question instructing the respondent to go to a different question) is accurate and then correct the response for the incorrect skip. Systematic errors or problems with a significant number of cases should be verified.

If you want to be absolutely certain that skip patterns were followed, you can require that only the children of parents who responded appropriately to the filter question are included when you create the new variables.

**Data Prep Step #6:** Assign missing values.

Missing values should be recoded in some way so that you know not to include them in the analyses. You should designate missing values in the data set in a way that ensures they are omitted when calculating measures. Also, recode the response options of "refused" to a missing value. Examine the number of "I don't know" responses that you get. If this total percentage is less than 2 percent, then you should recode them as missing values.



## STEP 4.3: Integrate updated child enrollment and utilization information

### ➔ What is the purpose of this step?

The purpose of this step to make sure that data for each child are as current as possible when you calculate your PHDS quality indicators and create reports of your findings for key audiences.

#### In this step you will:

- Identify variables that may need to be updated for each sampled child.
- Obtain and merge updated data variables into your analytic variable data set.



### Guidelines and Issues to Consider

- Identify variables that may need to be updated for each sampled child.

As discussed in Steps 2.2, 2.3, and 3.2, many analytic variables are derived from enrollment and utilization data sets and are valuable for analyzing and reporting PHDS findings.

A majority of the PHDS asks the parent to respond about care provided "in the last 12 months." Therefore, you want the variables in the analytic data file to accurately describe the 12 months prior to the date when the parent responded to the survey.

Examples of common variables that need to be updated from the time of sampling include:

- ⇒ Variables related to health care utilization: There is often a lag between when a child has a visit and when it shows up in the data systems. You want to wait to update your analytic file until the data systems are updated and correct for when the parent completed the survey.

*For example: If there is a three-month lag before a visit shows up in your data systems, and the survey was administered in September, then you want to wait until December to update your analytic data file with the information about health care utilization.*



⇒ Variables related to enrollment: Examples of these variables include the primary care provider with whom the child is enrolled.

- ☑ Obtain and merge updated data variables into your analytic variable data set.

Using the child-level unique identifier specified in Step 2.3, you merge the updated data variables into your analytic variable data set. This analytic variable data set will be what you use in Step 5 of this manual.



## **STEP 4.4: Identify and obtain additional descriptive information about the health system to inform analysis**

### **➔ What is the purpose of this step?**

The purpose of this step is to collect additional descriptive information about the health system to inform your analysis. This information should address the specific processes, systems, and resources that relate to the provision of preventive and developmental health care. This information can be used to identify which processes and systems are correlated with higher and poorer quality of care, and then inform policy and quality improvement decisions.

#### **In this step you will:**

- Identify health system characteristics related to the provision of preventive and developmental health care.
- Collect this descriptive information for each unit of analysis.



### **Guidelines and Issues to Consider**

- Identify health system characteristics related to the provision of preventive and developmental health care.

This important step will enhance the value and usefulness of the PHDS data in guiding future policy and improvement efforts. Review the PHDS survey items again and think about specific processes, systems, and resources in place that are related to the topics measured in the PHDS.

Below is a description of tools that can help you gather related descriptive information:

## 1. Office Systems Inventory

**Appendix 10** provides an example of the Office Systems Inventory (OSI) developed through the Healthy Development Collaborative.<sup>1</sup>

The OSI collects descriptive information about specific office systems related to:

- meeting parents' informational needs and addressing their concerns about their child's learning, development, and behavior;
- identifying children at risk through the use of structured developmental and psychosocial assessments and screening at appropriate visits;
- providing strong links to community resources for families who need or want them; and
- promoting optimal parent/child relationships.

The OSI can be completed by the office manager or another office staff member who has the knowledge needed to complete the tool.

The PHDS can then be analyzed by the office-specific OSI scores, and systems yielding higher quality of care scores can be identified.

### **Tip from the Field**

Where possible, you should collect information on the OSI for each office included in your starting sample. For example, if you are using the PHDS to examine quality of care in 10 pediatric offices, then you should collect the OSI for each office.

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<sup>1</sup> The Healthy Development Collaborative was a Commonwealth Fund–supported initiative designed to help primary care practices in Vermont and North Carolina engage families in a partnership to promote positive developmental outcomes for the families' children through the development of improved office systems. The OSI is part of the *Practical Guide for Healthy Development*, a set of materials and tools designed and tested in the Healthy Development Learning Collaborative, a 12-month quality improvement initiative. The OSI is also available at [http://www.cmf.org/usr\\_doc/Office\\_Systems\\_Inventory.pdf](http://www.cmf.org/usr_doc/Office_Systems_Inventory.pdf).

## 2. Posters and Handouts in the Office

Parents can receive information about the topics measured in the PHDS through posters and handouts located in the office of their child's health care provider. These resources may answer parents' questions and meet their informational needs without involving a discussion with their child's health care provider.

Given that the PHDS allows the parent to indicate whether they had their informational needs met, it can be useful to catalog the types of information available to the parent and analyze the PHDS findings using this descriptive information.

**Appendix 11** provides an example of a worksheet that can be used to catalog posters and handouts. The worksheet lists all of the topics that are included in the PHDS and has a column to indicate whether there is a related poster or handout that is provided in the office. It is important to catalog only those educational resources that are readily available to the parent and do not require a discussion with the office staff, as such discussions are included in the PHDS.

The PHDS can then be analyzed by the poster and handout scores, and educational resources correlated with higher quality of care scores can be identified.

## 3. Electronic Medical Records

Some health systems utilize electronic medical records (EMRs). Most EMR programs have standardized forms or templates that can be used by the provider for well-child visits. And most EMR programs allow users to develop standard parent education templates (often called an "After-Visit Summary") that are handed out by the health care provider. The worksheet provided in **Appendix 11** can also be used to catalog standard EMR text and handouts.

- Collect this descriptive information for each unit of analysis.

In Step 2.2 you specified the units of analysis for sampling and analysis. It is important to collect as much descriptive information for each unit of analysis as possible, as it will enhance the useability of your PHDS findings and will help you to identify possible reasons for high and lower performance within each unit of analysis.



## STEP 4.5: Weight your data set to represent your target population

### ➔ What is the purpose of this step?

The purpose of this step is to ensure that your final PHDS data set is representative of the desired sample of children on which you would like to report at the end of your project. Weighting is a standard component of most survey projects, especially if you oversampled for certain population subgroups (e.g., racial groups) or if there are response biases (e.g., some population subgroups are systematically less likely to respond to your survey).

#### In this step you will:

- Clarify your desired population of children to ensure that your findings are representative and determine whether weighted data are required.
- Develop a weighting methodology and construct sampling weights to use during your data analysis.



### Guidelines and Issues to Consider

- Determine whether weighting is required.

The goals of the sampling and survey administration strategy outlined in this manual are:

- 1) To obtain sufficient samples of completed surveys for the three age groups that correspond to the age-specific sections of the PHDS survey (3–9 months, 10–18 months, and 19–48 months).
- 2) To obtain specific units of analysis to focus your measurement effort.

You will need to weight your data if you want to be able to create reports that describe findings across your health system for all children.

Specifically, you will need to weight your data if one or more of the following is true about your PHDS project:

- ⇒ You over-sampled for specific groups.
- ⇒ You used age-stratifications that are not representative of your population.
- ⇒ The responding population is significantly different than your sampled population.

☑ Develop a weighting methodology.

Your survey department or vendor should be able to construct valid weights once you specify the population of children on which you want to report PHDS findings (e.g., all children enrolled in your health system who had at least one-well child visit).

Below are issues and tips to consider as your weighting method is developed.

1. Clarify the baseline population you will use to calculate the weights.

- ❖ Since the children eligible for the PHDS include ONLY those who met the eligibility criteria described in Step 2.2 (e.g., continuous enrollment and visit requirement; parents spoke the languages in which the survey was administered; and families had valid address information), you can only weight data to represent this group of children.
- ❖ A primary purpose of weighting is to ensure the PHDS findings accurately describe care for a group of children. It is important to clarify the group of children for which you want the report to provide generalizable findings.

For example:

- ⇒ Do you want the report to describe care provided across an entire health system? If so, then the baseline population is all eligible children enrolled in the health system.
- ⇒ Do you want the report to provide office-specific descriptive information? If so, office-specific weights will need to be created based on the eligible population of children in each of the pediatric offices.

2. Specify the factors you will use to calculate weights.

- ❖ At a minimum, you will need to weight your data according to age if your general population of children is not distributed in the way you stratified the sample in Step 2.2.
- ❖ To make your PHDS findings representative, you will need to determine the actual age distribution of the population of eligible children, according to the three groups specified in Step 2.2, and weight the data accordingly.
- ❖ Other variables you may need to include in your weighting methodology include:
  - 1) Variables you used for over-sampling such as race, geographic location, and type of health care provider or health plan.
  - 2) Variables for populations that are under- or over-represented in your completed sample due to a known response bias.

## **Step 5: Construct Quality Measures and Analytic Variables**

Step 5 provides detailed technical assistance on how to analyze the PHDS data and create quality measure scores. This section is intended primarily for data analysts. This section is also valuable for project managers to determine scoring models for the PHDS quality measures that best meet the project needs and goals.

The seven sections in this step focus on the construction of the PHDS quality measures and evaluating these measures in different ways (e.g., for specific units of analysis, by subgroups of children, by administrative and utilization data):

- 5.1: Calculate core PHDS quality measures specific to certain aspects of care
- 5.2: Calculate PHDS "got all care" composite measure
- 5.3: Calculate alternate versions of the PHDS quality measures
- 5.4: Construct additional PHDS analytic variables
- 5.5: Evaluate quality measurement results for specific units of analysis
- 5.6: Evaluate quality measurement results for subgroups of children
- 5.7: Review additional analytic tips



## STEP 5.1: Calculate the core PHDS quality measures specific to certain aspects of care

### ➔ What is the purpose of this step?

The purpose of this step is to construct child-level quality measures based on the PHDS responses. The scores can then be analyzed for specific groups.

#### In this step you will:

- Learn about the core PHDS quality measures.
- Recode item-level survey responses for each child.
- Calculate child-level, composite PHDS quality measures.
- Specify and assign "threshold level of quality" cut-points to each measure and calculate child-level versions of these quality measures.



### Guidelines and Issues to Consider

- Learn about the core PHDS quality measures.

There are 12 core PHDS quality measures.

Each measure summarizes information from between one and 18 individual PHDS items and assesses individual components of recommended preventive and developmental care.<sup>1</sup> The PHDS quality measures are scored on a 0–100 scale, where 0 indicates that recommended care is not received and 100 indicates that all aspects of care were received.

It is important to remember that the ProPHDS is a reduced-item version of the PHDS, therefore not all of the quality measures are in this shortened tool.

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<sup>1</sup> More information about the reliability and validity quality measures based on the PHDS items can be found in the *Pediatrics* articles and Commonwealth Fund report listed in Step 1.



**The 13 core PHDS quality measures are:**

1. Anticipatory guidance and parental education provided by doctors or other health care providers.
2. Assessment of parent concerns about their child's learning, development, and behavior.
3. Provision of specific information to address parental concerns.
4. Follow-up for children at risk for developmental, behavioral, or social delays.
5. Administration of a standardized, parent-completed developmental and behavioral screening tool.
6. Assessment of psychosocial issues in the family.
7. Assessment of smoking, substance abuse, and safety in the family.
8. Provision of family-centered care that respects, listens to, and partners with parents.
9. Coordination of care for children requiring multiple types of health care services or seeing more than one health care provider (items included in the PHDS only).
10. Helpfulness of care provided to parents (items included in the PHDS only).
11. Effect of care provided on parental confidence (items included in the PHDS only).
12. Provision of written or other types of health information to parents on caring for their child, preventing injuries, and ensuring optimal development (items included in the PHDS only).
13. Provision of information about resources in the community for parents.

**Table 5.1** provides a detailed description of the individual items that go into each of the 12 quality measures.

**Table 5.1: PHDS Items Included in Each Quality Measurement Topic**

Quality Measure	Topics Included in Quality Measure	PHDS/ ProPHDS- Survey Items	Number of Individual Items
<b>1. Anticipatory Guidance and Parental Education from Doctor or Other Health Care Providers (AGPE)<sup>2</sup></b>	<p>Assesses whether a core subset of recommended anticipatory guidance topics were discussed with child's health provider and if not, whether the parent wished topics had been discussed <u>or</u> if he/she already had information about the topics and did not need to discuss them.</p> <p><i>Age-Specific Topics:</i></p> <p><b>3–9 Months:</b> What parents can do to help their child grow and learn, behaviors to expect, breastfeeding, food and feeding, sleeping positions and sleep areas, night waking and fussing, how child communicates, what child understands, how child responds to others, burn avoidance, car seats, house safety, importance of picture books/reading, TV watching, and childcare.</p>	<p><b>Q7, Q8/ Q1, Q2</b></p>	<p>16</p>
	<p><b>10–18 Months:</b> What parent can do to help child grow and learn, behaviors to expect, vitamins and food, bedtime routines, words and phrases child uses and understands, preventing bottle mouth, child's independence, guidance and discipline techniques, parental education about toilet training, car seats, house safety, what to do if child swallows certain kinds of poisons, reading to child, TV watching, childcare.</p>	<p><b>Q9, Q10/ Q1, Q2</b></p>	<p>17</p>
	<p><b>19–48 Months:</b> What parent can do to help child grow and learn, behaviors to expect, nutrition and eating habits, bedtime routines, toilet training, words and phrases child uses and understands, how child gets along with others, guidance and discipline techniques, ways to teach child about dangerous situations, car seats, house safety, what to do if child swallows certain kinds of poisons, reading to child, TV watching, childcare.</p>	<p><b>Q11, Q12/ Q1, Q2</b></p>	<p>15</p>

<sup>2</sup> The items related to anticipatory guidance and parental education are different depending on the age of the child and as described in Step 2.4.

**Table 5.1: PHDS Items Included in Each Quality Measurement Topic (Continued)**

Quality Measure	Topics Included in Quality Measure	PHDS/ ProPHDS- Survey Items	Number of Individual Items
2. <b>Ask About Concerns</b>	Assesses whether providers ask parents whether he/she has concerns about child's learning, development, and behavior.	Q21/Q5	1
3. <b>Address Parental Concerns</b>	Assesses whether parents with concerns about their child's learning, development, and behavior received specific information addressing their concerns. (Note: Items derived from the PEDS© used to identify concerned parents [PHDS Q18-Q20, ProPHDS Q4])	Q22/Q6	1
4. <b>Follow-Up for Children at Risk for Delays</b>	Assesses whether children who are determined to be at significant risk for developmental, social, or behavioral delays (Note: Items derived from the PEDS© used to identify children at sig. risk [PHDS Q18–Q20, ProPHDS Q4])* had appropriate follow-up health care. Follow-up items include testing of child's learning development and behavior, referral to another doctor or speech/language testing, and/or whether a doctor or other health provider noted a concern that should be watched carefully.	Q23/Q7	4
5. <b>Administration of a Standardized Developmental and Behavioral Screening (SDBS) Tool</b>	Whether the child's health care provider administered a parent-completed standardized developmental and behavioral screening tool.	Q26, Q26a, Q26b/ Q9, Q9a, Q9b	1 stem, 2 follow-up
6. <b>Assessment of Psychosocial Issues in the Family</b>	Assesses whether health care providers asked the parent about their own psychosocial well-being, including depression, emotional support, changes or stressors in the home, and how parenting is working. (Note: This can be through the use of a parent-completed questionnaire)	Q27 c,d; Q28 c,d/ Q10 b-d	4/3
7. <b>Assessment of Smoking, Substance Abuse, and Safety in the Family</b>	Assesses whether health care providers asked the parent about smoking, substance abuse, safety, and firearms in the home. (Note: This can be through the use of a parent-completed questionnaire)	Q27 a,b; Q28 a,b/ Q10 a,e	4/2
8. <b>Family-Centered</b>	Parent reports that child's health care provider delivers care in a family-centered manner, e.g., understands		

<b>Care</b>	specific needs of child and concerns of parent, builds confidence in the parent, explains things in way the parent can understand, and shows respect for a family's values, customs, and how they prefer to raise their child.	<b>Q13, Q14/ Q3</b>	10/5
<b>9. Care Coordination</b>	Assesses whether children requiring more than one type of health care service received needed help coordinating care.	<b>Q5a/NA</b>	1
<b>10. Helpfulness of Care Provided</b>	Parent report of how helpful information from child's health care providers was in specific areas of parenting such as understanding child's behavior, protecting child from injuries, and helping the parent learn to meet their own needs.	<b>Q15/NA</b>	4
<b>11. Effect of Care on Parental Confidence</b>	Parent report on the effect of care on their confidence in: doing things for child to help him/her grow and learn, protecting child from injuries, addressing special concerns, and managing parenting responsibilities.	<b>Q16/NA</b>	4
<b>12. Health Information</b>	Assesses whether information was provided outside/inside the health care provider's office (mail, clinic pamphlets, videos, etc.) on the following: safety, health care utilization, developmental information.	<b>Q17/NA</b>	3
<b>13. Provision of information about resources in the community for parents</b>	Assesses whether information was provided by the child's doctor or other health providers about resources in the community for the parent.	<b>Q8i/Q2i Q10i/Q2i Q12i/Q2i</b>	1

\*See Table 5.4 for information on determining if a child is at high or moderate risk for developmental, behavioral, or social delays.

For each child, recode item-level survey responses.

The quality measures are scored for each child whose parent completed the survey. The first step in creating the quality measure is to recode each item that goes into the quality measure into a 0–100 value indicating whether quality of care is received.

### Tip from the Field

**CAHMI recommends** that you recode each individual item into a 0–100 value rather than transform the composite quality measure to a 0–100 value. We recommend this approach because many users will examine item-level findings in addition to the quality measure findings (e.g., the number of children whose parents were asked if they were experiencing symptoms of depression).

The following is the recommended process for recoding the individual survey items:

#### **Recoding Step 1:** Map Items to Quality Measures

Map the items to each of the corresponding quality measures, as shown in **Table 5.2** on the following page. Remember: If you added questions and re-numbered the survey, the question numbers in your survey may differ.

#### **Recoding Step 2:** Create New Items and Recode Response Options Used to Score Quality Measures

Assign a quantitative value to each survey item response options (e.g., "yes" vs. "no"). Recode the response options for each survey item used in a quality measure so that the values fall between 0 and 100, where zero indicates quality health care was not received and 100 indicates quality health care was received. Be sure not to recode the original items in the data set. Instead, you should create new items in case you make a mistake. Use Table 5.2 as a guide to rescore each of the items. Missing responses are NOT given a valid score and are NOT included in the calculation of the quality measure.

**Important Note:** There are two versions shown for how to score the anticipatory guidance and parental education (AGPE) quality measure presented in **Table 5.2**.

- Version A is the average proportion of recommended topics discussed by the child's health care provider. This measure answers the question of how many recommended AGPE topics on average are discussed and whether parent questions were answered.
- Version B is the average proportion of topics for which the parents had their informational needs met. This measure assesses the number of topics for which the parent reported "Yes, the topic was discussed," or "No, the topic was not discussed, but I wished it had been discussed." This measure answers the question of whether parents are having their informational needs met on recommended anticipatory guidance and parental education topics.

The version you decide to use should be based on your research questions and goals for the study.

**CAHMI recommends** that you create both versions, as each is valid and valuable and each one answers different questions about the level of care provided.

**Table 5.2: Item-Level Recodes for Core PHDS Quality Measures**

Quality Measure	PHDS/ ProPHDS	Original Response Options	Value Assigned to Response		
<p><b>1. Anticipatory Guidance and Parental Education from Doctor or Other Health Care Providers</b></p> <p><i>Version A: Average proportion of topics parents report were <u>discussed</u>.</i></p>	<p><b>Q7, Q8, Q9, Q10, Q11, Q12/</b></p> <p><b>Q1, Q2</b></p>	<p>1=Yes, the topic was discussed</p> <p>2=Yes, the topic was discussed but my questions were not answered completely</p>	<p><b>100</b></p>		
		<p>3=No, but I wish we had talked about that</p> <p>4=No, but I already had information about the topic and did not need to talk about it any more</p>	<p><b>0</b></p>		
		<p><i>Version B: Average proportion of topics parents had their <u>informational needs met</u>.</i></p>	<p>Same as above</p>	<p>1=Yes, the topic was discussed</p> <p>4=No, but I already had information about the topic and did not need to talk about it any more</p>	<p><b>100</b></p>
				<p>2= Yes, the topic was discussed but my questions were not answered completely</p> <p>3= No, but I wish we had talked about that</p>	<p><b>0</b></p>
<p><b>2. Ask About Parental Concerns About Their Child's Learning, Development, and Behavior</b></p>	<p><b>Q21/</b></p> <p><b>Q5</b></p>			<p>1 = Yes</p>	<p><b>100</b></p>
		<p>2 = No</p>	<p><b>0</b></p>		

**Table 5.2: Item-Level Recodes for Core PHDS Quality Measures (Continued)**

3. Address Parental Concerns	Q22/  Q6	Only recode the item for children whose parents responded "yes" or "a little" to one or more of the PEDS© items. See Table 5.1 for more detail.
		1 = Yes <b>100</b>
		2 = No <b>0</b>
4. Follow-Up for Children at Risk for Developmental Delays	Q23/  Q7	Only recode the items for children identified as at high or moderate risk for delays based on the PEDS© items. See text following Table 5.2 for additional specifications.
		1 = Yes <b>100</b>
		2 = No <b>0</b>
5. Administration of a Standardized Developmental and Behavioral Screening (SDBS) Tool	Q26, Q26a, Q26b/  Q9, Q9a, Q9b	1 = Yes <b>100</b>
		2 = No <b>0</b>
6. Assessment of Psychosocial Issues in the Family	Q27 c,d; Q28 c,d/  Q10 b-d	1 = Yes <b>100</b>
		2 = No <b>0</b>
7. Assessment of Smoking, Substance Abuse, and Safety in the Family	Q27 a,b; Q28 a,b/  Q10 a,e	1 = Yes <b>100</b>
		2 = No <b>0</b>
8. Family-Centered Care	Q13, Q14/  Q3	1 = Never <b>0</b>
		2 = Sometimes <b>0</b>
		3 = Usually <b>100</b>
		4 = Always <b>100</b>
9. Care Coordination	Q5a/  NA	1 = Yes <b>100</b>
		2 = No <b>0</b>
		3 = Child did not get care from different providers or use more than one service <i>Missing</i>
10. Helpfulness of Care Provided	Q15/  NA	1 = Very helpful <b>100</b>
		2 = Helpful <b>100</b>
		3 = Somewhat helpful <b>0</b>
		4 = Not at all helpful <b>0</b>

		5 = We did not discuss	<i>Missing</i>
<b>11. Effect of Care Provided on Parental Confidence</b>	<b>Q16/</b>	1= I feel a lot more confident	<b>100</b>
	<i>NA</i>	2= I feel a little more confident	<b>100</b>
		3= I do not feel more or less confident	<b>0</b>
		4= I feel less confident	<b>0</b>
<b>12. Health Information</b>	<b>Q17/</b>	1 = Yes	<b>100</b>
	<i>NA</i>	2 = No	<b>0</b>
<b>13. Provision of information about resources in the community for parents</b> <i>Version A: Resources Provided</i>	<b>Q8i/Q2i</b>	1=Yes, the topic was discussed	<b>100</b>
	<b>Q10i/Q2i</b>	2=Yes, the topic was discussed but my questions were not answered completely	
	<b>Q12i/ Q2i</b>	3=No, but I wish we had talked about that	
		4=No, but I already had information about the topic and did not need to talk about it any more	<b>0</b>
<i>Version B: Parents had their informational needs about resources in the community met.</i>	Same as above	1=Yes, the topic was discussed	
		4=No, but I already had information about the topic and did not need to talk about it any more	<b>100</b>
		2= Yes, the topic was discussed but my questions were not answered completely	<b>0</b>
		3= No, but I wish we had talked about that	

#### **Additional Specifications for Item-Level Recodes for Measure #4:**

##### *Follow-Up for Children at Risk for Developmental, Behavioral or Social Delays*

As noted in Table 5.2, this measure (and the individual item-level recodes) is scored only for children identified as at significant risk (high or moderate) for developmental, behavioral, or social delays. Children are identified as "at risk" based on parents' responses to the Parents' Evaluation of Developmental Status© items included in the PHDS/ProPHDS. The PHDS



includes nine items from the PEDS tool; the ProPHDS includes six items from the PEDS tool.

The scoring algorithm presented below is adapted from the Parents' Evaluation of Developmental Status© specifications and approved by Frances Glascoe, Ph.D., for identifying a denominator of children for whom follow-up care should have been received.

Overview of the scoring algorithm for the adapted PEDS© items in the PHDS:

- ⇒ Specific concerns parents have about their children at specific ages can be an indication of a child's risk for developmental, behavior or social delays.
- ⇒ Children whose parents have one or more "indicator" concerns (parent said "yes" or "a little") are identified as being at significant risk. Children whose parents have noted concerns for only one indicator item are at moderate risk for delays. Children whose parents note two or more concerns about indicator items are at high risk for delays.

**Table 5.3** below describes the age-specific "indicator" concerns for the PEDS© items in the PHDS and ProPHDS:

**Table 5.3: Risk Category based on the PEDS© Items in the PHDS/ProPHDS**

Age of Child*	High Risk	Moderate Risk	Low Risk	No Risk
3–17.99 mos.	Parent responded "yes" or "a little" to <b>two or more</b> of the following: <ul style="list-style-type: none"> <li>➤ 18a, 18b (PHDS)</li> <li>➤ 4a, 4b (ProPHDS)</li> </ul>	Parent responded "yes" or "a little" to <b>one</b> of the following: <ul style="list-style-type: none"> <li>➤ 18a-b, 20a with any other concerns for any other PEDS item (PHDS)</li> <li>➤ 4a, 4b, and 4f with any other concern for any other PEDS item (ProPHDS)</li> </ul>	Parent responded "yes" or "a little" to <b>one</b> of the following: <ul style="list-style-type: none"> <li>➤ 18c, 19a-c, 20b-c, 20a only (PHDS)</li> <li>➤ Q4c, 4d, 4f only (ProPHDS)</li> </ul>	Parent responded "not at all" to all PEDS© items
18–35.99 mos.	Parent responded "yes" or "a little" to <b>two or more</b> of the following: <ul style="list-style-type: none"> <li>➤ 18a-c (PHDS)</li> <li>➤ 4a, 4b, 4c (ProPHDS)</li> </ul>	Parent responded "yes" or "a little" to <b>one</b> of the following: <ul style="list-style-type: none"> <li>➤ 18a-c (PHDS)</li> <li>➤ 4a, 4b, 4c (ProPHDS)</li> </ul>	Parent responded "yes" or "a little" concern to <b>one</b> of the following: <ul style="list-style-type: none"> <li>➤ 19 a-c, 20 a-c</li> <li>➤ 4d, 4e, 4f (ProPHDS)</li> </ul>	Parent responded "not at all" to all PEDS© items
36–48 mos.	Parent responded "yes" or "a little" to <b>two or more</b> of the following: <ul style="list-style-type: none"> <li>➤ 18a-c, 19b (PHDS)</li> <li>➤ 4a, 4b, 4c, 4d (ProPHDS)</li> </ul>	Parent responded "yes" or "a little" to <b>one</b> of the following: <ul style="list-style-type: none"> <li>➤ 18a-c, 19b (PHDS)</li> <li>➤ 4a, 4b, 4c, 4d (ProPHDS)</li> </ul>	Parent responded "yes" or "a little" to <b>one</b> of the following: <ul style="list-style-type: none"> <li>➤ 19a, 19c, 20a-c (PHDS)</li> <li>➤ 4e, 4f (ProPHDS)</li> </ul>	Parent responded "not at all" to all PEDS© items

### Important Note

This four category age breakout is different than the age breakout for the age-specific versions of the survey (3–9.99 months, 10–18.99 months, 19–45.99 months). Therefore, you need to be sure to use the child's age, in months, that was collected at the time of sampling and described in Step 2.3.

- Calculate child-level, composite PHDS quality measures.

Once you have finished recoding the individual items, you are ready to use these variables to calculate a composite score for each quality measure summarizing the item-level scores for each child included in the study.

The scoring methods used for each of the quality measures are described in Table 5.3 and followed by examples so you can see exactly how the measure is calculated.

**CAHMI recommends** that you only score a quality measure for those children whose parents answered at least **half** of the items that are included in the quality measure.

If a child's parent answered less than half of the items in that measure, their score is considered missing.

If a measure has an odd number of items, round up.

**Table 5.4: Scoring Algorithm for Core PHDS Quality Measures**

Quality Measure	Type of Measure	What the Measure Tells You	How Quality Measure Is Calculated <i>(Note: For all measures, the denominator only includes those who answered at least half of the items in the scale)</i>
<p><b>1. Anticipatory Guidance and Parental Education (AGPE)</b></p> <p><i>Version A: Average proportion of topics parents report were <u>discussed</u>.</i></p>	<p><b>Mean</b></p>	<p>Avg. proportion of rec. topics discussed.</p>	<p><b>Numerator:</b> Number of "yes, item was discussed" responses.</p> <p><b>Denominator:</b> Number of items parent answered.</p>
<p><i>Version B: Average proportion of topics on which parents had their <u>informational needs met</u>.</i></p>	<p><b>Mean</b></p>	<p>Avg. proportion of rec. topics on which parents had their informational needs met.</p>	<p><b>Numerator:</b> Number of "yes, item discussed" or "no, but had info and did not want to discuss it" responses.</p> <p><b>Denominator:</b> Number of items parent answered.</p>
<p><b>2. Ask About Parental Concerns About Their Child's Learning, Development, and Behavior</b></p>	<p><b>Proportion</b></p>	<p>Proportion of children whose parents were asked about their concerns.</p>	<p><b>Numerator:</b> A "yes" response.</p> <p><b>Denominator:</b> Number of items parent answered.</p>
<p><b>3. Address Parental Concerns</b></p>	<p><b>Proportion</b></p>	<p>Proportion of children whose concerned parent received info.</p>	<p><b>Numerator:</b> A "yes" response.</p> <p><b>Denominator:</b> Number of items parent answered.</p>

**Table 5.4: Scoring Algorithm for Core PHDS Quality Measures (Continued)**

<p><b>4. Follow-Up for Children at Risk for Developmental, Behavioral or Social Delays</b></p>	<p><b>Proportion</b></p>	<p>Proportion of children at risk who received follow-up care.</p>	<p><b>Numerator:</b> Risk-specific scoring. Moderate Risk: Parent said "yes" at least once to any of follow-up questions (a-d). High Risk: Parent said "yes" to a, b, or d. <b>Denominator:</b> Parent who responded to 2/4 of the items and whose child is at high/moderate risk.</p>
<p><b>5. Administration of a Standardized Developmental and Behavioral Screening (SDBS) Tool</b></p>	<p><b>Mean</b></p>	<p>Proportion of children whose parents completed an SDBS.</p>	<p><b>Numerator:</b> Whether parent said yes to all three items. <b>Denominator:</b> Parent responded to all three items.</p>
<p><b>6. Assessment of Psychosocial Well-Being of Parent(s) in the Family</b></p>	<p><b>Mean</b></p>	<p>Avg. proportion of rec. topics assessed.</p>	<p><b>Numerator:</b> Number of "yes, item was discussed" responses. <b>Denominator:</b> Number of items parent answered.</p>
<p><b>7. Assessment of Smoking and Substance Use in the Family</b></p>	<p><b>Mean</b></p>	<p>Avg. proportion of rec. topics assessed.</p>	<p><b>Numerator:</b> Number of "yes, item was discussed" responses. <b>Denominator:</b> Number of items parent answered.</p>
<p><b>8. Family-Centered Care (FCC)</b></p>	<p><b>Mean</b></p>	<p>Avg. proportion of rec. aspects of FCC regularly received.</p>	<p><b>Numerator:</b> Number of "usually or always" responses. <b>Denominator:</b> Number of items parent answered.</p>
<p><b>9. Care Coordination (CC)</b></p>	<p><b>Proportion</b></p>	<p>Proportion of children whose parents received CC.</p>	<p><b>Numerator:</b> A "yes" response. <b>Denominator:</b> Number of items parent answered.</p>

**Table 5.4: Scoring Algorithm for Core PHDS Quality Measures (Continued)**

<p><b>10. Helpfulness of Care Provided</b></p>	<p><b>Mean</b></p>	<p>Avg. proportion of topics for which parent reported care was helpful or very helpful.</p>	<p><b>Numerator:</b> Number of "very helpful–helpful" responses. <b>Denominator:</b> Number of items parent answered.</p>
<p><b>11. Effect of Care Provided on Parental Confidence</b></p>	<p><b>Mean</b></p>	<p>Avg. proportion of topics parent reported positive influence on confidence.</p>	<p><b>Numerator:</b> Number of "I feel a lot more confident–I feel a little more confident" responses. <b>Denominator:</b> Number of items parent answered.</p>
<p><b>12. Health information</b></p>	<p><b>Mean</b></p>	<p>Avg. proportion of topics health info. received.</p>	<p><b>Numerator:</b> Number of "yes, item was discussed" responses. <b>Denominator:</b> Number of items parent answered.</p>
<p><b>13. Provision of information about resources in the community for parents</b></p>	<p><b>Proportion</b></p>	<p>Proportion of children whose provide discussed resources in the community (version A) OR Proportion of children whose parents had their information needs met on resources in the community (version B).</p>	<p><b>Version A:</b> <b>Numerator:</b> Number of "yes, item was discussed" responses. <b>Denominator:</b> Number of items parent answered <b>Version B:</b> <b>Numerator:</b> Number of "yes, item discussed" or "no, but had info and did not want to discuss it" responses. <b>Denominator:</b> Number of items parent answered.</p>

### Example 5.1: Health Information Quality Measure

Here is the scoring for Joel, Anne, and Steve for "Health Information." This quality measure includes items 17 a–c.

Their responses were as follows:

Joel:	17a. Yes	17b. No	17c. Yes
Anne:	17a. Yes	17b. Yes	17c. Yes
Steve:	17a. Yes	17b. Missing	17c. Missing

Their responses are given the following values:

Joel:	17a. 100	17b. 0	17c. 100
Anne:	17a. 100	17b. 100	17c. 100
Steve:	17a. 100	17b. No value	17c. No value

Therefore, their scores on the Quality Measure are:

$$\text{Joel: } \frac{\text{Numerator}}{\text{Denominator}} = \frac{100 + 0 + 100}{3} = \frac{200}{3} = \underline{\underline{66.7}}$$

$$\text{Anne: } \frac{\text{Numerator}}{\text{Denominator}} = \frac{100 + 100 + 100}{3} = \frac{300}{3} = \underline{\underline{100}}$$

Steve: No score since he did not answer at least two of the three items included in the quality measure.

### Example 5.2: Helpfulness of Care Provided

Here is the scoring for Ted's answers to the items for "Helpfulness of Care Provided." This measure includes items 15a-d.

Responses and corresponding values:

15a. Somewhat helpful	100
15b. Very helpful	100
15c. Not at all helpful	0
15d. Helpful	100

Ted's score for the quality measure is:

$$\frac{\text{Numerator}}{\text{Denominator}} = \frac{(100 + 100 + 0 + 100)}{4} = 75$$



**Example 5.3: For Follow-Up Children  
at Risk of Developmental, Behavioral, or Social Delays**

Here is the scoring for Jack, Janet, and Chris for "Follow-Up for Children at Risk of Developmental Delay." This measure is comprised of items 24a–d in the PHDS (7 a–d in the ProPHDS) and is scored only for those children who have been identified as being at risk for a developmental delay.

Jack and Janet are both at high risk for developmental delay. Chris and Larry are both at moderate risk for developmental delay.

Their responses were as follows:

Jack (high risk):	24a. Yes	24b. No	24c. Yes	24d. No
Janet (high risk):	24a. No	24b. No	24c. Yes	24d. No
Chris (mod. risk):	24a. No	24b. No	24c. No	24d. No
Larry (mod. risk):	24a. Yes	24b. No	24c. Yes	24d. Missing

Therefore, their scores on the quality measure are:

Jack: **100** (answered "yes" to at least one of the necessary items)

Janet: **100** (answered "yes" to both 24c and 24e)

Chris: **0** (did not answer "yes" to any of the items)

Larry: **100** (answered "yes" to at least one item, even though one item was missing)

- Specify and assign 'threshold level of quality' cut-points to each measure and calculate child-level versions of these quality measures.

Once you have calculated the core PHDS quality measures, it is helpful to identify those children who received a threshold level of care.

The threshold scoring method creates a discrete, binomial measure for each aspect of care and assesses how **many children** received a certain level of an aspect of care.

The quality measures that are proportions are already scored in a way that indicates children who did or did not receive the aspect of care (Measures 2, 3, 4, 5, and 9). The threshold scoring method **recodes the mean quality measures** into a binomial variable, where 100 equals children who received a sufficient level of quality of care and 0 is children who received less than the threshold level of care specified.

**Table 5.4** provides a description of threshold measures that can be created for each of the mean, core PHDS quality measures. These thresholds are based on the following: 1) validity analyses of the cut points for these measures as related to other indicators of health care quality in the PHDS, 2) consensus obtained in interviews with frontline health care providers, system leaders, and advisors to CAHMI. Additional information about

these interviews and the threshold can be found at [www.cahmi.org](http://www.cahmi.org). Lastly, a thorough description of threshold measures based on PHDS items can be found in the Bethell et al. article, "Measuring the quality of preventive and developmental services for young children: national estimates and patterns of clinicians' performance" (*Pediatrics*. 2004 Jun;113(6 Suppl):1973–83).

### **Tip from the Field**

**CAHMI recommends** that you determine the "threshold" level of care based on your own project goals. We recommend that you conduct key stakeholder interviews about the scoring approach you plan to use for each quality measure.

**Table 5.5: Scoring Algorithm for "Threshold Version" of Measures**

Quality Measure	Threshold Score for Quality Measure	Level of Quality Care Threshold Scoring Represents
<p><b>1. Anticipatory Guidance and Parental Education (AGPE)</b></p> <p><i>Version A: Average proportion of topics parents report were <u>discussed</u>.</i></p>	<p>Mean <math>\geq</math> 80</p>	<p>Children whose parents responded that the topic was discussed 80% or more of the AGPE items.</p>
<p><i>Version B: Average proportion of topics on which parents had their <u>informational needs met</u>.</i></p>	<p>Mean=100</p>	<p>Children whose parents had their informational needs met on all AGPE items.</p>
<p><b>2. Ask About Parental Concerns About Their Child's Learning, Development, &amp; Behavior</b></p>	<p>Already a proportion measure</p>	<p>Children whose parents were asked about their concerns.</p>
<p><b>3. Address Parental Concerns</b></p>	<p>Already a proportion measure</p>	<p>Children with concerned parents who got information.</p>
<p><b>4. Follow-Up for Children at Risk for Developmental, Behavioral, or Social Delays</b></p>	<p>Already a proportion measure</p>	<p>Children at risk for developmental, behavioral, or social delays who received follow-up care.</p>
<p><b>5. Administration of a Standardized Developmental and Behavioral Screening (SDBS) Tool</b></p>	<p>Already a proportion measure</p>	<p>Children whose parents completed an SDBS.</p>
<p><b>6. Assessment of Psychosocial Well-Being of Parent(s) in the Family</b></p>	<p>Mean <math>&gt;</math> 0</p>	<p>Children whose parents were assessed for 1 or more topics related to psychosocial well-being.</p>
<p><b>7. Assessment of Smoking and Substance Use in the Family</b></p>	<p>Mean <math>&gt;</math> 0</p>	<p>Children whose parents were assessed for one or more topics related to smoking, substance abuse or safety.</p>
<p><b>8. Family-Centered Care (FCC)</b></p>	<p>Mean = 100.</p>	<p>Children whose parents routinely receive all aspects of family-centered care.</p>

**Table 5.5: Scoring Algorithm for "Threshold Version" of Measure (Continued)**

<b>9. Care Coordination (CC)</b>	Already a proportion measure	Children whose parents received CC.
<b>10. Helpfulness of Care Provided</b>	Mean = 100	Children whose parents reported care provided as helpful or very helpful.
<b>11. Effect of Care Provided on Parental Confidence</b>	Mean = 100	Children whose parents reported care had a positive influence on their confidence.
<b>12. Health information</b>	Mean = 100	Children whose parents got all health information.
<b>13. Provision of information about resources in the community for parents</b>	Proportion=100	Children whose health care providers discussed resources in the community (version A) OR whose parents had their informational needs met on resources in the community (version B).



## STEP 5.2: Calculate PHDS "Got all care" composite measure

### ➔ What is the purpose of this step?

The purpose of this step to specify and construct a composite "got all care measure" that summarizes how many children received all of the individual components of care measured in the PHDS. This measure represents what Thomas Nolan, Ph.D., and Donald Berwick, M.D., M.P.P., refer to as an "All or None" measure.<sup>1</sup>

#### In this step you will:

- Learn about the value of a composite "got all care" measure.
- Learn about options for creating a composite "got all care" measure.
- Consider key methodological issues in calculating a "got all care" measure.
- Specify and calculate the "got all care" measure to be used for your project.

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<sup>1</sup> Thomas Nolan, Donald Berwick. All or None Measurement Raises the Bar on Performance .*JAMA*. March 8, 2006- Vol 295, No (10).



## Guidelines and Issues to Consider

- ☑ Learn about the options for creating a composite "got all care" measure.

As explained in "All or Nothing," the *Journal of the American Medical Association* article by Nolan and Berwick, composite measures describing how many children got all aspects of recommended care are powerful because they:

1. Reflect the interests and likely the desires of patients.
2. For the PHDS, reflect the comprehensive care recommended.
3. Foster a system perspective.
4. Are sensitive to assessing improvements.

However, for the "got all care" composite measure to be meaningful and useful, your project team needs to think critically about a scoring approach that maps to the standard and level of care believed to be optimal and achievable in your system.

Specifically, your project team needs to consider the following before constructing a "got all care" composite measure:

⇒ **Your project goals**

*For example: Will you use the "got all care" composite measure as part of a pay-for-performance effort? If so, you will want to ensure that each individual PHDS measure included in your "got all care" measure meets your standards for pay for performance and is achievable.*

⇒ **Outcomes you hope to achieve**

*For example: The PHDS focuses on many aspects of care. Perhaps your goal is to have providers initially focus their quality improvement efforts on specific aspects of the PHDS. Therefore, you may want to include only those aspects of care in the "got all care" measure.*

⇒ **The perspective of the providers being assessed**

*For example: You want providers to have buy-in on the "got all care measure" so that it is informative and is used to improve care. What version of the anticipatory guidance and parental education measure is most valued by providers in your health system?*

**Tip from the Field**

**CAHMI recommends** you conduct key stakeholder interviews about the "got all care" composite measure and the individual measures and scoring approach you plan to use. In past projects, this has been an important component of the project to ensure that there is buy-in from various stakeholders about the level of care that is expected.

- Learn about options for creating a composite "got all care" measure.

**Table 5.4** describes the individual, "threshold" versions of the core PHDS quality measures. Because the composite "got all care" variable is a discrete variable that indicated those who "got all aspects of care" versus those who did not, it is valuable to use the threshold versions of the specific aspect of care measures.

The first step in creating your "got all care" measure is determining which of the individual, topic-specific measures you will use.

Below are some options to consider:

- ⇒ **Option 1:** Include all of the measures listed in Table 5.4.
- ⇒ **Option 2:** Include only those measures that are anchored to specific aspects of care recommended. (This option does NOT include the measures focused on the experience of care such as *Family-Centered Care* and *Helpfulness of Care* quality measures.)
- ⇒ **Option 3:** Include only those measures that are anchored to specific aspects of care recommended and that are dependent on the health care provider. (This option does NOT include the *Family Centered Care*, *Helpfulness of Care*, and *Health Information* measures.)
- ⇒ **Option 4:** Include only those measures that are anchored to specific aspects of care recommended and are applicable to every child in the survey. (This option does NOT include the *Family Centered Care*, *Helpfulness of Care*, *Health Information*, *Give Concerned Parents Information*, *Follow-Up for Children at Risk* measures.)
- ⇒ **Option 5:** Include only those measures that you plan to address with targeted quality improvement efforts and/or that you will use for pay-for-performance efforts.

Once you have identified what measures you will include in your "got all care" measure, you then need to specify the version of the individual, topic-specific measures you intend to use. Specifically, you need to clarify the following:

- ⇒ Anticipatory Guidance and Parental Education (AGPE) quality measure: Will you use Version A or Version B? Version A should be used if the goal is for the provider to discuss all recommended AGPE topics. Version B should be used if the goal is to ensure that parents informational needs are met on all topics.

The last step is to then calculate, for each child, how many received all components of care (i.e., scored 100 on every measure). The "got all care" quality measure should be scored ONLY for children who have a score for each of the individual measures. (Important Note: If you decide to include measures that are only applicable to certain children (e.g., *Follow-up for Children at Risk*), be sure that you only score the variable for those quality measures the child should have received.)

Therefore, the "got all care" variable is a discrete, binomial variable:

100 = Child received all aspects of care

0 = Child did not receive one or more aspects of care



In the past, we have calculated the "got all care" variable through one of two methods:

- 1) Create a **count variable** across the individual threshold measures specified in Table 5.4. Recode the count variable so that those children who have the highest count possible get a 100 and those children with less than the highest score get a 0.

*Important Note: This count variable is a valuable measure on its own, providing information about the range of individual components of care received.*

- 2) Create a **mean variable** across the individual threshold measures. Then recode the mean variable so that those children with a mean score of 100 get a 100 and those with a mean score of less than 100 get a 0.

*Important Note: This mean variable is a valuable measure on its own, providing information about the mean number of individual components of care received.*

#### **Example 5.4: "Got All Care" Measure**

The **Healthy Development Collaborative** used the ProPHDS to evaluate their quality improvement efforts. Their trainings focused on four aspects of developmental care:

- 1) Anticipatory guidance and parental education (AGPE).
- 2) Asking about parental concerns.
- 3) Assessing the parent for depression.
- 4) Assessing the parent for other issues.

Participating practices were asked to focus on at least three out of four components of care for their improvement efforts.

A "got all care" quality measure was created to identify how many children received at least three out of four components of care.

They used the following "threshold" versions of the measures:

- 1) Child had parents with their information needs met on AGPE.
- 2) Child's parent was asked about his/her concerns.
- 3) Child's parent was asked about whether he/she felt depressed.
- 4) Child's parent was asked about one or more of the items in measures 6 and 7.

A count variable was created across these four "threshold" versions of care. Children who received at least three-fourths of the components of care were identified as having "got all" components of care focused on in the Healthy Development Collaborative.

- Consider other key issues in calculating "got all care" composite measure.

There are many options for the "got all care" measure, and the previous section focused on some of the methodologies recommended by CAHMI. Again, the value of the "got all care" is its ability to provide meaningful and relevant summary information. Therefore, we know that it is important to explore various versions of the measure to be sure that it matches with your project goals.

Below are two additional issues you may consider in creating a "got all care" quality measure that are often encountered by users of the PHDS:

- **Mean-based "got all care" measure:** The methodology described earlier used the discrete, threshold versions of the core PHDS quality measures (Table 5.4). Another option is to take the mean of the threshold versions and identify a specific number of individual components of care that should have been received for a child to have received a sufficient level of care. For example, you may feel that if the child received 10 of 12 individual components of care, this would meet a sufficient level of quality. A third methodology is to calculate the sum of the mean versions of the quality measures (Table 5.3), and to determine a "cut off point" for the sum value that equals a sufficient level of quality.
- **Weighting:** The methodology described by CAHMI assigned an equal weight to each of the measures. You may feel that certain measures should have a higher weight than others.

- Specify and calculate the "got all care" measure.

Once your team has reviewed the options for the "got all care" variable and decided upon your goal and the appropriate, related scoring, you will then calculate the "got all care" measure for each child.

Because the "got all care" measure is meant to describe the proportion of children that received all aspects of care, **CAHMI recommends** that you only score the "got all care" measure for those children with scores to all of the individual quality measures. For example, a child who only has valid scores for two out of the eleven individual, aspect of care specific quality measures should not be included in the "got all care" measure scoring.



## **STEP 5.3: Calculate alternate versions of the PHDS quality measures**

### **➔ What is the purpose of this step?**

The purpose of this step is to construct additional versions of the core PHDS quality measures.

#### **In this step you will:**

- Consider other options for scoring PHDS quality measures.
- Calculate negative indicator measures.
- Calculate topic-specific Anticipatory Guidance and Parental Education (AGPE) versions of the measures.



### **Guidelines and Issues to Consider**

- Consider other options for scoring PHDS quality measures.

It is often helpful to look at information from different angles and perspectives to gain a more complete, multidimensional picture. Think about your research questions and which of the scoring methods outlined here best answers those questions and makes a compelling story. Be creative when approaching your scoring. While we have provided recommendations here, there is no "one-size-fits-all" method.

Additional and useful ways to consider scoring one or more of the PHDS measures include:

⇒ Negative indicator measures: Proportion of children who did NOT receive recommended care.

The measures described in Step 5.1 tell you whether children receive recommended care. You can also create measures that highlight care that children did not consistently receive. This approach provides information for doctors and health care providers on missed opportunities to provide aspects of recommended care.

For example, instead of reporting that 39.2 percent of parents indicated that their child's doctor or health care provider discussed all topics included in the Anticipatory Guidance and Parental Education quality measure, you could report that 60.8 percent of parents indicated that their child's doctor or health care provider did not discuss one or more of the anticipatory guidance topics with them. You use the same score, but report it in a different way.

**Example 5.5: Positive and Negative Indicators Using the PHDS Quality Measures**

<u>Measure</u>	<u>Positive Indicator</u>	<u>Negative Indicator</u>
Anticipatory Guidance and Parental Education	% of parents responding "yes," items were discussed" to <u>all</u> items.	% of parents responding "no, item was not discussed" to <u>one or more</u> of the items.
Follow-Up for Children at Risk for Developmental Delays	% of parents responding "yes" to <u>at least one</u> of the items	% of parents responding "no" to <u>all</u> of the items.
Family-Centered Care	% of parents responding "usually or always" to <u>all</u> items.	% of parents responding "never" or "sometimes" to <u>at least one</u> item.

⇒ Topic-specific versions of the Anticipatory Guidance and Parental Education (AGPE) measure.

The quality measure focused on AGPE is comprised of approximately 15 to 17 age-specific items and represents a number of recommendations for topics to discuss during a well-child visit.

One valuable way to assess this important aspect of care is to examine whether AGPE focused on specific topics, such as:

- The physical care of the child
- Development and behavior issues
- Injury prevention

Past studies using the PHDS have shown that providers are significantly less likely to talk about (and parents have more unmet informational needs about) development, behavior, and injury prevention, compared with the physical care of the child. Second, providers who systematically provide AGPE on one set of topics are not necessarily more likely to provide AGPE on another set of topics. Therefore, this additional scoring approach to the AGPE measure will allow you to assess variations in the provision of specific kinds of AGPE.

Using the same recodes that you created in **Step 5.1**, you can create three topic-specific versions of the AGPE quality measures. We recommend that you create the two versions for each measure: Version 1 should address whether health care providers talk about recommended topics, and Version 2 should address whether parents have their informational needs met on the topic.

**Table 5.6** provides a detailed summary of each topic-specific version of the AGPE measure.

#### **Tip from the Field**

Consider using topic-specific versions of the AGPE measure in your "got all care" variable. By doing so, you will further highlight the importance of these topics by having three measures related to this aspect of care, and you will be able to assess variations in the kinds of AGPE provided.

**Table 5.6 Overview of the Topic-Specific Version of the Anticipatory Guidance and Parental Education (AGPE) Measure**

<b>Topic-Specific Version of the AGPE Quality Measure</b>	<b>Overview of Topics Included<sup>1</sup></b>	<b>PHDS Items</b>	<b>ProPHDS Item</b>
<b>Physical Care</b>	What parent can do to help child grow and learn, breastfeeding, vitamins and food, feeding, sleeping positions and sleep area, bedtime routines, preventing bottle mouth, whether child watches TV, and childcare.	7a,7c,7d, 7e,7f, 8g, 8h, 9a,9c,9d,9g, 9h,10g, 10h, 11a,11c,11d, 12f,12g	<b>3-9 mo. Version:</b> 1a,1c,1d, 1e,1f, 2g, 2h <b>10-18 mo. Version:</b> 1a,1c,1d,1g, 1h,2g, 2h <b>19-48 mo. Version:</b> 1a,1c,1d,2f,2g
<b>Development and Behavior</b>	Behaviors to expect, night waking and fussing, how child communicates needs (words and phrases child uses and understand), what child is able to understand, how child responds to and gets along with others, child's independence, toilet training, guidance and discipline techniques, importance of showing a picture book/reading to child.	7b,7g,7h,8a,8b, 8f, 9b,9e,9f,9i, 10a,10b,10f, 11b,11e,11f,11g, 11h, 12e	<b>3-9 mo. Version:</b> 1b,1g,1h,2a,2b, 2f <b>10-18 mo. Version:</b> 1b,1e,1f,1i, 2a,2b,2f <b>19-48 mo. Version:</b> 1b,1e,1f,1g,1h, 2e
<b>Injury Prevention</b>	Car seats, house safety, how to avoid burns, what to do if child swallows poisons.	8c,8d,8e 10c,10d,10e 12a,12b,12c,12d	<b>3-9 mo. Version:</b> 2c,2d,2e <b>10-18 mo. Version:</b> 2c,2d,2e <b>19-48 mo. Version:</b> 2a,2b,2c,2d

<sup>1</sup> The AGPE section is specific to the age of child. The wording presented in the table summarizes key topics in the survey and does not reflect the exact wording used the survey. See the PHDS and ProPHDS surveys provided in the Appendices for the exact wording of each survey item. Second, not all topics listed are included in each age-specific version of the survey (e.g., some items are only asked for children of a specific age).



## STEP 5.4: Construct additional analytic variables

### ➔ What is the purpose of this step?

The purpose of this step is to construct additional analytic variables that you will use to examine the PHDS quality measures by child and/or family characteristics, health system characteristics, and other units of analysis specified in Step 2 and Step 3.

In this step you will:

- Calculate the analytic variables you decided to use in the analysis of your PHDS findings based on **Steps 2.4, 2.5, and 3.2.**



### Guidelines and Issues to Consider

- Calculate the analytic variables you decided to use in the analysis of your PHDS findings based on **Steps 2.4, 2.5, and 3.2.**

Your analytic variables are constructed using three sources of data:

- 1) Survey responses from items included in PHDS or ProPHDS that were not used to calculate the quality measures. These items are included to provide additional descriptive information about children and families included in the PHDS and cover:
  - Utilization of the health care system (e.g., emergency room, doctor's office, hospital visits, and access to care issues).
  - Whether the child has had one person whom parents consider to be a personal doctor or nurse, and if applicable, the name of the provider(s) the parent identified.
  - Socio-demographic characteristics of child and parent.
  - Parenting behaviors and family activities.
  - Children with Special Health Care Needs (CSHCN) Screener (PHDS Q32-35. See [www.cahmi.org](http://www.cahmi.org) for detailed information about how to score the CSHCN screener.)

- Screener for maternal depression (PHDS Q41-Q43) using the scoring algorithm recommended by Kathi Kemper, M.D.<sup>1</sup> (Positive response for two or more items indicates the parent is currently experiencing symptoms of depression.)
- Impact of care on parental confidence.
- Financial barriers to care.

These data can be used to provide descriptive information about the sample on their own, and to stratify the results of quality measures using cross-tabulations. Cross-tabulations often present the results in a way that is easier to understand and can be more actionable for quality improvement because they highlight the quality of care findings for specific groups.

- 2) Administrative and Utilization Data: These are the data collected when pulling the sampling frame for the entire sample.

For example:

- Number of Health Plan Employer Data and Information Set (HEDIS)-defined well-child visits.
- Provider with whom the child had the most well-child visits.
- Provider with whom the child is currently enrolled.

- 3) Supplemental Items: These are additional survey items you may have decided to include in the PHDS during Step 2.4.

These data can be used to provide descriptive information about the sample on their own, to stratify the results of quality measures using cross-tabulations. Cross-tabulations often can present the results in a way that is easier to understand and can be more actionable for quality improvement because they highlight the quality of care findings for specific groups.

- 4) Descriptive information about the health system: These are additional descriptive data collected in Step 4 collected from the Office System Inventory, assessments of poster or handouts in the office, and the provider's standard templates for well-child visits.

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<sup>1</sup> Kemper KJ, Babonis TR. Screening for maternal depression in pediatric clinics. *Am J Dis Child*. 1992 Jul;146(7):876-8.





## STEP 5.5: Evaluate quality measurement results for specific units of analysis

### ➔ What is the purpose of this step?

In Step 2, you identified specific units of analysis for which you would assess the quality of care. The purpose of this step is to calculate the quality measure findings for these specific units of analysis.

#### In this step you will:

- Calculate the PHDS quality measures for each unit of analysis being measured.
- Consider issues related to provider-level scoring.
- Consider an additional PHDS quality measure.



### Guidelines and Issues to Consider

- Calculate the PHDS quality measures for each unit of analysis being measured.

Once scores are calculated for each individual child on each quality measure, these individual-level scores need to be combined into a score for the entire unit you are measuring, such as a health plan, office, provider, or total population sampled. This is done by averaging all of the individual scores on a quality measure.

$$\text{Group-level score} = \frac{\sum \text{each individual respondents' quality measure scores}}{\text{\# of individuals with a quality measure score}}$$

In other words, the group-level score is an average score for all respondents for whom a score could be calculated on that measure. Therefore, the denominator for the group-level score for the quality measure is NOT the total number of respondents; rather, it is the number of children whose parent answered at least half of the items for that quality measure.

### Example 5.6: Group-Level Score

Let's say that you are scoring the *Health Information* quality measure for the Happy Health Plan, and Charlie, Lynn, Polly, and Sam are the children in the health plan whose parents have responded to the survey. (Forget about small numbers for the moment.)

The individual quality measure scores for each of the respondents are as follows:

Charlie = 75

Lynn = 100

Polly = 0

Sam = no score (only answered 1 of the 4 items included in the quality measure)

The group-level score for Quality Measure #2 is:

$$\text{Score} = \frac{75 + 100 + 0}{3} = \frac{175}{3} = \mathbf{58.33}$$

Notice that Sam was not included in the calculation (numerator and denominator) since he did not have an individual score for the quality measure.

All of the group-level scores for each quality measure are calculated in this manner. Note that most statistical packages can calculate these scores for you automatically.

- Consider issues related to provider-level scoring.

There are two primary issues you need to consider when using the PHDS for provider-level analysis:

- 1) Provider to whom you should assign the completed PHDS or ProPHDS survey. This step determines what data source(s) will be used to identify the provider who most likely provided a majority of the care the parent responded about in the survey and therefore the survey scores should be assigned to that specific provider.
- 2) Minimum number of completed surveys required to conduct provider-level analysis.

Below are specifications for addressing these two issues:

**Issue #1:** Provider to whom you should assign the completed PHDS or ProPHDS survey.

The PHDS items are not anchored to one provider, but instead ask the parent whether the child's "doctor or other health providers" did specific things. This wording allows for a team to provide well-child care (e.g., medical assistant, nurse, and physician), and allows for a child to have received well-child care from multiple people.

As highlighted in Step 2.4, CAHMI recommends that you include an item asking the parent to identify their child's personal doctor or other health provider(s) if you intend to use the results for provider-level analysis.

Therefore, most users will have three data sources that can be used to identify a provider to assign the completed PHDS survey.

**Data Source #1:** Parent report of their child's personal doctor or nurse.

- This is the person(s) the parent identified in the PHDS. Only those parents who report their child has a personal doctor or nurse are asked the follow-up question to indicate the specific person(s).

**Data Source #2:** Utilization data.

- For the most part, the care asked about in the PHDS should be provided during well-child visits. Therefore, it is valuable to identify the provider who was responsible for a majority of the well-child visits the child received in the last 12 months or since the child was born. If two providers were responsible for an equal number of visits, then you should identify the person(s) responsible for the most recent well-child visits.

**Data Source #3:** Enrollment data (applicable to managed care systems).

- In most managed care systems, the child is enrolled or assigned to a specific provider. Therefore, it is valuable to identify the provider with whom the child has been enrolled for the longest time in the last 12 months or since the child was born. If the child was enrolled with two providers for an equal amount of time, then you should identify the person(s) responsible for the most recent well-child visits.

A single source or combination of these three data source(s) can then be used to identify the provider to whom you should assign the PHDS. **CAHMI recommends** that you explore the following before deciding which data source(s) to use:

- Examine the level of agreement between parent report and the utilization and enrollment data. If there is a low level of agreement, CAHMI recommends that you use parent-report as the gold standard.
- Examine the level of agreement between the enrollment and utilization data. If there is a low level agreement, then the utilization data should be used.
- Consider using multiple data sources. For example, a managed care plan used the PHDS to create a provider-level report. A high degree of agreement was observed between parent report and the utilization and enrollment data, and a high level of agreement was observed between the utilization and enrollment data. Therefore, the managed care plan assigned the completed PHDS survey to the provider the child was enrolled with as his/her primary care provider, AND required that the child saw the provider for at least one well-child visit.

**Issue #2:** Minimum number of completed surveys required to conduct provider-level analysis.

As described in **Step 2.2** (Table 2.2), **CAHMI recommends** that you have **30 completed surveys** per provider if you are creating un-blinded provider-level reports.

If a provider-level report is being disseminated to inform quality improvement activities and is only shared with the specific provider, you can create a report for a provider for whom you have **15 completed** surveys.

Other issues you should be sure to examine are:

- ⇒ Sample sizes for the age-specific groups (3–9 months old, 10–18 months old, and 19–48 months old) to address any sample size issues.
- ⇒ Sample size for the PHDS quality measures that only apply to specific groups of children (e.g., *Address Parental Concerns*, *Follow-Up for Children at Risk for Developmental, Behavioral, or Social Delays*).

- ⇒ Individual provider variation in the care he/she provides to various children and families: Providers who are very consistent in the care they provide across patients will need fewer surveys, as compared with providers who target certain discussions to certain patients.
- ⇒ Care Team: If the provider and nurse each provide components of the well-child visit, then more surveys may be needed as the provision of care by two individuals increases the level of variation in this communication-dependent measure.

- Consider an additional PHDS quality measure.

Another valuable way to assess the quality of comprehensive care provided at the office or provider level is to calculate the maximum number of individual care components routinely provided by a specific office or by a specific provider. This value can then be assigned to each child (using the provider or office to which the survey was assigned), and descriptive analyses can be conducted for children by the maximum number of individual care components their provider/office gave to children assessed in the PHDS.

This measure, called the "maximum number" quality measure, assesses the degree to which individual providers or groups of providers focus on specific aspects of preventive and developmental care.

**Example 5.7** provides an example of the "maximum number" quality measure.

### Example 5.7: Maximum Number Measure

The Healthy Happy Plan implemented the PHDS and is using the survey to assess for care in two offices (East and West). The Happy Health Plan created a count variable (**See Step 5.2**) of the number of components of care each child received (Maximum number=12). They then assessed, in each office, the maximum number of care components a child in that office received.

The individual "Maximum Number" measure scores for each of the office were as follows:

East Office:

Olivia = Received 4/12 individual care components

Christian = Received 5/12 individual care components

Henry = Received 6/12 individual care components

*Range: 4–6 Maximum Number of Care Components = 6*

West Office:

Mary= Received 10/12 individual care components

Billy= Received 11/12 individual care components

James = Received 10/12 individual care components

*Range: 10–11 Maximum Number of Care Components = 11*

The East Office providers seem to provide only certain aspects of care, while the providers in the West Office focus more globally on the various aspects of care measured in the PHDS.



## STEP 5.6 Evaluate quality measurement results for subgroups of children

### ➔ What is the purpose of this step?

Past studies of the PHDS have shown significant variations in quality of care by child, family, health care provider, and health system characteristics. Therefore, it is valuable to assess your PHDS quality measure findings by the descriptive variables in the PHDS survey and by the analytic variables collected in **Step 2, Step 3, Step 4, and Step 5.4.**

The purpose of this step is to analyze the PHDS findings for subgroups of children based on these descriptive variables.

#### In this step you will:

- Analyze the PHDS findings by child and family characteristics.
- Analyze the PHDS findings by administrative and utilization data.
- Analyze the PHDS findings by health system characteristics.



### Guidelines and Issues to Consider

- Analyze the PHDS findings by child and family descriptive characteristics.

The PHDS quality measures should be stratified by basic demographic information. Demographic information can be important in quality improvement reports. Providers can use the information to evaluate their own behavior and detect differences in care between various demographic groups. However, the level of detail may be overwhelming in consumer reports, so you might choose to highlight only striking results in a consumer report.

Specifically, be sure to examine the PHDS quality measures by the following:

### **Demographic information about parent and child**

- Information about children's:
  - Gender
  - Race, ethnicity
  - Birth order
  - Age
- Information about parent/family's:
  - Age
  - Number of children in household
  - Education

### **Health information about the child and parent**

- Child health characteristics:
  - Children at risk for developmental, behavioral, or social delays (See **Step 5.1** for more detail)
  - Children with special health care needs
- Parent health characteristics:
  - Risk for depression
  - Overall health status

### **Child health care characteristics**

- Whether the child has a personal doctor or nurse
- Analyze the PHDS findings by administrative and utilization data.

The PHDS quality measures can be stratified by the administrative and utilization data variables you created in **Step 5.4**.

Specifically, it might be valuable to stratify your findings by the following:

- Number of well-child visits
- Number of providers the child has been enrolled with in the last 12 months
- Number of providers the child has received well-child care from in the last 12 months



- ☑ Analyze the PHDS findings by health system characteristics.

**Step 4.4** specified three data sources that can be used to assess the PHDS findings by specific health system characteristics:

- 1) Office system inventory
- 2) Posters and handouts in the office
- 3) Provider well-child templates in the electronic medical record

That step also described how to construct a variable representing the number of relevant systems or materials the office or provider had in place for each data source.

Before stratifying the results by these count variables we recommend the following:

- Run a frequency on the count variable and examine the distribution in order to identify groups of offices and/or providers with similar characteristics.
- Create a categorical variable based on these groups. You can then stratify the PHDS quality measure findings by the count variable AND the categorical variable and identify system/provider trends.
- Consider creating topic-specific versions of the count variables that map to the PHDS quality measures.

***For example:***

- Create a count variable of the section of the Office System Inventory (OSI) that specifically related to Anticipatory Guidance and Parental Education (APGE). Stratify the AGPE quality measure by this topic-specific count variable.
- Create a count variable of the posters and handouts related to psychosocial issues in the family. Stratify the *Assessment of Psychosocial Issues in the Family* quality measure by this topic-specific count variable.



## STEP 5.7: Review additional analytic tips

### ➔ Statistical Analyses

When comparing performance or scoring among different groups, statistical analyses are required to test and see if the differences are meaningful and real. However, the statistical test that is used will depend on the type of data you are testing. It is beyond the scope of this manual to be a statistical primer. Therefore we suggest that when you compile your team you identify someone to be the lead person for these analyses. As an introduction to those analyses, the following table lists three of the most common statistical tests used in the analyses described in this section. Your vendor may also be able to provide these services.

**Table 5.7: Typical Statistical Tests Run in Quality Health Care Reporting**

Type of Comparison	Statistical Test	Example Research Question
1. Differences in mean scores between two groups	T-test	Do parents who are at risk for depression have a lower mean score on the <i>Helpfulness of Care</i> quality measure than parents who are not at risk for depression?
2. Differences in mean scores between three or more groups	Analysis of Variance (ANOVA)	Are there differences in the mean scores for the Assessment of Smoking, Substance Abuse and Safety Within the Family by racial, ethnic groups (e.g., white, African American, Hispanic, other)
3. Differences in binomial scores for two or more groups (e.g., cross-tabulations of threshold scores)	Chi-square ( $\chi^2$ )	Are parents of children with special health care needs more likely to meet the threshold for having discussed the anticipatory guidance topics than parents of children without special health care needs?

## **Step 6: Report Your PHDS Findings to Stimulate and Inform Improvement**

The PHDS data is only meaningful if it is reported back in a way that is salient and relevant to the target recipient. Step 6 focuses on how the PHDS findings can be reported in a way that stimulates and informs improvements. This section is intended for the project managers who will oversee the development of reporting templates and for any vendors that will develop the final reports.

The six sections focus on designing and implementing a PHDS reporting strategy:

6.1: Plan your reporting and dissemination strategy

6.2: Review guidelines and tips for reporting to health system leaders

6.3: Review guidelines and tips for reporting to front-line health care providers

6.4: Review guidelines and tips for reporting to consumers

6.5: Compare your PHDS findings with others

6.6: Review additional resources on reporting health care quality findings



## STEP 6.1: Plan your reporting and dissemination strategy

### ➔ What is the purpose of this step?

As we have emphasized throughout this manual, it is important to begin where you want to end up. The purpose of this step is to clarify your reporting and dissemination strategy.

#### In this step you will:

- Learn about the key components of a successful reporting strategy.
- Confirm each of your reporting audiences (*the who*).
- Confirm what PHDS findings will be of interest to each reporting audience (*the why and what*).
- Confirm the best way to present this information by selecting a format and dissemination strategy (*the where, when, and how*).



### Guidelines and Issues to Consider

- Learn about the key components of a successful reporting strategy.

Research shows that successful use of quality information is achieved when:

- ⇒ You give the right kind of information, including: (1) general, framing information about the importance of the topic evaluated, (2) overall quality-of-care findings, (3) specific information about individual aspects of care, and (4) specific actions to improve health care.
- ⇒ The right people receive the information, such as health care providers who provide preventive and developmental care in the office setting and parents/guardians who bring their child in for well-child care and who are primarily responsible for ensuring the healthy development of their child.
- ⇒ The information is given at the right time. For example, for parents the right time is before or during a well-child visit.

⇒ The information is given in the right way, such as through a multimedia approach, and delivered more than one time.

- ☑ Confirm each of your reporting audiences (*the who*).

In **Step 2** you identified your project team and your key goals for the project. You now must ensure that each of the audiences and stakeholders you identified receive a report of the PHDS findings.

Learning more about your audience increases the likelihood that your project and reporting strategies will be successful. We encourage you to review and discuss the following questions as you design your reporting templates:

- ? What format for findings do they prefer?
- ? What other information do they need to help them understand and find your PHDS results credible?
- ? Do they need support to help them use the information?
- ? How do they receive other health-related information?
- ? What are the best ways to reach them?
- ? When are they most receptive to this type of information?
- ? Will they trust the information?

If you cannot answer these questions, you may want to consider conducting some research about your audience to learn more about them. You can use this information to make sure your quality report is relevant and useful to your audience. We suggest you do the following:

- **Go directly to the source.** One of the best ways to learn more about your audience is to talk with members of your audience directly. This can be done via interviews, focus groups, or even with a small survey. The benefit of interviews and focus groups is that you can modify your questions based on their responses. Be sure to document what you learn from your audience and how it might affect the development of your report.
- **Contact groups or organizations that may already know your audience.** There may be groups or organizations that function as intermediaries for your audience. Not only are they likely to be able to answer your questions, they may have channels for audience research, dissemination, and marketing of the final report. Examples of intermediaries include consumer advocacy groups, employer business coalitions for employers, and professional provider organizations.
- **Consider similar information that your audience may already have received.** You may not have the resources necessary to conduct your own audience research, so looking at reporting strategies for other reports may help you understand your audience and their health information environment. For example, parents may already receive information about all children rather than just young children, who are the

focus of the PHDS. Think about what information is contained in these other reports. Who sponsors these reports and how are they disseminated? What are the messages conveyed by these report? Does the audience trust the information? What does the audience do with the information?

- Confirm what PHDS findings will be of interest to each reporting audience (*the why, what*).

Your PHDS report should contain both the PHDS results and contextual information that readers will need to understand the report. When deciding what information to include, consider the messages you want your report to convey.

To ensure that your data from the PHDS are relevant and meaningful it must:

- 1) Be communicated and presented in a way that is understandable and useful to each stakeholder, and
- 2) Inform and guide actions that can be taken by each stakeholder to address the issues you present.

Worksheet 6.1 will help your team brainstorm the type, format, content, and dissemination medium of a report to each key audience. Keep in mind that you can also consider integrating other data using the worksheet. The pages that follow provide more detailed information about the concepts included in each row of the worksheet.

**Example 6.1: Worksheet to Design Your Reports on Your PHDS Data Findings**

Your Audience/Stakeholder: _____	
Individual topics or measures from the PHDS to include.	1. 2. 3.
Relevant subgroup of children and youth and geographic comparison areas for each PHDS topic or measure.	1. 2. 3.
Other data to include and source of these data.	1. 2. 3.

**Example 6.1: Design Your Reports on Your PHDS Data Findings (Continued)**

Background information and key points to establish relevance of your PHDS data findings for your audience.	1. 2. 3.
Tone of the communication (e.g., motivate by emphasizing the negative vs. positive; emphasize the gaps/needs vs. what can be done).	1. 2. 3.
Format and length (e.g., one-page summary, PowerPoint slides).	1. 2. 3.
Explanation of data source and validity of findings required.	1. 2. 3.
Actions you want them to take and resources you want them to know about (e.g., come to our meeting, go to our Web site, tell your doctor).	1. 2. 3.
Dissemination and follow-up strategy (e-mail with phone follow-up, etc.).	1. 2. 3.

**Presenting Technical Information in a Manageable Way**

Presenting technical information about health care quality can be challenging for several reasons. First, this information typically involves statistical methods that may be difficult to describe. Second, how well your audience will understand the results and how the results were calculated may vary tremendously. Finally, you most likely have a lot of information to choose from when deciding which measures and results should be included in your report. Including too little can be a missed opportunity to communicate quality to your audience; however, including too much can be overwhelming to your audience. The guidelines in the box below offer some tips on making your report as useful as possible.

### Example 6.2: General Guidelines on Report Content

- Tailor the report to the audience and purpose.
- Provide background information on the data you use—who are the data about?
- Include pictures, graphics, quotes, or stories that connect the findings to real people.
- Break out the information in text boxes to make it more digestible
- Keep it brief.
- Give an overall picture, then targeted findings.
- Display the data in meaningful ways that put a "face on the data," e.g., 20 percent of households or "1 of 5 households."
- Use specific numbers when possible, e.g., 9.8 million children nationally have special health care needs, or 12.8 percent of all children.
- Balance positive and negative ways of expressing the findings according to the point you are trying to make: less than a quarter; more than 75 percent.
- Be careful when dealing with very small numbers.
- Provide findings in relation to a benchmark, such as office level findings compared with the health plan.
- Explain why the findings presented are important.
- Suggest ways a specific audience might use the data to improve care.
- Credit the source of the data and include when, how, and by whom it was collected.
- Provide links to additional resources.
- Provide contact information for questions.

Other methods to consider include:

- **Layering information.** Members of your audience will have different needs in terms of both the amount of information they want to have and the way the information is presented. An easy way of creating one report that meets the needs of various members in your audience is to layer the information. This approach is almost like creating multiple sub-reports that are contained in one final report. Each sub-report has a different level of detail and/or presentation. Think of a tabbed report where each tab is intended for a different subgroup of your audience.

The first layer might include very general information—the view from 10,000 feet. This layer is intended for those who do not have a lot of time or are only minimally interested in reviewing quality information. You may only want to include a few aggregate measures in this layer, and refer readers to subsequent layers for more information.



You might consider adding two additional layers for this more detailed information. The first might be the "ground-level view," which would include a few more measures with slightly more detail for those who are interested in quality information but not highly technical information. The second could be the "microscopic view," which would include a greater level of detail for those who are interested in technical aspects of the survey.

- **Comparing your findings with other findings.** It is often valuable to compare your findings with others' findings. **Step 6.5** provides you with a summary of the quality of care findings observed for past users of the PHDS.
- **Avoiding relative benchmarks!** CAHMI does not recommend comparison to relative benchmarks since such comparisons can be VERY misleading to readers. Relative benchmarks are benchmarks that change based on the results of the survey sponsors, such as a state average among all health plans.

Here is an example of how such a comparison can be misleading:

A health plan is creating a public report that includes results from all the offices that they contract with to provide pediatric care. This is the first year that the PHDS was administered. As you might expect, the scores in each office are fairly low when compared with national recommendations or even other health plans; however, the health plan is confident that simply reporting the results will spur quality improvement efforts among the plans. Instead of comparing the results to national guidelines, they choose a relative benchmark: the average across the entire health plan. Consequently, several offices have results that are higher than the average. When the report is released, these offices feel they have results that are "above average" and do not prioritize quality improvement initiatives focused on preventive care for young children. In reality, these plans are performing well below the recommended national guidelines.

- **Combining the PHDS with other data sources.** Combining your PHDS results with data from other sources can help to make the findings more valuable to the reader. Commonly used quality measures that are related to the PHDS are the HEDIS well-child visit measures, the HEDIS immunization measure, consumer satisfaction data, and any more detailed quality-of-care data gathered about well-child visits (e.g., medical chart reviews).
- **Organizing information into smaller segments.** Readers often have a difficult time processing large amounts of information. Breaking the information into sections that offer "bite-sized" pieces can help. Readers can then process the information in one text area before moving on to the next. This approach is effective not only for consumers but also for providers and purchasers. Graphics that are meaningful to the target audience can also be added.

## **Presenting Statistical Information and Methodology**

Presenting statistical information and methodology is one of the most challenging parts of reporting the results. Most consumers do not understand statistical tests, confidence intervals, or probability. However, statistical comparisons must be used to ensure that true differences are identified.

The following are suggestions for targeted reports:

- **Non-technical audiences (consumers, some purchasers, policymakers).** Most consumers and some purchasers will not understand the statistics behind the analysis. And policymakers often do not have the time to review detailed information and are more interested in a summary of the findings. It is probably enough to indicate that statistical tests have been used to identify true differences in the results and provide a way for readers to get additional information if they are interested. Again, layering information is the best way to meet the needs of different members of your audience.
- **Technical audiences (providers, health plans, some purchasers, regulators, policymakers' staff members).** Many of these readers will be interested in the more detailed statistical aspects of the analyses. Still, these audiences vary. While some will have the background and expertise to understand the statistical formula that you used in the analysis, others may be turned off by having that detail in the body of the report. Reports for these audiences should include a description of the statistical methods used; however, this information is best included as an appendix to the main report. Details that you may want to consider presenting in graphs and charts in the body of the report include the sample size, confidence intervals, and p-values.
- **Balancing positive and negative measures.** The same information can be used to present results in a positive or negative measure. Positive measures illustrate high or quality performance, whereas negative measures highlight poor performance. The key is to balance positive and negative measures.

- ☑ Confirm the best way to present this information (Format and dissemination strategy) (*the where, when, and how*).

There are two main components to this step:

1. Decide on the format of the report.
2. Determine how you will disseminate the report.

### ➡ **Decide on a Format**

How you present your message can be as important as what you have to say. Two commonly used formats for reports include the following:

**1. Written reports/materials.** Written reports can be brief, such as a pamphlet or brochure, or lengthier, such as a booklet or binder. If a written report is the format you choose, consider any logistical requirements that you may have such as reproduction costs, size (Does it have to fit in a certain size envelope for mailing?), weight (Are you limited by weight in terms of postage costs?), number of pages, binding, etc.

**2. Web-based reports** are becoming more popular. One advantage to web-based reports is that the reports can be easily tailored to specific users. One disadvantage of web-based reports is that they will only be available to those with access to the Internet.

### ➡ **Determine how you will disseminate the report**

One of the most important factors in the overall success of your ability to "tell the story" is your ability to have the report received and read by the audience. If they never read your report, they cannot use it! How, where, and when are all important questions you need to consider when planning the dissemination. Here are some different ways you may want to think about dissemination of a data report. **CAHMI recommends that you use multiple strategies to ensure that your key stakeholders receive information about the PHDS findings.**

- In-Person Meetings – In-person meetings are an extremely valuable way to provide information. In-person meetings allow you to connect eye-to-eye with the participant(s) and provide a larger context about the report findings and how they may be valuable.
- Mail – Mail can be an effective way to reach each member of your audience as long as you have reliable mailing addresses. Include an introductory letter from someone they trust.
- List Servs and Web Site Postings – Increasingly, materials are being disseminated electronically. By distributing information through a listserv or Web site, you may allow many others to disseminate your information. Be sure that it is posted in a secure format.
- Fax – Fax can be an effective way to reach each member of your audience as long as you have reliable fax addresses. Some focus groups and interviews with health care providers have shown that they are more likely to read information when it is faxed as opposed to when it is mailed to their offices.
- Intermediaries – Think about intermediaries that could disseminate this information for you. Are there other family or professional groups or organizations through which you could reach your desired audience? Consider the influence that the intermediary may have on your audience in disseminating the report.
- Public Availability – Making the report available for the public to request or access through public places, such as a local library, is an option. This is a good way to provide additional copies once the initial distribution has been conducted.

**Again, no one method is most effective.** The key to successfully disseminating your report is to make sure you are reaching your audience where and when they need it. Regardless of how you disseminate the report, it is important to indicate where readers can go if they have questions. This could be a phone number, a Web site, or other information source.



## STEP 6.2: Review guidelines and tips for reporting to health system leaders

### ➡ What is the purpose of this step?

The purpose of this step is to provide you with reporting templates that can be used to share the PHDS findings with health system leaders. We also highlight tips and issues to consider, based on past CAHMI experiences.

#### In this step you will:

- Review CAHMI templates for reporting the findings to health system leaders.
- Review tips and issues to consider in reporting the findings to health system leaders.



### Guidelines and Issues to Consider

- Review CAHMI templates for reporting the findings to health system leaders.

The goal for reporting the PHDS findings to health system leaders is to ensure that they understand the following:

- The key findings
- How these findings compare with quality measures they currently collect
- What should be done to address the gaps in care described by the PHDS findings

For the most part, health system leaders will only read documents that are short and succinct. **Appendix 12** provides an example of a two-page executive summary of the PHDS findings. **Appendix 13** provides an example of a five-page summary of PHDS findings. This example is derived from a reporting template developed for Medicaid directors. However, the document can be a useful model for reporting the findings to

other senior-level administrators, such as a health plan's director of quality measurement.

Review tips and issues to consider in reporting the findings to health system leaders.

- **Use the PHDS quality measures for an overall snapshot of care.**

In most cases, health system leaders want to know whether recommended and eligible services are received. Therefore, the report designed for them should provide an overall picture of quality and performance.

Specifically, the report to health system leaders should include the findings from the "got all care" measure and the findings from the individual quality measures, using the threshold level scoring.

- **Compare the findings with current quality measures used by the health system.**

The PHDS findings are valuable when they are put in context with other quality measures used by the health system.

Most health systems collect information about the HEDIS well-child visit rates. The PHDS provides information about the quality of care children received during well-child visits. Therefore, it is important to explain to health system leaders that the HEDIS well-child visit is telling them how many kids come in, and the PHDS is telling them what happens during the well-child visit.

Other possible related quality measures include immunization measures, medical chart reviews of the content of well-child care, and satisfaction measures (such as the Consumer Assessment of Health Plans Survey).

### Example 6.3: Comparing the PHDS with Currently Used Quality Measures

Kaiser Permanente Northwest (KPNW) implemented the PHDS and wanted to compare the finding with other measures. Related quality measures used by KPNW were the HEDIS well-child visit and immunization measures, and a satisfaction and experience of care survey called the Medical Office Visit (MOV) survey.

KPNW therefore did the following:

- Compared whether offices/providers with the highest/lowest immunizations rates were the offices/providers with the highest/lowest on the PHDS quality measures.
- Compared whether offices/providers with the highest/lowest well-child visit rates were the offices/providers with the highest/lowest scores on the PHDS quality measures.
- Compared whether offices/providers with the highest/lowest scores on the MOV were the offices/providers with the highest/lowest scores on the PHDS quality measures.

An example of the comparative findings:

KPNW found that there was not a high level of agreement between the offices and/or providers who scored the highest on the MOV survey and the offices and/or providers who scored the highest on the PHDS quality measures. This helped them to understand that each data source provided valid information about quality, but that they should not assume that providers who score high on their MOV survey are providing all aspects of recommended care.

- **Spotlight specific items that are hot issues in your health system.**

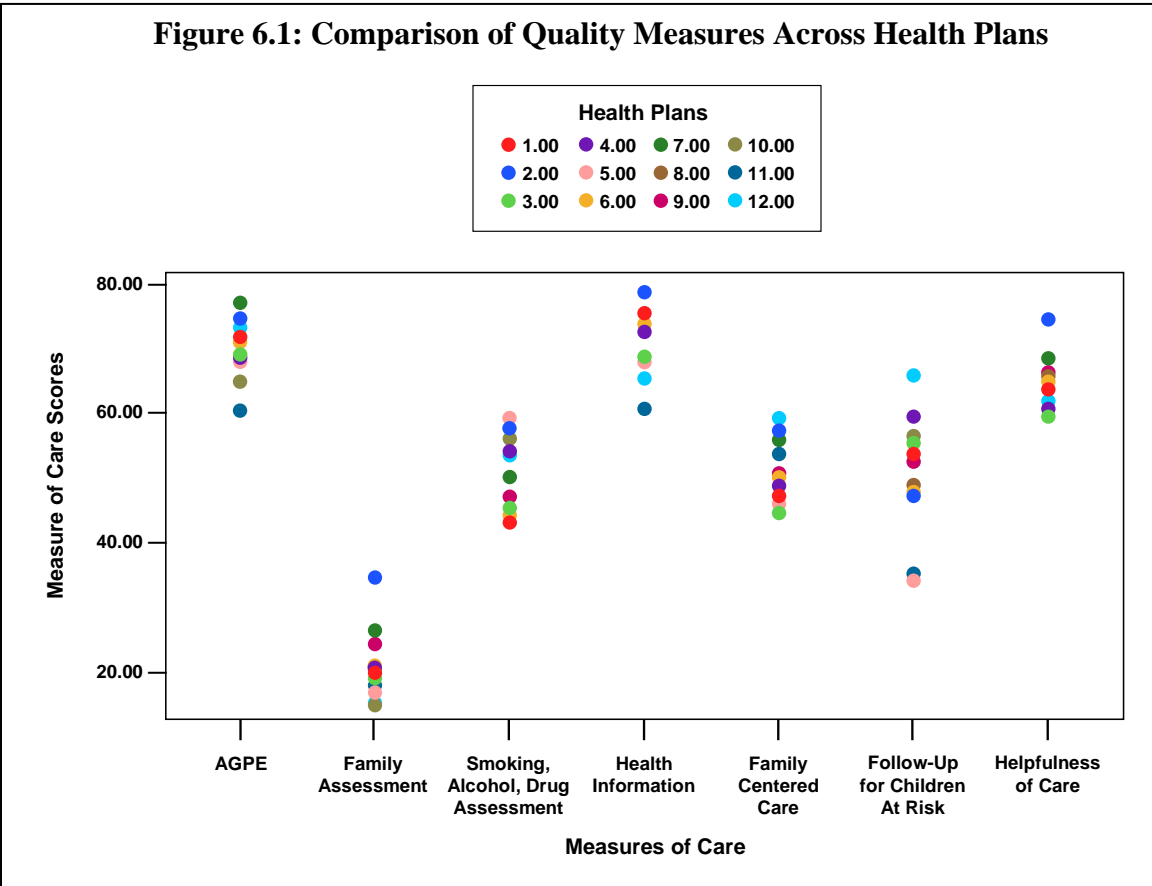
Many of the individual items and/or areas included in the PHDS are useful to report if your system has a specific topical focus (e.g., car seat use, reading, *Healthy People 2010* goals such as smoking, etc.).

**Appendix 14** provides an example of a topic-specific issue brief highlighting PHDS findings on parental depression: the prevalence, the relationship of parental depression to other child health and health care utilization characteristics, and the degree to which pediatric providers are assessing parents for depression.

- **Compare quality of care.**

Displaying PHDS quality measures side-by-side for easier evaluation is most useful for health system leaders. One way to present comparative information on the quality measures across different units of analysis is shown in **Figure 6.1**. Not only does the graphic show which quality measures need the greatest

improvement, but it also displays the relative performance of each of the health plans. Notice that no one health plan does the best in every single category, which leaves room for targeted improvement. This type of figure could be used to make comparisons by subgroups of children and across offices and/or providers.





**Present results using a layered approach.**

Purchasers use a great deal of information when making contracting decisions, so a layered approach is suggested when preparing these types of reports for health system leaders. The first "layer" should provide a summary of aggregated results that can be reviewed quickly. Since health system leaders may be technically savvy, we recommend stratifying the measures by key groups to demonstrate variations in the level of quality care.



## **STEP 6.3: Review guidelines and tips for reporting to frontline health care providers**

### **➡ What is the purpose of this step?**

The purpose of this step is to provide you with a reporting template that can be used to share the PHDS findings with frontline health care providers. We also highlight tips and issues to consider based on past CAHMI experiences.

#### **In this step you will:**

- Review the CAHMI template for reporting the findings to frontline health care providers.
- Review tips and issues to consider in reporting the findings to frontline health care provider.



### **Guidelines and Issues to Consider**

- Review the CAHMI template for reporting the findings to frontline health care providers.

**Appendix 13** provides a report template for displaying the PHDS findings to frontline health care providers. This template is based on cognitive interviews and focus groups conducted by CAHMI with frontline health care providers in five private practices in Vermont and Kaiser Permanente Northwest.

Important characteristics about the dissemination of this template include the following:

1. The report should come from someone the health care providers trust. If the report cannot come from someone they trust, it should be followed with a note of encouragement from someone they trust and/or their boss/manager, such as the chief of pediatrics.

2. The report should be followed by an in-person meeting so that a summary of the survey and key findings can be shared and questions answered. In past projects this was accomplished through the monthly office-level meetings.
3. Each individual provider should personally receive the report. In some health systems, it may be best to fax the report to each provider so that it does not become buried under the rest of the mail that providers receive.

Review tips and issues to consider in reporting the findings to frontline health care providers.

Below are general tips and issues to consider when reporting the findings to senior health system leaders.

- **Show comparative data to "pull them in" and give them a sense of overall findings.** It is important to start the report with overall quality of care findings and how they compare with others (See Step 6.5 for comparison PHDS data). It can be valuable to use charts for this purpose. However, **CAHMI recommends** that you do not include ONLY charts in the report. The qualitative studies conducted by CAHMI found that providers prefer reports that combine graphics and text.
- **Explain the measures of care.** It is important to provide a description of the recommendations behind each quality measures, the items that are included in each of the quality measures, and how you scored each measure.
- **Provide item-level findings, shown by categories.** The quality measures are important to give providers a sense of how they are doing. However, they do not describe specific ways providers can improve care. Therefore, it is invaluable to include BOTH the quality measure and item-level findings in the provider-level report.
- **Include the areas in which providers are doing well and the areas most in need of improvement.** The report needs to highlight areas of excellence and areas of improvement. If the entire report has a negative tone, it will not be well received or used by health care providers to improve care.

- **Link findings to health behaviors and other indicators of high-quality care.**  
To reinforce the validity of your results and emphasize its importance, it is helpful to link your findings to broad issues surrounding the health of young children, such as child's risk of developmental, social, or behavioral delays, as well as correlates of higher quality, such as having a personal doctor or nurse. It is also invaluable to show the relationship between children whose parents reported that they had their informational needs met on specific anticipatory guidance and parental education topics with positive parent and family behaviors reported in the survey (e.g., breastfeeding, reading, minimal television watching).
- **Provide background information, links to additional resources.** It is important to include links to background information about the PHDS and the aspects of care included. Also include links to resources that can help providers conduct quality improvement efforts in the areas addressed in the PHDS. Examples of these links to related information can be found in [Appendix 2](#) and the final page of [Appendix 13](#).
- **Provide contact information to address questions.**



## **STEP 6.4: Review guidelines and tips for reporting to consumers (parents of young children)**

### **➔ What is the purpose of this step?**

The purpose of this step is to provide you with a reporting template that can be used to share the PHDS findings with consumers, which for the PHDS are parents of young children. We also highlight tips and issues to consider, based on past CAHMI experiences.

#### **In this step you will:**

- Review the CAHMI template for reporting the findings to consumers.
- Review tips and issues to consider in reporting the findings to consumers.



### **Guidelines and Issues to Consider**

- Review the CAHMI template for reporting the findings to consumers.

There are two main reasons that quality-of-care information is shared with consumers:

- 1) To help them choose a health care provider or system.
- 2) To provide information about the current level of care provided in their system, what they should be receiving, and how they can ask questions and raise important issues so that recommended care is provided.

**Appendix 15** provides a report template about providing information to parents. The parent handout is based on focus groups and cognitive interviews CAHMI conducted with parents about how the PHDS findings could be reported in ways that would help them understand the current level of care their child receives and motivate them to be partners in the improvement process. A detailed summary of the qualitative findings can be found on the CAHMI Web site in the report "[Summary of Interviews & Focus Groups with Parents of Young Children: Reporting the Promoting Healthy Development Survey \(PHDS\) Findings to Parents.](#)"

Important characteristics about this template and how to disseminate it include the following:

- The template should be formatted as a brochure or pamphlet. Parents who participated in the one-to-one interviews and focus groups indicated a strong preference that they receive this pamphlet before OR during their child's well-child visit from their child's health care providers and/or other office staff.
- It is important that parents understand why this information is being given to them and how the health care providers in their office plan to use the information to improve the health care they provide. Office staff who give the brochure to the parent can explain how the survey findings are being used. This important information can also be noted in a cover letter that accompanies the brochure if it is mailed.

- Review tips and issues to consider in reporting the findings to consumers.

Below are some general tips and issues to consider in reporting the findings to consumers:

**If you are using the report to inform consumer choice:**

- *Provide comparative information.*

If the report is intended to provide consumers with information to make more informed health care decisions, such as deciding between pediatric offices, then a data display that facilitates comparison is useful. Also, certain consumers may need assistance in interpreting the information to inform their decision.

- *Layer information to account for all types of consumers and make the results easier to interpret.*

Since everyone has different health information needs and experiences with the health care system there is no

**Additional Tips for Creating Consumer Reports**

- Conserve white space. White space makes the document appear more manageable to consumers at first glance. Too little white space can be overwhelming.
- Be concise. While background and context are important, presenting the information in a clear, succinct way is critical.
- Use bullets and lists when possible. Lists are easier to read and process than paragraphs. Moreover, bullets and lists result in more white space.

"average" consumer. Consequently, creating a report for one subgroup of this audience will likely make the report less effective for another subgroup. Also, different groups of people put more or less value on different aspects of quality care. Thus, layering information is probably your best strategy for creating a report that different consumers will find useful. This allows those who are not interested in a lot of detail to quickly glean the necessary information from the report. Parents can also pick and choose aspects of care from among the quality measures that most resonate with them.

- ***Provide some background information on quality measurement to help consumers understand the information presented.***

The general public may have little or no knowledge of health care and how quality is measured. Also, parents may be skeptical of the source of the information. Therefore, significant background information will be necessary to help them understand the information and why it is important to them. Background information includes descriptions and definitions that explain:

- Why measuring health care quality is important.
  - Which aspect of health care quality you are addressing in the report (e.g., health plan, providers, etc.).
  - Why consumer assessments are important to understanding health care quality.
  - The source of the PHDS information and/or who sponsored the survey.
  - What PHDS results can tell you and how to use that information.
- ***Consult with your audience to see if the information is easily understood.***

Qualitative testing of your report is critical to ensure the audience understands the information and uses it in the ways you intended. Even if you ask just one or two people who represent each of your stakeholders to review and provide feedback about your report, it will be invaluable in ensuring that the findings are readable and the key messages are conveyed.

**If you are using the report to inform and educate the parent to be a partner in improving care:**

- ***Research findings about the content that should be included.***

Parents reported that they wanted the following information in their report:

- 1) General information about the PHDS, how many parents completed the survey, and how their child's health care providers are going to use the information to improve care.
- 2) Item-level findings coupled with specific tips or actions that parents can take to improve care.
- 3) General statements about what health care parents should expect at their child's well-visits.
- 4) An emphasis on the parent's role as a partner in their child's health care.
- 5) Additional resources listed that provide parents with information about the survey, the topics assessed in the PHDS, and how he/she can work with their child's health care providers.

- ***Avoid comparative information, but do include a "gold standard."***

Since parents are not making a choice about their child's health care, comparative information is generally not useful and can interfere with the message you are trying to convey. Instead, present details on the care that parents should expect from their child's health care providers and demonstrate how close those providers are to the goal.

- ***Avoid complex tables and charts.***

The majority of parents are not versed in reading and interpreting data tables and charts, so they should generally be avoided. However, a simple bar chart showing how close the doctor is to a certain standard or goal can be very effective.

- ***Present both positive and negative information.***

Parents want to see a balance of what their child's doctor is doing right and the areas where he or she could improve. Focusing only on the negative may make



the parent feel overwhelmed or helpless. Using a mixture of positive and negative indicators when presenting the results helps parents feel good about the care their child is receiving and also helps the parent to set goals in certain areas.

- ***Highlight which aspects of care can be improved.***

Present results in terms of what action can be taken. Is there a list of questions or checklist the parent can bring to the next visit?

### **Additional Tips for Reporting PHDS Data to Parents**

- ***Collaborate with groups that are respected by the audience.***

To add perceived credibility to your report, mention any collaborative efforts with respected organizations or groups.

- ***Provide additional information and/or resources.***

Provide information about related resources such as Web sites, books, and telephone numbers parents can use to answer questions about the reports and/or aspects of care presented.

- ***Be aware of issues surrounding the confidentiality of results.***

Only report on practices or providers that have a sufficient number of respondents, so that the risk of breaching confidentiality is minimized.

- ***Display the findings in a multimedia format.***

When possible, enable parents to view the findings in multiple formats, such as on a Web site as well on paper.



## STEP 6.5: Compare your PHDS findings with others

### ➔ What is the purpose of this step?

As was noted in Steps 6.1–6.4, it is valuable to compare your findings with the findings of others. The purpose of this section is to provide you with information about the PHDS findings from other parties who have used the PHDS or ProPHDS through a mail mode of administration.

#### In this step you will:

- ☑ Review the PHDS findings of others around the country.
- ☑ Consider alternate sources for PHDS benchmark information.



### Guidelines and Issues to Consider

- ☑ Review the PHDS findings of others around the country.

As was described in **Step 1**, the PHDS tools have been implemented at the national, state, health plan, practice, and provider level. To date, more than 45,000 surveys have been collected by nine Medicaid agencies, four health plans, 46 pediatric practices, and through the National Survey of Early Childhood Health (NSECH).

However, given that this manual is specific to the implementation of the PHDS or ProPHDS by a mail mode of administration, **Table 6.1** provides comparison PHDS findings for data collected via a mail mode of administration. As has been demonstrated in numerous studies, survey findings vary significantly depending on the mode of administration (*e.g., differences between survey findings in the same setting and for the same topic if the survey is mailed vs. given by phone*) and therefore it is important to compare findings appropriately.

The data in Table 6.1 represent nearly 10,000 children and are based on applications of the PHDS through Medicaid in Maine and Washington; Kaiser Permanente Northwest, in Portland, Oregon; and 26 pediatric and family medicine practices in Vermont and North Carolina.

The quality measure findings presented in Table 6.1 are for those quality measures that are presented in a graphic format in Appendices 12–13, 15–16. When presenting comparison information, it is best to use graphics.

**Important Note from the CAHMI:** As was described in Steps 5 and 6, there are a number of options for scoring the PHDS quality measure. Table 6.1 provides the benchmark data for the quality measure scoring approach used for the figures presented in Appendices 12–13, 15–16. Contact the CAHMI ([cahmi@ohsu.edu](mailto:cahmi@ohsu.edu), 503-494-1930) for the benchmark data using alternate scoring approach, quality measures based on reduced-items, or for item-level comparative findings.

**Table 6.1: Comparison Data for the PHDS and ProPHDS Administration by Mail<sup>1</sup>**

<b>PHDS Measure of Care</b>	<b>All PHDS Data by Mail N=9763<sup>2</sup></b>	<b>Range Observed at a Health Plan Level N=6301<sup>3</sup></b>	<b>Range Observed at an Office Level N=4067<sup>3</sup></b>	<b>Range Observed at a Provider Level N=2990<sup>3</sup></b>
<b>Anticipatory Guidance and Parental Education</b>				
Average Percentage of Topics Discussed	<b>50.0</b> std=31.0	<b>36.7-58.3</b>	<b>37.4-67.6</b>	<b>31.5-69.7</b>
Proportion of Children for Whom 80% of Topics Were Discussed	<b>21.8</b>	<b>3.78-37.8</b>	<b>11.5-40.6</b>	<b>0-52.9</b>
Average Percentage of Topics on Which Parents Had Informational Needs Met	<b>82.1</b> std=24.4	<b>67.6-92.1</b>	<b>74.2-93.6</b>	<b>69.4-92.6</b>
Proportion of Children Whose Parents Had Their Informational Needs Met	<b>42.5</b>	<b>29.7-71.0</b>	<b>23.1-67.9</b>	<b>22.2-66.7</b>
<b>Addressing Parental Concerns</b>				
Proportion of Children Whose Parents Were Asked About Their Concerns	<b>55.4</b>	<b>31.2-88.9</b>	<b>42.4-84.8</b>	<b>20.0-92.3</b>
Proportion of Children with Concerned Parents Who Were Asked About Concerns	<b>53.2</b>	<b>31.8-68.6</b>	<b>30.8-85.2</b>	<b>25.0-93.8</b>
Proportion of Children with Concerned Parents Who Received Information that Addressed Their Concerns	<b>59.4</b>	<b>44.4-64.6</b>	<b>18.2-87.0</b>	<b>18.2-91.7</b>

<sup>1</sup> Table 6.1 shows selected PHDS measures of care displayed in the charts of the reporting templates found in Appendices 12–13, 15–16. The table does not show item-level findings or alternate versions for scoring the quality measures that are described in Step 5. For additional information, please see the CAHMI Web site at [www.cahmi.org](http://www.cahmi.org) or contact CAHMI at [cahmi@ohsu.edu](mailto:cahmi@ohsu.edu) or 503-494-1930.

<sup>2</sup> Includes only PHDS and ProPHDS data collected via a mail mode of administration. Overall, CAHMI has collected over 40,000 cases of PHDS data via mail, telephone, and in-office administration. For additional information, please see the CAHMI Web site at [www.cahmi.org](http://www.cahmi.org) or contact the CAHMI at [cahmi@ohsu.edu](mailto:cahmi@ohsu.edu) or 503-494-1930.

<sup>3</sup> The denominator for each of the columns is not the same because health plan, office and/or provider-level analysis were not possible in all of the sites represented in the benchmark data. Therefore, the figures shown represent the range observed for the PHDS benchmark data that was able to be analyzed for the specific unit of analysis and different sites are represented in the columns of the table.

**Table 6.1: Comparison Data for the PHDS and ProPHDS Administration by Mail (Continued)**

<b>PHDS Measure of Care</b>	<b>All PHDS Data by Mail N=9763<sup>4</sup></b>	<b>Range Observed at a Health Plan Level N=6301<sup>5</sup></b>	<b>Range Observed at an Office Level N=4067<sup>3</sup></b>	<b>Range Observed at a Provider Level N=2990<sup>3</sup></b>
<b>Follow-Up for Children at Risk</b>				
Proportion of At-Risk Children Receiving Follow-Up Care	<b>58.3</b>	<b>34.5-67.3</b>	<b>38.9-91.7</b>	<b>33.3-92.8</b>
<b>Assessment of the Family for Psychosocial Issues</b>				
Average Number of Topics Asked About	<b>25.9</b> std=32.8	<b>16.7-34.3</b>	<b>11.6-52.9</b>	<b>11.8-55.4</b>
Proportion of Children Whose Parents Were Asked About One or More Topics	<b>50.7</b>	<b>38.1-70.1</b>	<b>26.5-74.1</b>	<b>18.6-79.4</b>
<b>Assessment of the Family for Substance Abuse, Firearms, and Safety</b>				
Average Number of Topics Asked About	<b>38.5</b> std=33.2	<b>27.2-50.9</b>	<b>15.3-55.8</b>	<b>23.0-63.4</b>
Proportion of Children Whose Parents Were Asked About One or More Topics	<b>70.8</b>	<b>61.3-84.3</b>	<b>26.5-96.7</b>	<b>32.4-98.3</b>
<b>Family-Centered Care</b>				
Average Number of Topics for Which Parent Responded "Usually or Always"	<b>76.3</b> std=30.9	<b>60.1-92.9</b>	<b>59.2-100.0</b>	<b>57.1-99.0</b>

<sup>4</sup> Includes only PHDS and ProPHDS data collected via a mail mode of administration. Overall, CAHMI has collected over 40,000 cases of PHDS data via mail, telephone, and in-office administration. For additional information, please see the CAHMI Web site at [www.cahmi.org](http://www.cahmi.org) or contact the CAHMI at [cahmi@ohsu.edu](mailto:cahmi@ohsu.edu) or 503-494-1930.

<sup>5</sup> The denominator for each of the columns is not the same because health plan, office and/or provider-level analysis were not possible in all of the sites represented in the benchmark data. Therefore, the figures shown represent the range observed for the PHDS benchmark data that was able to be analyzed for the specific unit of analysis and different sites are represented in the columns of the table.

- Consider alternate sources for PHDS benchmark information.

**Table 6.1** provides comparison data for the PHDS/ProPHDS quality measures presented in graphs of the reporting templates provided in Appendices 12–15. Contact CAHMI ([cahmi@ohsu.edu](mailto:cahmi@ohsu.edu), 503-494-1930) if you are interested in the comparison data for item-level findings or alternate versions of the quality measures that were discussed in **Step 5**.

Second, the comparative information provided was based only on the PHDS applications by mail. Additional benchmark data about the PHDS findings obtained via telephone and in-office administration (representing over 15,000 children) are available upon request and reports about these applications are available on the CAHMI Web site ([www.cahmi.org](http://www.cahmi.org)).

Lastly, a majority of the PHDS items were included in the **National Survey of Early Childhood Health (NSECH)**. This survey was conducted by telephone and was only administered to parents of children 3–35 months old. The NSECH data are available online at <http://www.cdc.gov/nchs/about/major/slats/nsech.htm>. The CAHMI article "Measuring the quality of preventive and developmental services for young children: national estimates and patterns of clinicians' performance"<sup>6</sup> describes the PHDS quality measure findings from the NSECH.

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<sup>6</sup> Bethell C, Reuland CP, Halfon N, Schor EL. *Pediatrics*. 2004 Jun;113(6 Suppl):1973–83.



## **STEP 6.6: Review additional resources on reporting health care quality findings**

- 1) For more information about creating health care quality reports, visit the TalkingQuality Web site at [www.talkingquality.gov](http://www.talkingquality.gov).
- 2) Visit [www.nschdata.org](http://www.nschdata.org) for additional tips and resources on communicating data findings to stimulate system change.
- 3) For more information about focus groups and cognitive interviews the Child and Adolescent Health Measurement Initiative has conducted about reporting quality of care findings, visit the Web site at [www.cahmi.org](http://www.cahmi.org).
- 4) For an example of an issue brief that can be created for audiences such as the state Medicaid director, visit the Kansas Health Foundation Web site at [www.kansashealth.org](http://www.kansashealth.org).
- 5) For more information about work the National Academy for State Health Policy (NASHP) has done in working with states to use health and health care findings to implement changes in state programs and policies, visit their Web site at [www.nashp.org](http://www.nashp.org).
- 6) Visit [www.familyvoices.org](http://www.familyvoices.org) for additional family-friendly information on using data and for links to other data sources and sample reports.
- 7) For more information about strategies the Center for Children with Special Needs has used to convene various stakeholders, visit their Web site at [www.cshcn.org](http://www.cshcn.org).
- 8) For more information about how to work with families of children and adolescents with mental health conditions, visit the Federation of Families for Children's Mental Health at [www.ffcmh.org](http://www.ffcmh.org).

## Glossary of Terms for the PHDS Implementation Manual

### A

**Address Correction Service:** A service that allows the sender, **on request** using the appropriate ancillary service endorsement, to obtain the addressee's new (forwarding) address (if the addressee filed a change-of-address order with the USPS) or the reason for non-delivery.

**Adjusted response rate:** A modified response rate that removes from the numerator people who do not fully complete the survey (e.g., answered 80 percent of the items in the survey) and removes from the denominator individuals who were sent the survey but could not complete it because the survey was not delivered to them (due to bad address) or individuals who identified themselves as ineligible to complete the survey (e.g., they do not belong to the health system).

**American Academy of Pediatrics (AAP):** An organization of 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. The AAP offers everything from general child health information to specific guidelines on pediatric issues.

**American Board of Pediatrics (ABP):** One of the 24 certifying boards of the American Board of Medical Specialties. ABP certification provides a standard of excellence by which the public can select pediatricians and pediatric subspecialists.

**Analysis of variance (ANOVA):** A statistical method for analyzing differences.

**Analytic variables:** In this context, analytic variables are the PHDS survey responses, administrative and utilization data, supplemental items, and descriptive information about the health system. These are described in more detail in Section 5.4.

**Anticipatory Guidance and Parental Education (AGPE):** Assesses whether a core subset of recommended anticipatory guidance and parental education topics are discussed, and if not, whether the parent wished the topic had been discussed or if he/she already had information about the topic and did not need to discuss it with their child's health care provider. The AGPE section of the PHDS is based on what is recommended for discussion during well-child care in the American Academy of Pediatrics Health Supervision Guidelines and the Maternal and Child Health Bureau's Bright Futures recommendations.



## B

**Bad address rate:** The rate of addresses in your database that are estimated to be incorrect.

**Behavioral Risk Factor Surveillance Survey (BRFSS):** A state survey of U.S. adults designed to gather information about a wide range of behaviors that affect health. The primary focus of these surveys has been behaviors and conditions linked with the leading causes of death—heart disease, cancer, stroke, diabetes, and injury.

## C

**CAHMI recommendations:** Recommendations from the Child and Adolescent Health Measurement Initiative based on its learning and experiences since 1997.

**Care coordination (CC):** Services that promote the effective and efficient organization and utilization of resources to ensure access to necessary comprehensive services for children.

**Care team:** The various caregivers who provide different components of care i.e., the physician (pediatrician, family physician), nurse practitioner, and nurse.

**Change concepts:** Strategies for improving the quality of care provided.

**Child and Adolescent Health Measurement Initiative (CAHMI):** CAHMI is a national initiative based out of Oregon Health & Science University in the Department of Pediatrics. Originally housed at FACCT (Foundation for Accountability), CAHMI was established in 1998 to develop and facilitate the implementation of a comprehensive set of consumer-centered quality measurement tools. The CAHMI Web site is [www.cahmi.org](http://www.cahmi.org)

**Chi-squared ( $x^2$ ) test:** A statistical method for testing differences in proportions.

**Coded responses:** Responses designated by a code. For example: 1=yes, 2=no.

**Cognitive ease:** The ease of processing information, applying knowledge, and changing preferences.

**Cognitive testing:** Testing any self-designed new items added to the survey to make sure the wording is interpreted in the way you intended.

**Comparative information:** A data display that facilitates comparison by showing quality of scores for different groups of children or by specific characteristics

**Comprehensive-care composite or “got all care”:** Summarizes the number of children who received all aspects of the recommended care assessed by the PHDS. The “got all care” measure summarizes the quality of care findings across the individual, topic-specific measures of care in the PHDS.

**Confidentiality:** Ensuring that information is accessible only to those authorized to have access. For the PHDS, confidentiality is the process used to ensure that no personal health information about the child or parent is maintained at the end of the project.

**Consumer Assessment of Health Providers and Systems (CAHPS®):** A private–public initiative that develops and supports the use of a comprehensive and evolving family of standardized surveys that ask consumers and patients to report on and evaluate their experiences with health care.

**CAHPS-CCC (Children with Chronic Conditions):** A set of measurements that assesses children with chronic conditions developed by CAHMI. More information about this tool can be found on the CAHMI Web site at [www.cahmi.org](http://www.cahmi.org).

**Consumer information framework (CIF):** The CIF was developed by CAHMI staff while CAHMI was part of the Foundation for Accountability. The CIF has four components: *messages* to inform consumers and enable their decisions; a *model* to organize information; *measures* that support meaningful and understandable evaluations of performance; and *methods* for scoring and grading performance and presenting results. The CIF model organizes health care quality information into four categories: the basics/staying healthy; getting better; living with illness; and changing needs.

**Count variable:** A count variable is one which may take on only a countable number of distinct values such as 0, 1, 2, 3, 4, ...

**Cross-tabulation:** A table of survey results, with several rows and columns of figures.

## D

**Data dictionary:** Contains a description of the variables that will be in a data set and describes the response codes and definitions for each of the variables.

**Desired population:** The population that represents a group that you want to apply your research to. Populations are often defined in terms of demography, geography, occupation, time, care requirements, diagnosis, or some combination of the above.

**Discrete, binomial measure:** A discrete, binomial variable is one which may take on only a countable number of distinct values such as 0, 1, 2, 3, 4, ... Discrete, binomial variables are usually (but not necessarily) counts. A discrete variable X is said to follow a binomial distribution with parameters.

## E

**Early and Periodic Screening, Diagnostic and Treatment (EPSDT):** The comprehensive and preventive child health program for individuals in Medicaid under age 21. The program includes periodic screening, vision, dental, and hearing services and was defined by law as part of the Omnibus Budget Reconciliation Act of 1989 (OBRA 89) legislation. EPSDT consists of two mutually supportive operational components: (1) assuring the availability and accessibility of required health care resources; and (2) helping Medicaid recipients and their parents or guardians effectively use these resources. See <http://www.cms.hhs.gov/medicaid/epsdt/>.

**Electronic medical records:** A computer-based patient medical record.

**External quality review:** Current federal regulations issued by the Centers for Medicare and Medicaid Services (CMS) obligate states to develop a written strategy for assessing the quality of care for Medicaid beneficiaries in managed care plans. These regulations require states to adopt standardized methods for quality review activities, specify mandatory and optional quality review activities, and provide specific protocols for conducting quality reviews. In return, the regulations give states an enhanced federal match for quality review activities and broaden the types of organizations eligible to conduct reviews. (Definition obtained from [http://www.cmwf.org/publications/publications\\_show.htm?doc\\_id=278078](http://www.cmwf.org/publications/publications_show.htm?doc_id=278078))

**External vendor/team:** Partners outside of your team hired to handle the parts of the process of implementing the PHDS that you may not be able to handle internally due to time constraints or lack of expertise.

## **F**

**Family-centered care (FCC):** A system or philosophy of care that incorporates the family as an integral component of the health care system. The PHDS measure assessing family-centered care focuses on the quality of the communication between the health care provider and the family, as well as the overall experience of care.

**Frequencies, or frequency distribution:** In a survey, a table showing what number (or percentage) of respondents gave each answer to a question.

**Frontline health care providers:** Providers who work in clinical settings and provide the health care measured in the PHDS.

## **G**

**“Gold standard”:** What is achievable or what parents should expect from their child’s health care providers.

## **H**

**Health care utilization:** How much health care people use. For example: how many visits they have, the kinds of visits they have.

**Health Insurance Portability and Accountability Act (HIPAA):** The U.S. Congress passed the Health Insurance Portability and Accountability Act (HIPAA) in 1996. Title I of HIPAA protects health insurance coverage for workers and their families when they lose or change their jobs. Title II of HIPAA, the Administrative Simplification (AS) provisions, requires the establishment of national standards for electronic health care transactions and national identifiers for providers, health insurance plans, and employers. The AS provisions also address the security and privacy of health data. The purpose of all these standards is to improve the efficiency and effectiveness of the nation's health care system by encouraging the widespread use of electronic data interchange in health care. (Definition derived from [www.hipaacompliance.biz](http://www.hipaacompliance.biz))

**Health system characteristics:** Specific processes, systems, and resources in the health system that are related to the topics measured in the PHDS.

**Health Plan Employer Data and Information Set (HEDIS):** A collection of standardized performance measures and their definitions designed to ensure that purchasers and consumers can reliably compare the performance of managed health care plans. The performance measures are related to public health issues such as cancer, heart disease, and asthma and also include

well-child visits. HEDIS is sponsored, supported, and maintained by the National Committee for Quality Assurance. See <http://www.ncqa.org/Programs/HEDIS>.

## I

**Individual provider variation:** The dissimilarity of care that a provider gives to various children and families.

**Ineligible cases:** Children who do not meet the sampling criteria for age and continuous enrollment.

**Institutional review board (IRB):** An appropriately constituted group that has been formally designated to review and monitor biomedical and behavioral research involving human subjects. In accordance with Food and Drug Administration (FDA) and HHS regulations, an IRB has the authority to approve, require modifications in (to secure approval), or disapprove research. An IRB performs critical oversight functions for research conducted on human subjects that are *scientific, ethical, and regulatory*.

**Interim data sets:** Early versions of the data set provided when a specific number of surveys have been received and/or are complete.

**Internal team:** The team within your office involved in implementing the PHDS survey.

**Item-level survey responses:** Responses to each question in the survey.

## K

**Kaiser Permanente Northwest (KPNW):** A managed care organization. KPNW covers the Oregon and Washington region for Kaiser Permanente.

## M

**Maintenance of Certification (MOC):** The American Board of Medical Specialties adopted MOC to replace periodic recertification. MOC consists of four components: demonstration of professionalism (part I); commitment to life-long learning (part II); demonstration of cognitive expertise (part III); and evaluation of performance in practice (part IV).

**Maternal and Child Health Bureau (MCHB):** A bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services. MCHB provides leadership to both the public and private sectors for the delivery of health care services to all mothers and children.

**MCHB Bright Futures:** Bright Futures is a national initiative begun by MCHB to promote and improve the health and well-being of children from birth through adolescence. Bright Futures is dedicated to the principle that every child deserves to be healthy and that optimal health involves trusting relationships among the health professional, the child, the family, and the community as partners in health practice.

**Mean variable:** The mean is the arithmetic average of a data set (the sum of the values divided by number of values). (Definition derived from the BRFSS site <http://www.cdc.gov/brfss>)

**Medicaid:** The U.S. health insurance program for individuals and families with low incomes and resources. It is jointly funded by the states and federal government, and is managed by the states. Among the groups of people served by Medicaid are eligible low-income parents, children, seniors, and people with disabilities. Medicaid is the largest source of funding for medical and health-related services for people with limited income.

**Medical chart:** A chronological written account of a patient's examination and treatment that includes the patient's medical history and complaints, the physician's physical findings, the results of diagnostic tests and procedures, and medications and therapeutic procedures.

**Medline:** Medical Literature Analysis and Retrieval System Online (Medline) is an international literature database of life sciences and biomedical information. It covers the fields of medicine, nursing, pharmacy, dentistry, veterinary medicine, and health care.

**Microsystems:** Clinical microsystems are the frontline units that provide most health care to most people. They are the places where patients, families, and care teams meet. Microsystems also include support staff, processes, technology and recurring patterns of information, behavior and results. Central to every clinical microsystem is the patient. (Definition derived from <http://www.clinicalmicrosystem.org>)

## N

**National Academy for State Health Policy (NASHP):** An organization that works with states to use health and health care findings to implement changes in state programs and policies. (<http://www.nashp.org>).

**National Committee for Quality Assurance (NCQA):** A private, not-for-profit organization dedicated to improving health care quality. NCQA generates useful, understandable information about health care quality to help inform consumer and employer choice. It also works to generate information and feedback that helps physicians, health plans, and others to identify opportunities for improvement and make changes that enhance the quality of patient care.

**National Health Interview Survey (NHIS):** Obtains information about the amount and distribution of illness, its effects in terms of disability and chronic impairments, and the kinds of health services people receive.

**National Healthcare Quality Report:** A report developed by the Agency for Healthcare Research and Quality (AHRQ) that is the first national comprehensive effort to measure the quality of health care in America. The report includes a broad set of performance measures that can serve as baseline views of the quality of health care. The report presents data on the quality of services for seven clinical conditions, including cancer, diabetes, end-stage renal disease, heart disease, HIV and AIDS, mental health, and respiratory disease. It also includes data on maternal and child health, nursing home and home health care, and patient safety.

**National Survey of Children with Special Health Care Needs (NS-CSCHN):** A survey sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration. The primary goal of the NS-CSCHN is to assess the prevalence and impact of special health care needs among children in all 50 states and the District of Columbia. This survey explores the extent to which children with special health care needs (CSHCN) have medical homes, adequate health insurance, and access to needed services. Other topics include care coordination and satisfaction with care. (Definition derived from [cdc.org](http://cdc.org))

**National Survey of Children's Health (NSCH):** A survey sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration that examines the physical and emotional health of children ages 0–17 years of age. Special emphasis is placed on factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. (Definition derived from [cdc.org](http://cdc.org))

**National Survey of Early Childhood Health (NSECH):** This survey provides national baseline data on pediatric care (and its impact) from the parent's perspective. Questions focus on the delivery of pediatric care to families with children under 3 years of age and the promotion of young children's health by families in their homes. Parents of more than 2,000 children were interviewed for this survey.

**Negative indicator measures:** Proportion of children who did not receive recommended care.

## O

**Office Systems Inventory (OSI):** Collects descriptive information about specific office systems related to meeting informational needs and addressing concerns, identifying children at risk, providing strong links to community resources, and promoting optimal parent/child relationships.

**Over-sample:** A sampling procedure designed to give a demographic or geographic population a larger proportion of representation in the sample than the population's proportion of representation in the overall population. Over-samples are often used to study the attitudes or behavior of groups that make up a small proportion of the total population. For instance, one might over-sample African Americans for a study on discrimination, or people ages 65 and over for a study about Medicare.

## P

**Parents Evaluation of Developmental Status (PEDS®):** The PEDS is a methodology developed by Frances Glascoe, Ph.D., for detecting developmental and behavioral problems in children from birth to 8 years of age. This methodology involves asking parents to complete a 10-item questionnaire, which takes only a few minutes. More information about the PEDS can be found at: <http://www.pedstest.com>

**Patient-centered care:** Health care where patients are respected, listened to, and partnered with so that their needs and preferences are met. In this context, it applies to the helpfulness of care provided to parents and the effect of care on parental confidence.

**Payor:** The person to whom a note or bill has been or should be paid. In health care, the payor is typically the insurance company, Medicare, Medicaid, or the individual.



**Person-identifiable data:** Information that can be linked, directly or indirectly, to individual people. Examples include name, geographical subdivisions, phone numbers, social security number, and health records to name a few.

**Practice-level assessment:** Examines the quality of the health care by specific health care providers or by the place (e.g., office) where care was received.

**Pre-notification letter:** A letter sent to each selected child in a strategy to maximize response rates, ensure confidentiality, describe how results will benefit the respondent, and provide instructions on how to complete the survey

**Pro-PHDS:** The reduced item version of the PHDS that includes three age-specific versions: 3–9.99 months old, 10–18.99 months old, and 19–47.99 months old.

**PHDS-PLUS:** An additional version of the PHDS for telephone administration.

**Provider well-child templates:** Standardized forms that can be used by the provider for well-child visits that list topics to cover in the visit.

**Psychosocial issues in the family:** Asking the parent about their own psychological and social aspects of well-being, including depression, emotional support, changes or stressors in the home, and how parenting is working.

## Q

**Quality chasm:** A term drawn from a report from the Institute of Medicine's Committee on the Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the 21st Century*, which urgently calls for fundamental change to close the quality gap. The report authors recommend a redesign of the American health care system, and provide overarching principles for policymakers, health care leaders, clinicians, regulators, purchasers, and others. It offers a set of performance expectations for the 21st century health care system, a set of 10 new rules to guide patient-clinician relationships, a suggested organizing framework to better align incentives inherent in payment and accountability with improvement in quality, and key steps to promote evidence-based practice and strengthen clinical information systems.

**Quality measures:** Measures that summarize information from between one and 18 individual PHDS items and assess individual components of recommended preventive and developmental care. They are scored on a 0–100 scale, where 0 indicates that recommended care is not received and 100 indicates that all aspects of care were received.

**Quality scores:** Scores on quality measures.

## R

**Raw response rate:** The number of questionnaires returned divided by the number of children in your starting sample.

**Recode:** Reassigns the values of existing variables or collapses ranges of existing values into new values.

**Reporting audience:** The audience that you are reporting survey results to.

**Request for Proposals (RFP), or invitation to bid:** A proposal made by a commercial organization inviting bids from possible suppliers of a product or service, or by a government or other funding agency inviting bids from possible research bodies.

## S

**Socio-demographic characteristics:** Characteristics of human populations, such as risk for depression, relationship to child, education level, and marital status.

**Stakeholder:** A person who is (or might be) affected by any action taken by an organization or group. Examples are parents, children, customers, owners, employees, associates, partners, contractors, suppliers, and people that are related or located near by. Any group or individual who can affect or who is affected by achievement of a group's objectives.

**Standardized Developmental and Behavioral Screening (SDBS):** Screening for developmental and behavioral delays that occurs through the use of a standardized, valid screening tool.

**Staying Healthy domain of the Consumer Information Framework:** The Consumer Information Framework (CIF) is a customer-centered framework for quality measurement that is based on what consumers conveyed as their health care needs across the lifespan, encompassing the following four domains: Staying Healthy, Getting Better, Living with Illness or Disability,

and Coping with the End of Life. The "Staying Healthy" domain focuses on health care aimed at prevention and early detection of health or developmental problems.

**Survey disposition:** The current status of the survey in the survey administration process (e.g., whether the survey was completed, and if so, when in the process it was sent back).

## T

**T-test:** Differences in mean scores between two groups.

**Threshold measure:** A threshold measure is a binomial measure identifying children who did and did not receive a threshold level of quality of care. The thresholds for the PHDS measures were based on consensus obtained from the PHDS advisors about the level of care considered "high quality" for each measure and concurrent validity runs of the threshold measures with other PHDS measures and child/parent outcomes. More information about the threshold measures can be found in the papers listed in Appendix B.

## U

**Units of analysis:** The entities, areas, or groups by which the PHDS findings are analyzed. Each unit has different specifications for sampling.

**Utilization data:** Data representing the amount of services used prior to the survey.

## W

**Weekly tracking reports:** Reports that describe the survey response rates throughout the administration process and reported on a weekly basis by your vendor.

**Weighting methodology:** A technique used to assure representation of certain groups in the sample. Data for underrepresented cases are weighted to compensate for their small numbers, making the sample a better representation of the underlying population.

**Well-child care:** Well-child examinations are intended to assess children's growth and development, recognize problems early on, provide immunizations, educate parents, and provide treatment for existing problems. The American Academy of Pediatrics and the Maternal and Child Health Bureau provide guidelines and a schedule for well-child visits.



## Appendix 1



### **Call to Action for Health System Leaders: Why Health System Should Use the PHDS**



## The Promoting Healthy Development Survey (PHDS)

*A Tool to Address the Quality Chasm in Well-Child Care for Young Children*

Well-child care is the **heart of health care** for children. There is a **quality chasm** in the **provision of well-child care** that needs to be addressed.

**9 in 10** young children have one or more UNMET preventive and developmental service need.

**6 in 10** young children have parents who DO NOT receive needed guidance and education they want on key issues related to promoting their child's health and development.

**Only half** of young children with significant risks to their development receive some type of follow-up addressing their risks.

**Only half** of young children have parents who were asked about smoking, alcohol and drug use in the home.

**Fewer than half** of mothers of young children who have symptoms of depression are screened for depression.



The PHDS can build **partnerships** among health plans, providers and parents to **create solutions** for closing the quality gap in well-child care for young children.

**A Tool for Health Plans:** Most health plans are **required by purchasers** to provide a range of specific preventive and developmental services to young children, yet the well-visit rate and satisfaction **measures used are not valid** for assessing what happens during well-child visits.

**Solution:** Health plans need valid, feasible, cost efficient strategies like the PHDS to demonstrate their commitment to being a **child-centered health plan** and **attract and keep families** with young children as members.

**A Tool for Providers:** Pediatric providers **prioritize well-child visits** with parents, yet many struggle to address all well-child care recommendations and **cannot meet parents needs** with the available time, tools and resources.

**Solution:** Providers need tools and strategies to **customize care** to better meet the needs of their families. The PHDS provides actionable information from parents about how to **better target services** to meet their needs during well-child visits.

**A Tool for Health Plan Members:** Parents of young children **want more** information and resources from their pediatric providers and health plans, yet many parents do not **effectively utilize the well-child visit** and provider and health plan resources to best **meet their needs** and the needs of their child.

**Solution:** Using the PHDS, parents **learn and provide feedback** about where their needs are and are not being met. Health plan **websites and pre-visit questionnaires** anchored to PHDS measures **optimize time spent** with providers and engage the family as active partners during well-visits.

### MEASUREMENT THAT MATTERS

Health care to promote the healthy development of young children mostly relies on **good communication and partnerships** with parents and valid tools and strategies to **assess and minimize risks** and **optimize assets** of children and families.

The Promoting Healthy Development Survey (PHDS) provides health plans, providers and parents with a reliable, valid and feasible tool to assess the quality of what happens during well-child visits in order to target tailored improvements that meet the needs of parents AND providers and promote children's healthy development.

**The only way to know if quality care was provided is to ask parents.**





## PROMOTING HEALTHY DEVELOPMENT SURVEY (PHDS) *Fast Facts!*

The Promoting Healthy Development Survey (PHDS):

- ◆ Is a survey of parents, requiring **12-15 minutes** to complete.
- ◆ Focuses on **clinical aspects of recommended** well-child care.
- ◆ Focuses on topics **parents can validly report on**.
- ◆ Focuses on topics where **there is the strongest evidence**.
- ◆ Has been **validated and tested** for use in health plans, pediatric offices and geographic areas.
- ◆ Has been used in numerous State Medicaid agencies and incorporated into national surveys

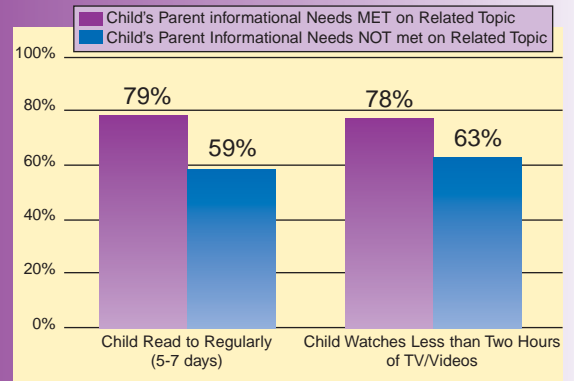
### Meeting Parents Informational Needs

#### Actionable Information Obtained In The PHDS

- ◆ Priority Topics: Approximately 18 recommended anticipatory guidance and parental education topics parents care about and can report are included.
- ◆ Responses that Inform: If a topic is not discussed with parents, parents indicate whether or not they would have liked providers to discuss the topic.
- ◆ Descriptive information is captured about key parenting behaviors that protect and promote a child's health and development (e.g. reading to children, safety precautions, TV watching, etc.)

#### Why Does This Matter?

Parents with their Informational Needs Met are More Likely to do Positive Family Activities



### Asking about and Addressing Parental Concerns

#### Actionable Information Obtained In The PHDS

- ◆ Whether parents are asked about and get information about their concerns.
- ◆ Whether children are at-risk for developmental delays and receive some level of follow-up care.
- ◆ What specific concerns parents have about their child. (*Items from the Parent Evaluation of Developmental Status® tool included in the PHDS*)

#### Why Does This Matter?

- ◆ Asking about parent concerns using a standardized developmental screening tool is essential to determining a child's risk for delays.
- ◆ Children who are identified and receive treatment earlier are more likely to enter school ready to learn.

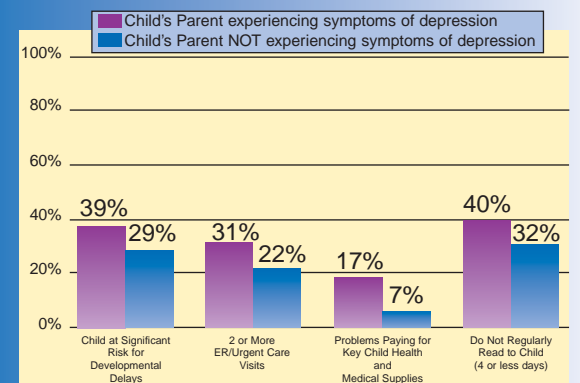
### Screening Families for Risks to the Child's Health

#### Actionable Information Obtained In The PHDS

- ◆ Whether pediatric providers screen parents for key risks to the child's health, including substance abuse, parental depression and physical and emotional safety in the home.
- ◆ Descriptive information about the number of parents currently experiencing symptoms of depression. (*Items from the Kathi Kemper, MD Depression Screener included in the PHDS*)

#### Why Does This Matter?

Relationship between children with parents who are depressed and other family/child factors



**“We would not be engaged in national discussions about developmental services without the information provided by the PHDS.”**

*The Chairman of the Board of the National Initiative for Children's Healthcare Quality, David Bergman, M.D.*

# HOW CAN A HEALTH PLAN USE THE PHDS?

## BASELINE QUALITY MEASUREMENT

Health plans can use the PHDS to gather baseline data and to compliment and enhance their current quality measurement activities. The PHDS has been used by health plans to evaluate quality across the entire system and by **specific office settings and individual providers**. The PHDS has been feasibly administered using a **mail or telephone mode of administration**.

## ENHANCED USE OF HEALTH PLAN WEBSITE FOR MEMBERS

The PHDS can be added to a **health plan's member website**. Parents can **complete the survey and get feedback** about questions they should ask at their child's well-child visit. Information about the topics asked about in the PHDS can be placed on the website. On the back-end, health plans can gather baseline data from these completed surveys and identify improvement opportunities.

## IN-OFFICE ADMINISTRATION

A **reduced-item version of the PHDS** has been developed, tested and **implemented pediatric office settings**. The parent can complete the PHDS when the check-in using either a paper/pencil version or computer kiosks available in the waiting room.

## How does the PHDS compare to other commonly used measures of quality?

### HEDIS Well-Child Visit:

- ◆ The current HEDIS measure focused on well-child visit provides information about children's access to well-child care, not what they receive when they come in.
- ◆ A national study published in *Pediatrics* showed that only about one third of children who had well-visits received a basic set of recommended well-child care services measured by the PHDS.

### Consumer Satisfaction Surveys

(For example: CAHPS, Picker, Art of Medicine Surveys)

- ◆ Satisfaction surveys yield different results about quality than a survey about clinical-quality like the PHDS.
- ◆ A study conducted in a large health plan showed that the PHDS and a common consumer experience and satisfaction surveys agreed less than 50% of the time in identifying high and poor quality providers.

**“The PHDS altered the whole way I provide care. It made me think about how I can put my families first and meet their needs better.”**

*Fred Holmes, M.D.  
Mousetrap Pediatrics*

## AN EXAMPLE OF HOW A HEALTH PLAN USED THE PHDS:

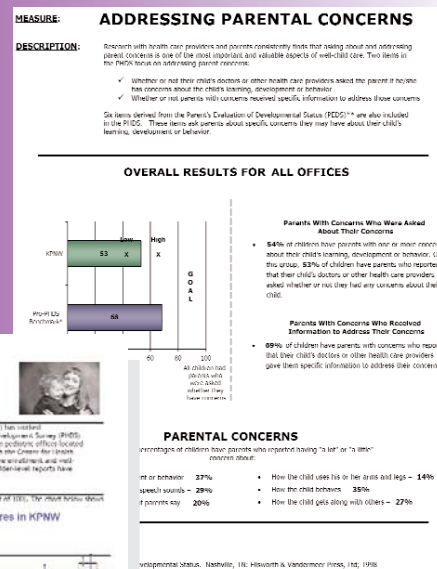
Kaiser Permanente Northwest (KPNW) implemented the PHDS to assess health care quality and identify improvement opportunities across the health plan, within pediatric offices and across pediatric providers. **Office- and provider-level reports** were disseminated to front-line health care providers and a strategic report was used by senior leaders to identify leverage arms for improvement and engage key stakeholders to identify champions in leveraging member health education efforts and website and electronic medical record systems to implement **feasible change concepts**, including:

### Meet Parents Informational Needs:

- ◆ Enhance and focus parent education and activation materials on areas where PHDS shows parent needs are least likely to be met.
- ◆ Prompt providers to focus on areas where parent needs are not met using the electronic medical record.

### Use Pre-Visit Questionnaires for Standardized Screening:

- ◆ Advance the pre-visit use of parent completed standardized developmental screening tools and standardized parental depression screening tools.
- ◆ Report findings to pediatric providers for use during the child's well-visit.



## Examples of Reports



## The Promoting Healthy Development Survey (PHDS)

*Produced with support from The Commonwealth Fund.  
The PHDS and related tools are available for free on the CAHMI website at [www.cahmi.org](http://www.cahmi.org)  
and the Commonwealth Fund website at [www.cmwf.org](http://www.cmwf.org).*

### PHDS Availability and Benchmark Data

The PHDS and related tools are available for free on the CAHMI website at [www.cahmi.org](http://www.cahmi.org).

To date, the CAHMI has worked with State Medicaid agencies, health plans and pediatric practices to implement the PHDS, collecting over 20,000 cases of benchmark data and representing over a half million young children. In addition, items from the PHDS are included in the National Survey of Early Childhood Health and the National Survey of Children's Health.



### Implementation Support

The PHDS was initially developed and tested for use in health plans and is the only available, valid and reliable parent reported tool to assess the receipt of many aspects of recommended well-child care essential to ensuring the healthy development of young children that are not currently measured in most health plans.

The PHDS development team welcomes the opportunity to engage in strategic conversations with interested health plans in how they can use the PHDS and other CAHMI consumer-based quality measurement tools as part of their quality measurement and improvement strategy.

#### The Child and Adolescent Health Measurement Initiative

Oregon Health & Science University  
Department of Pediatrics, School of Medicine  
707 S.W. Gaines Road, Mail Code CDRCP  
Portland, Oregon 97239-2998

### PHDS Tools and Resources

Available on the CAHMI Website:  
[www.cahmi.org](http://www.cahmi.org)

Tools and resources for using the PHDS available on the CAHMI website include:

1. Downloadable versions of the PHDS for administration  
(mail, telephone, online or in-office versions available)
2. Administration protocols and materials  
(For example: process, timelines, cover letters, reminder post cards)
3. Example results reporting templates  
(For example: Reporting templates to use in sharing the findings with front-line health care providers)
4. Examples from past users  
(For example: Highlights of how Kaiser Permanente Northwest used the PHDS)
5. Other PHDS related publications and resources, such as peer reviewed papers and

### CAHMI Contact Information

Website: [www.cahmi.org](http://www.cahmi.org)

Email: [cahmi@ohsu.edu](mailto:cahmi@ohsu.edu)

Phone: 503.494.1930







## Appendix 2: PHDS tools and resources



### *CAHMI Contact Information*

- **Website:** [www.cahmi.org](http://www.cahmi.org)
- **Phone Number:** 503-494-1930
- **Email:** [cahmi@ohsu.edu](mailto:cahmi@ohsu.edu)

*For more information on the development of the PHDS and quality measures included in the PHDS, refer to the following publications, review the CAHMI website ([www.cahmi.org](http://www.cahmi.org)) or contact the CAHMI:*

- Bethell C, Reuland C, Schor E. Assessing health system provision of well-child care: The Promoting Healthy Development Survey. *Pediatrics*. 2001 May; 107(5):1084-94.
- Bethell C, et al. Partnering with Parents to Promote the Healthy Development of Young Children Enrolled in Medicaid. September 2002. Available at:  
[http://www.cmwf.org/programs/child/bethell\\_partnering\\_570.pdf](http://www.cmwf.org/programs/child/bethell_partnering_570.pdf)
- Bethell, C, et al, Measuring the quality of preventive and developmental services for young children: National estimates and patterns of clinicians' performance. *Pediatrics*. 2004 Jun;113(6 Suppl):1973-83.
- Reuland C, Bethell C. Key Measurement in Screening, Referral, and Follow-Up for Care for Young Children's for Children's Social and Emotional.  
[http://www.nashp.org/Files/measurement\\_paper\\_for\\_web\\_final\\_4.7.05.pdf](http://www.nashp.org/Files/measurement_paper_for_web_final_4.7.05.pdf)
- Blumberg SJ, Halfon N, Olson LM. The National Survey of Early Childhood Health *Pediatrics*. 2004 Jun;113(6 Suppl):1899-906.  
[http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list\\_uids=15173460&query\\_hl=5&itool=pubmed\\_docsum](http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=15173460&query_hl=5&itool=pubmed_docsum)
- Kogan MD et. al. Routine assessment of family and community health risks: parent views and what they receive. *Pediatrics*. 2004 Jun;113(6 Suppl):1934-43. Erratum in: *Pediatrics*. 2005 Sep;116(3):802.  
[http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list\\_uids=15173464&query\\_hl=1&itool=pubmed\\_docsum](http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=15173464&query_hl=1&itool=pubmed_docsum)

- Halfon N et. al. Assessing development in the pediatric office. Pediatrics. 2004 Jun;113(6 Suppl):1926-33.  
[http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list\\_uids=15173463&query\\_hl=4&itool=pubmed\\_docsum](http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=15173463&query_hl=4&itool=pubmed_docsum)
- Zuckerman B et. al. Prevalence and correlates of high-quality basic pediatric preventive care. Pediatrics. 2004 Dec;114(6):1522-9.  
[http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list\\_uids=15574610&query\\_hl=5&itool=pubmed\\_docsum](http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=15574610&query_hl=5&itool=pubmed_docsum)

*For more information about the Promoting Healthy Development Tools and Implementation Guidelines, visit the CAHMI website for the following documents:*

- Promoting Healthy Development Survey Toolkit  
<http://cahmi.org/ViewDocument.aspx?DocumentID=128>
- In-Office Administration of the Reduced-Item Promoting Healthy Development Survey (ProPHDS) Manual  
<http://cahmi.org/ViewDocument.aspx?DocumentID=184>
- Promoting Healthy Development Survey-PLUS (PHDS-PLUS) Implementation Guidelines  
[http://www.commonwealthfund.org/publications/publications\\_show.htm?doc\\_id=463475](http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=463475)
- Measure of Standardized Developmental and Behavioral Screening: Users Tip Sheet <http://cahmi.org/ViewDocument.aspx?DocumentID=69>

Examples of reports and presentations highlighting how the PHDS has been used and key findings:

- A comprehensive list of references used in the development of the Promoting Healthy Development Survey.  
<http://cahmi.org/ViewDocument.aspx?DocumentID=162>
- Background on the Promoting Healthy Development Survey, which measures the quality of preventive and developmental care for young children. <http://cahmi.org/ViewDocument.aspx?DocumentID=183>
- The PHDS-PLUS is a telephone administered version of the PHDS. The PHDS-PLUS contains additional items about the child's health and health care utilization and items asking the parent about their health and other socio-demographic characteristics.  
<http://www.cahmi.org/pages/Topics.aspx?section=8&topic=82&parent=8>

- Learn how the PHDS has been implemented in pediatric offices.  
<http://cahmi.org/ViewDocument.aspx?DocumentID=135>
- Get quick information about the PHDS.  
<http://cahmi.org/ViewDocument.aspx?DocumentID=54>
- This slideshow was presented at the 2001 Association of Maternal and Child Health Programs annual meeting and provides background information on the PHDS. It also describes how the PHDS was implemented in Washington state.  
<http://cahmi.org/ViewDocument.aspx?DocumentID=201>
- This slideshow describes how CAHMI worked with the Maine Medicaid program to implement the PHDS for quality assessment and improvement purposes. <http://cahmi.org/ViewDocument.aspx?DocumentID=203>
- This report highlights key findings from a state-wide PHDS survey to parents of Medicaid clients in Washington State.  
<http://cahmi.org/ViewDocument.aspx?DocumentID=136>
- A presentation at the National Initiative for Children's Healthcare Quality (NICHQ) Annual Forum about work CAHMI is doing with pediatric offices to implement the PHDS as part of their quality improvement strategies.  
<http://cahmi.org/ViewDocument.aspx?DocumentID=43>
- This presentation is about how the PHDS can be used at a state level for various quality measurement and improvement purposes. This Users Liason Program meeting was sponsored by the Agency for Healthcare Research and Quality (AHRQ) and coordinated by National Academy for State Health Policy.  
<http://cahmi.org/ViewDocument.aspx?DocumentID=202>
- A poster presentation on the development and testing of the Promoting Healthy Development Survey in three health plans. Presented at the AcademyHealth (formerly Association for Health Services Research) 2001 annual meeting. <http://cahmi.org/ViewDocument.aspx?DocumentID=205>
- Summary of Interviews & Focus Groups with Parents of Young Children: Reporting the Promoting Healthy Development Survey (PHDS) Findings to Parents. <http://cahmi.org/ViewDocument.aspx?DocumentID=167>
- A summary of CAHMI's practice-level Promoting Healthy Development Survey (PHDS) project.  
<http://cahmi.org/ViewDocument.aspx?DocumentID=135>
- More than 19 pediatric and family medicine practices in Vermont will receive practice-specific data findings as a result of this project. Learn how the PHDS was implemented and some of its high level findings.  
<http://cahmi.org/ViewDocument.aspx?DocumentID=142>

*For more information on national guidelines and recommendations measures by the PHDS:*

### **Federal Maternal and Child Health Bureau's Bright Futures**

- <http://www.brightfutures.org/bf2/about.html>
- Green M, ed. Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents. Arlington, VA: National Center for Education in Maternal and Child Health; 1994.
- Important Note: The Bright Futures recommendations are currently being revised by the American Academy of Pediatrics. For information about the update recommendations, please review the following resource:  
<http://brightfutures.aap.org/web/>

### **American Academy of Pediatrics Health Supervision Guidelines**

- <http://www.aap.org>
- American Academy of Pediatrics. Guidelines for health supervision III. Chicago, IL: American Academy of Pediatrics; 1997.

### **US Preventive Services Task Force**

- <http://www.ahrq.gov/clinic/uspstfix.htm>
- U.S. Preventive Services Task Force. Guide to Clinical Preventive Services, 2nd ed. Washington, DC: Office of Disease Prevention and Health Promotion, U.S. Government Printing Office, 1996.

*For more information about national surveys that have incorporated items from the PHDS:*

### **National Survey on Early Childhood Health (NSECH)**

- <http://www.cdc.gov/nchs/about/major/slait/nsech.htm>

### **National Survey of Children's Health**

- <http://www.cdc.gov/nchs/about/major/slait/nsch.htm>
- <http://www.nschdata.org/Content/Default.aspx>

*For more information about improvement efforts focused on preventive and developmental services:*

Note: The list below only represents those organizations that the CAHMI has worked with in considering how the PHDS fits within their models for improvement and is not a full listing of quality improvement resources related to preventive and developmental health care.

## Center for Health Care Quality

- Established at Cincinnati Children's Hospital Medical Center, the center is a resource for health care providers throughout the world to make the highest-quality care a reality for children and their families. The Center for Health Care Quality is the result of a merger of the Center for Children's Healthcare Improvement, formerly based at the University of North Carolina at Chapel Hill, and the [Center for Health Policy and Clinical Effectiveness](#) at Cincinnati Children's, which not only does improvement work but also conducts research into interventions that improve health outcomes in the community and the home.

<http://www.cincinnatichildrens.org/svc/alpha/h/health-policy/>

## UCLA Center for Healthier Children, Families and Communities (CHCFC).

- The Center is a multi-disciplinary program of the UCLA School of Medicine, Department of Pediatrics and the UCLA School of Public Health, dedicated to improving society's ability to provide children with the best opportunities for health and well-being, and the chance to assume productive roles within families and communities.  
<http://www.healthychild.ucla.edu/>
- **Specific Report of Interest:** Quality of Preventive Health Care for Young Children: Strategies for Improvement, Neal Halfon, M.D., M.P.H., Moira Inkelas, Ph.D., M.P.H., Melinda Abrams, M.S., and Gregory Stevens, Ph.D., M.H.S., The Commonwealth Fund, May 2005 Quality of Preventive Health Care for Young Children: Strategies for Improvement:  
[http://www.cmwf.org/publications/publications\\_show.htm?doc\\_id=275484](http://www.cmwf.org/publications/publications_show.htm?doc_id=275484)

## Healthy Development Collaborative

- A Practical Guide for Improving Child Developmental Services.  
[http://www.cmwf.org/tools/tools\\_show.htm?doc\\_id=372065](http://www.cmwf.org/tools/tools_show.htm?doc_id=372065)

## Healthy Steps Model

- Healthy Steps for Young Children is a national initiative aimed at enhancing the quality of preventive health care for infants and toddlers. Established with Commonwealth Fund support, the program emphasizes a close relationship between health care professionals and parents in addressing the physical, emotional, and intellectual development of children from birth to age 3.  
[http://www.cmwf.org/general/general\\_show.htm?doc\\_id=246567](http://www.cmwf.org/general/general_show.htm?doc_id=246567) OR  
<http://www.healthysteps.org>

### **Help Me Grow**

- Help Me Grow Roundtable: Promoting Development through Child Health Services Supplement to the Journal of Developmental and Behavioral Pediatrics. [http://www.cmwf.org/publications/publications\\_show.htm?doc\\_id=379780](http://www.cmwf.org/publications/publications_show.htm?doc_id=379780)

### **National Initiative for Children's Health Care Quality**

- The National Initiative for Children's Healthcare Quality (NICHQ) is an education and research organization dedicated solely to improving the quality of health care provided to children. Founded in 1999, NICHQ's mission is to eliminate the gap between what is and what can be in health care for all children. <http://www.nichq.org>

### **Vermont Child Health Improvement Program**

- The Vermont Child Health Improvement Program (**VCHIP**) is a population-based child and adolescent health services research and quality improvement program of the University of Vermont. VCHIP's mission is to optimize the health of Vermont's children by initiating and supporting measurement-based efforts to enhance private and public child health practice. <http://www.med.uvm.edu/vchip/HP-DEPT.asp?SiteAreaID=513>



## Appendix 3



# The Promoting Healthy Development Survey (PHDS) (Full-Length Version)

# Your Voice Counts!

***We need your help on a very important project!***

We want to improve the care we provide your child.  
Please help us learn more about the care we provide by filling out the following survey. Your feedback is very important to us!

*By completing this survey, you are indicating that you have given your consent to participate. Your name will not be recorded. Results will be kept completely confidential. If you choose to not answer the survey, the decision will have no effect on the care your child receives. If you begin to answer the questions, and then change your mind you may stop at any time. Also, if there are particular questions that you don't want to answer, you may skip them.*

## Instructions

---

1. In this survey, the word child is used to refer to the child or foster child noted in the letter that came with this survey. Answer all the questions in the survey for only that child.

2. Answer all the questions by filling in the circle completely. See the example below for how the circle should be filled in.

                       
Yes                              No

3. You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow and then a note that tells you what question to answer next, like this:

                                               
Yes ↓                                              No → (Go to page 8 and continue with question 12)  
So, if you choose to answer "No" to this question, then you will go to page 8 of this survey and continue the survey with question #12.

**BEFORE you begin, please answer this question:**

Do you have a child that is between the ages of 3 month and 50 months old?

<sup>1</sup>                                              <sup>2</sup>  
Yes → (Go to page 2 and continue with question 1)                      No → (Please STOP NOW and RETURN this survey)



**SECTION I: GENERAL INFORMATION YOUR CHILD'S HEALTH CARE**

1. In the **last 12 months**, how many times did your child go to an emergency room?

- 0 times     
  1 time     
  2-3 times     
  4-5 times     
  6-10 times     
  10 or more times

2. In the **last 12 months** (not counting times your child went to an emergency room) how many times did your child go to a doctor's office or clinic?

- 0 times     
  1 time     
  2-3 times     
  4-5 times     
  6-10 times     
  10 or more times

3. In the **last 12 months**, how many times was your child a patient in a hospital overnight or longer?

- 0 times     
  1 time     
  2-3 times     
  4-5 times     
  6-10 times     
  10 or more times

4. In the **last 12 months**, has your child needed care right away for an illness or injury?

- Yes     
  No → Go to Question 5

4a. When your child needed care right away for an illness or injury, **how often** did your child get this care as soon as you wanted?

- Never     
  Sometimes     
  Usually     
  Always

5. In the **last 12 months**, did your child get care from more than one kind of health care provider or use more than one kind of health service?

- Yes     
  No → Go to Question 6

5a. In the **last 12 months**, did anyone from your child's doctor's office or clinic help coordinate your child's care among these different providers or services?

- Yes     
  No     
  My child did not get care from different providers or use more than one service

[Empty box for Confidential ID Code]

6. How old is your child?

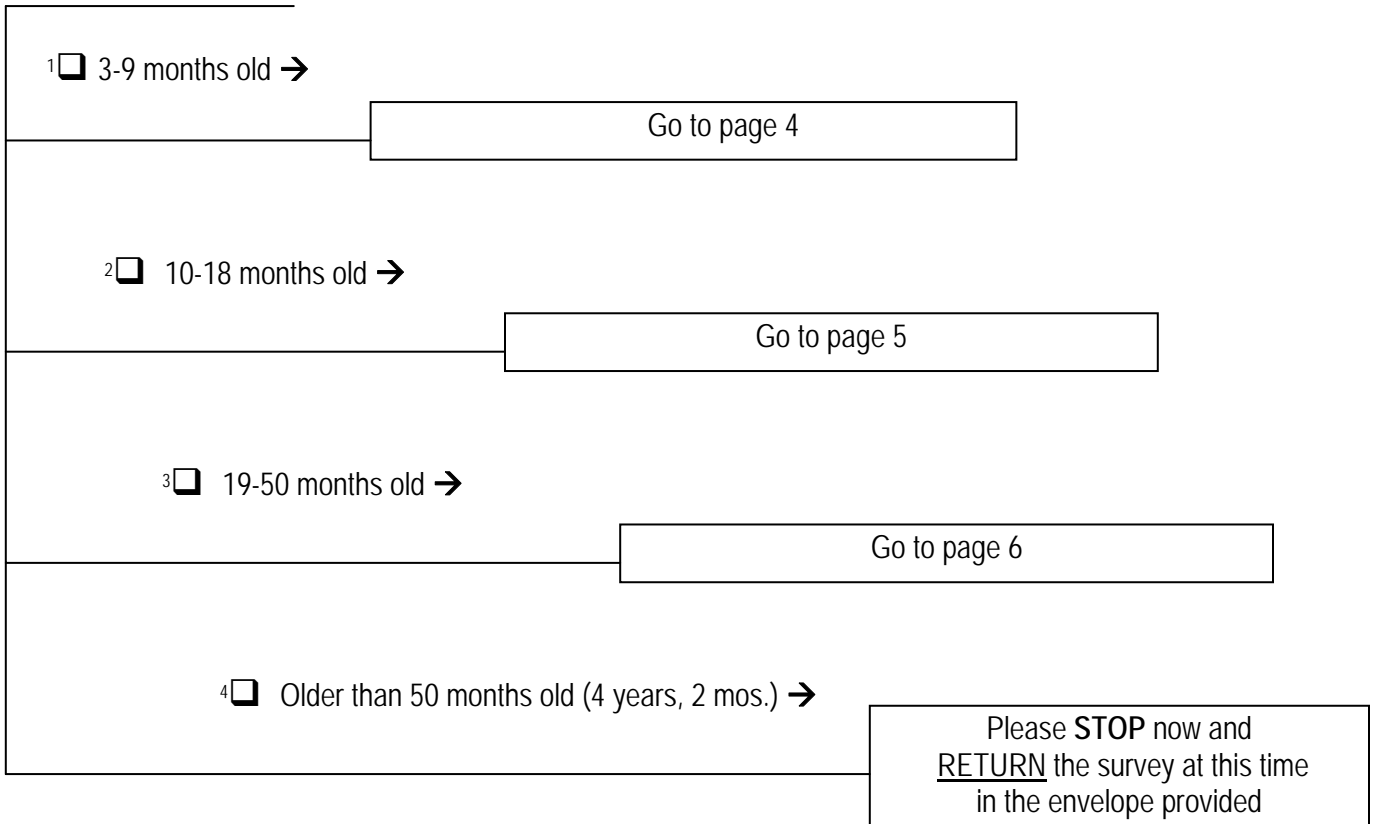
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<i>Years</i>		<i>Months</i>	

A doctor or other health provider could be a general doctor, a specialist doctor, a pediatrician, a nurse practitioner, a physician assistant, a nurse or any one else you would see for health care.

Your child’s doctors or other health providers may talk with you about certain topics that are important for your child’s development and growth. Some topics are specific to your child’s age. The next questions ask you about these age-specific topics and whether your child’s doctors or other health providers talked about them.

**NOTE:** Use the diagram below and please find the page that matches the age of your child. Turn to this page and answer **ONLY** the questions found on this page. Then continue with the rest of the survey on page 7.

How old is your child?



**Answer if child is 3-9 months old**

**SECTION II: DISCUSSIONS WITH YOUR CHILD'S DOCTORS OR OTHER HEALTH PROVIDERS**

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
<b>7. Since your child was born, did your child's doctors or other health providers talk with you about the following:</b>				
a) Things you can do to help your child grow and learn	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) The kinds of behaviors you can expect to see in your child as he/she gets older	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Breastfeeding	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Issues related to food such as the introduction of solid foods	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) The importance of placing your child on his or her back when going to sleep	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Where your child sleeps (such as the location and type of crib of your child may sleep in)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Night waking and fussing	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) How your child communicates his/her needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
<b>8. Since your child was born, did your child's doctors or other health providers talk with you about the following:</b>				
a) What your child is able to understand	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) How your child responds to you, other adults, and caregivers	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) How to avoid burns to your child, such as changing the hot water temperature in your home	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Using a car-seat	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) How to make your house safe	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Importance of showing a picture book to or reading with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Whether your child watches television (TV)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) Issues related to childcare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
i) Resources for parents and families in your community	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

**SECTION II: DISCUSSIONS WITH YOUR CHILD’S DOCTORS OR OTHER HEALTH PROVIDERS**

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
9. In the <b>last 12 months</b> , did your child’s doctors or other health providers talk with you about the following:				
a) Things you can do to help your child grow and learn	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) The kinds of behaviors you can expect to see in your child as he/she gets older	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Vitamins and foods your child should eat	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Bed and naptime routines	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Words and phrases your child uses and understands	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Night waking and fussing	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Whether your child uses a bottle	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) How your child may start to explore away from you	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
10. In the <b>last 12 months</b> , did your child’s doctors or other health providers talk with you about the following:				
a) Guidance and discipline techniques to use with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Toilet training	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) What you should do if your child swallows certain kinds of poisons	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Using a car-seat	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) How to make your house safe	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Importance of reading with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Whether your child watches television (TV)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) Issues related to childcare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
i) Resources for parents and families in your community	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Now go to question 13 on page 7.

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**SECTION II: DISCUSSIONS WITH YOUR CHILD’S DOCTORS OR OTHER HEALTH PROVIDERS**

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
11. In the <u>last 12 months</u> , did your child’s doctors or other health providers talk with you about the following:				
a) Things you can do to help your child grow and learn	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) The kinds of behaviors you can expect to see in your child as he/she gets older	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Issues related to food and feeding	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Bedtime routines and how many hours of sleep your child needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Toilet training	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Words and phrases your child uses and understands	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) How your child is learning to get along with other children	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) Guidance and discipline techniques to use with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
12. In the <u>last 12 months</u> , did your child’s doctors or other health providers talk with you about the following:				
a) Ways to teach your child about dangerous situations, places and objects	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Using a car-seat	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) How to make your house safe	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) What you should do if your child swallows certain kinds of poisons	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Importance of reading with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Whether your child watches television (TV)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Issues related to childcare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
i) Resources for parents and families in your community	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

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**SECTION III: HEALTH COMMUNICATION AND INFORMATION**

The next questions ask about your overall experiences with the health care your child has received from his or her doctor or other health providers in the last 12 months.

13. In the **last 12 months**, how often did your child's doctors or other health providers. . .

	Never	Sometimes	Usually	Always
a) Take time to understand the specific needs of your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Listen carefully to you	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Respect you as an expert about your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Build your confidence as a parent	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Help you feel like a partner in your child's care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

14. In the **last 12 months**, how often did your child's doctors or other health providers. . .

	Never	Sometimes	Usually	Always
a) Explain things in a way that you can understand	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Ask you about how you are feeling as a parent	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Show respect for your family's values, customs and how you prefer to raise your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Talk to you about resources for parents and families in your community	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Talk to you about issues in your community that may affect your child's health and development (such as lead poisoning, pool safety, community violence and gun safety)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

--

15. In the **last 12 months**, how *helpful* were your **discussions** with your child's doctors or other health providers in:

	Very Helpful	Helpful	Somewhat Helpful	Not at all helpful	We did not discuss
a) Helping you understand your child's behavior	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b) Learning how to protect your child from injuries	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c) Giving you the information you needed <u>when</u> you needed it	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d) Helping you learn how to meet your own needs while caring for your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

16. Overall, do you feel *more or less confident* in doing the following things because of the information or guidance you received from your child's doctors or other health providers?

	I feel a lot more confident	I feel a little more confident	I do not feel more or less confident	I feel less confident
a) Doing things for your child that help him or her grow and learn	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Protecting your child from injury and accidents	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Addressing any special concerns you have about your child's development and behavior	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Managing your parenting responsibilities	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

**Health information** can include written pamphlets, videos you could have seen in the waiting room, recorded information over the telephone while waiting to make an appointment or information on the Internet. You could have seen or heard this information inside or outside your doctor's office.

17. In the **last 12 months**, did you see or hear any information about:

	Yes	No
a) <b>Safety Tips:</b> How to make your house and car safe for your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b) <b>Health Care Tips:</b> When and how often your child should see the doctor, immunization reminders, information about other health care services available for your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c) <b>Developmental Information:</b> Information about your child's development and how you can help your child grow and learn	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d) <b>Child Care Tips:</b> Helpful tips about how to care for your child and issues related to childcare.	1 <input type="checkbox"/>	2 <input type="checkbox"/>

**SECTION IV: HEALTH CONCERNS ABOUT YOUR CHILD**

The next few questions ask about concerns parents or guardians sometimes have about their child.

18. * Do you have any <b>concerns</b> about . . .	<b>Yes</b>	<b>A little</b>	<b>Not at all</b>
a) Your child's learning, development or behavior	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b) How your child talks and makes speech sounds	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c) How your child understands what you say	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

19. * Do you have any <b>concerns</b> about . . .	<b>Yes</b>	<b>A little</b>	<b>Not at all</b>
a) How your child uses his or her hands and fingers to do things	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b) How your child uses his or her arms and legs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c) How your child behaves	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

20. * Do you have any <b>concerns</b> about ...	<b>Yes</b>	<b>A little</b>	<b>Not at all</b>
a) How your child gets along with others	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b) How your child is learning to do things for himself/herself	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c) How your child is learning pre-school skills	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

21. In the **last 12 months**, did your child's doctors or other health providers ask if you have concerns about your child's learning, development and behavior?

- 1       2       3   
 Yes              No              I don't remember

22. In the **last 12 months**, did your child's doctors or other health providers give you specific information to address your concerns?

- 1       2       3       4   
 Yes              No              I don't remember      I did not have any concerns

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23 Did your child's doctors or other health providers ever:		Yes	No
a)	Refer your child to another doctor or other health provider	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b)	Test your child's learning and behavior	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c)	Note a concern about your child that should be watched carefully	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d)	Refer your child for speech-language or hearing testing	1 <input type="checkbox"/>	2 <input type="checkbox"/>

24. In the **last 12 months**, did your child's doctors or other health providers tell you that they were doing an assessment or test of your child's development?

- 1  Yes                     
 2  No                     
 3  I don't remember

25. In the **last 12 months**, did your child's doctors or other health providers have your child pick up small objects, stack blocks, throw a ball or recognize different colors?

- 1  Yes                     
 2  No                     
 3  I don't remember                     
 4  My child is too young to do these kind of activities

26. In the **last 12 months**, did your child's doctor or other health care provider have you fill out a questionnaire about specific concerns or observations you may have about your child's physical ability, communication or social behaviors?

- 1  Yes → Go to Question 26a                     
 2  No → Go to Question 27

26a. Did this questionnaire ask about your concerns or observations about how your child **talks or makes speech sounds**?

- 1  Yes                     
 2  No

26b. Did this questionnaire ask about your concerns or observations about how your **child behaves and gets along with you and others**?

- 1  Yes                     
 2  No

--

**SECTION V: YOUR FAMILY**

A child's doctors or other health providers sometimes ask questions about a child's family. These questions help them provide the best care possible for your child. These questions can be asked in a survey that you fill out before the visit, in the waiting room or when you talked with your child's doctor or other health provider during your child's visit.

27. In the <b>last 12 months</b> , did your child's doctors or other health providers <b>ask</b> you:	Yes	No
a) If you or someone in your household smokes	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b) If you or someone in your household drinks alcohol or uses other substances	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c) If you ever feel depressed, sad or have crying spells	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d) If you have someone to turn to for emotional support	1 <input type="checkbox"/>	2 <input type="checkbox"/>

28. In the <b>last 12 months</b> , did your child's doctors or other health providers <b>ask</b> you:	Yes	No
a) If you feel safe at home	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b) If you have any firearms in your home	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c) To talk about any changes or stressors in your family or home	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d) How parenting works into your daily activities and future plans in life	1 <input type="checkbox"/>	2 <input type="checkbox"/>

**SECTION VI: YOUR CHILD'S HEALTH**

The next questions are about your child's health.

29. Overall, how would you rate **your child's health** in the last 12 months?

- 1  Excellent     
 2  Very Good     
 3  Good     
 4  Fair     
 5  Poor

30. Was your child **born prematurely**, that is, more than 4 weeks early?

- 1  Yes     
 2  No

31. In the **last 12 months**, have night waking and fussing been an issue with your child?

- 1  Yes     
 2  No

32. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?

1

2

Yes → Go to Question 32a

No → Go to Question 33

32a. Is this because of ANY medical, behavioral or other health condition?

1

2

Yes → Go to Question 32b

No → Go to Question 33

32b. Is this a condition that has lasted or is expected to last for at least 12 months?

1

2

Yes

No

33. Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age?

1

2

Yes → Go to Question 33a

No → Go to Question 34

33a. Is this because of ANY medical, behavioral or other health condition?

1

2

Yes → Go to Question 33b

No → Go to Question 34

33b. Is this a condition that has lasted or is expected to last for at least 12 months?

1

2

Yes

No

34. 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?

1

2

Yes → Go to Question 34a

No → Go to Question 35

34a. Is this because of ANY medical, behavioral or other health condition?

1

2

Yes → Go to Question 34b

No → Go to Question 35

34b. Is this a condition that has lasted or is expected to last for at least 12 months?

1

2

Yes

No

35. Does your child need or get special therapy, such as physical, occupational or speech therapy?

1

2

Yes → Go to Question 35a

No → Go to Question 36

35a. Is this because of ANY medical, behavioral or other health condition?

1

2

Yes → Go to Question 35b

No → Go to Question 36

35b. Is this a condition that has lasted or is expected to last for at least 12 months?

1

2

Yes

No

36. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets treatment or counseling?

1

2

Yes → Go to Question 36a

No → Go to Question 37

36a. Has this problem lasted or is it expected to last for at least 12 months?

1

2

Yes

No

## SECTION VII: YOUR CHILD'S PERSONAL DOCTOR OR NURSE

37. A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner or a physician assistant. Do you have one person you think of as your child's personal doctor or nurse?

1

2

Yes

No → Go to Question 38

37a. Do you have more than one person you think of as your child's personal doctor or nurse?

1

2

Yes

No

37b. In the last 12 months, have you needed to call your child's personal doctor's or nurse's office or clinic for help or advice over the phone?

1

2

Yes

No → Go to Question 38

37c. In the last 12 months, when you called your child's personal doctor or nurse for help or advice over the phone, how often were you able to get the help or advice you needed for your child?

1

2

3

4

Never

Sometimes

Usually

Always

**SECTION VIII: YOU AND YOUR HEALTH**

The next questions are about you and your health. We are asking these questions to better understand the children and families we care for so that we can improve our services. Remember this survey is **confidential** and results will be kept completely anonymous.

38. Are you male or female?

Male

Female

39. What is **your age** right now?

Under 18

18 to 24

25-34

35-44

45-54

55-64

65-74

75 or older

40. Overall, how would you rate your health in the **last 12 months**?

Excellent

Very Good

Good

Fair

Poor

41. How many days in the **last week** have you felt depressed?

0 days

1 day

2 days

3 days

4 days

5 days

6 days

All 7 days

42. In the **last 12 months**, have you had two weeks or more during which you felt sad, blue, depressed or lost pleasure in things you usually cared about or enjoyed?

Yes

No

43. Have you had **two or more years** in your life when you felt depressed or sad most days, even if you felt okay sometimes?

Yes

No

**SECTION IX: HOUSEHOLD ACTIVITIES AND INFORMATION**

The next questions ask about some of the activities in your family.

44. When laying your child down to sleep at night or for a nap, in what position do you usually place your child ?

- 1 On Back     
  2 On Stomach     
  3 On Side     
  4 No Special Position     
  5 My child is too old to place in any specific sleeping position

45. How many days in **a typical week** do you or other family members read a book with your child?

- 1 Everyday (7 days)     
  2 5-6 days     
  3 3-4 days     
  4 1-2 days     
  5 No Days (0 days)

46. Have you ....

	Yes	No
a) Put locks on cabinets where things such as cleaning agents or medicines are kept	<input type="checkbox"/> 1	<input type="checkbox"/> 2
b) Put padding around hard surfaces or sharp edges	<input type="checkbox"/> 1	<input type="checkbox"/> 2
c) Put stoppers or plugs in electrical outlets	<input type="checkbox"/> 1	<input type="checkbox"/> 2
d) Turned down the hot water temperature on your hot water heater	<input type="checkbox"/> 1	<input type="checkbox"/> 2
e) Kept the Poison Control Center phone number on or near your phone	<input type="checkbox"/> 1	<input type="checkbox"/> 2
f) Kept Syrup of Ipecac in your home	<input type="checkbox"/> 1	<input type="checkbox"/> 2

47. How long did you breastfeed your child?

- 1 My child was not breastfed     
  2 Less than a month     
  3 A month or more     
  4 I am still breastfeeding

48. In the **last 12 months** has your child drank from a bottle?

- 1 Yes     
  2 No

49. Does anyone living in your household smoke?

- 1 Yes     
  2 No

These questions are general questions about your child, you and your family. They are being asked for grouping purposes only so that we can understand who answered this survey.

50. Is your child a male or a female?

Male

Female

51. Is your child of Hispanic or Latino origin or descent?

Hispanic or Latino

NOT Hispanic or Latino

52. What is your child's race? Please mark one or more.

White

Black or African  
American

Asian

American Indian  
or Alaskan Native

Native Hawaiian or  
Other Pacific Islander

53. Is the child named in this survey your first child?

Yes

No

The question does not apply to me

54. How many children under the age of 18 are living in your household (including the child named in this survey)?

1

2

3

4

5 or more

55. How are you related to the child named in this survey?

Mother

Father

Aunt or uncle

Older brother or  
sister

Grandmother or  
grandfather

Guardian

Other relative

56. What is the highest grade or level of school that you have completed?

8<sup>th</sup> grade  
or less

Some high school,  
but did  
not graduate

High school  
graduate  
or GED

Some college  
or  
2-year degree

4 year college  
graduate

More than  
a 4 year college  
degree

57. What is your current marital status?

- 1 I have never been married     
  2 Married     
  3 Living with significant other     
  4 Widowed     
  5 Divorced     
  6 Separated

These last questions ask how much trouble you have had paying for particular kinds of expenses.

58. How much trouble have you had paying for...	A Lot of Trouble	Some Trouble	No Trouble
a) Prenatal care during pregnancy	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
b) Medical expenses for child's birth	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
c) Child's health and medical expenses	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
d) Supplies like formula, food, diapers, clothes and shoes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
e) Healthcare for yourself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

## YOU'RE DONE!!

**Thank you for completing the survey.  
You have helped to make a difference**

Please return the completed survey  
in the envelope provided.





## **Appendix 4**



**Promoting Healthy Development Survey - Reduced-item Version  
(ProPHDS)**

**Version for Parents of Children 3 to 9 Months Old**

(3 – 9 months)

# Your Child's Health Care

- ❖ This survey is about discussions you may have had with your child's doctors or other health providers since your child was born.
- ❖ By completing this survey, you are indicating that you have given your consent to participate.
- ❖ This survey is confidential. Do not write your name or your child's name on this survey.
- ❖ If you choose to not answer the survey, the decision will have no effect on the health care you or your child receive or on your health care benefits.
- ❖ If you begin to answer the questions and then change your mind, you may stop at any time. Also, if there are particular questions that you don't want to answer, you may skip them. If you choose to skip or not answer any questions it will have no effect on the health care you or your child receive or on your health care benefits

---

## Instructions

1. Please use a BLUE or BLACK ink pen to complete this survey.
2. Answer all the questions by checking the box on top of your answer like this:

Yes

No

**SECTION I: DISCUSSIONS WITH YOUR CHILD'S DOCTORS OR OTHER HEALTH PROVIDERS**

A doctor or other health provider could be a general doctor, a specialist, a pediatrician, a nurse practitioner, a physician assistant, a nurse or any one else your child would see for health care.

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
<b>1. Since your child was born, did your child's doctors or other health providers talk with you about the following:</b>				
a) Things you can do to help your child grow and learn	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) The kinds of behaviors you can expect to see in your child as he/she gets older	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Breastfeeding	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Issues related to food such as the introduction of solid foods	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) The importance of placing your child on his or her back when going to sleep	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Where your child sleeps (such as the location and type of crib of your child may sleep in)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Night waking and fussing	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) How your child communicates his/her needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
<b>2. Since your child was born, did your child's doctors or other health providers talk with you about the following:</b>				
a) What your child is able to understand	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) How your child responds to you, other adults, and caregivers	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) How to avoid burns to your child, such as changing the hot water temperature in your home	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Using a car-seat	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) How to make your house safe	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Importance of showing a picture book to or reading with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Whether your child watches television (TV)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) Issues related to childcare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
i) Resources for parents and families in your community	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

### SECTION II: EXPERIENCE OF CARE

The next questions ask about your overall experiences with the health care your child has received from his or her doctors or other health providers since your child was born.

3. Since your child was born, how often did your child's doctors or other health providers. . .	Never	Sometimes	Usually	Always
a) Take time to understand the specific needs of your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Respect you as an expert about your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Help you feel like a partner in your child's care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Explain things in a way that you can understand	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Show respect for your family's values, customs and how you prefer to raise your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

### SECTION III: HEALTH CONCERNS ABOUT YOUR CHILD

The next few questions ask about concerns parents or guardians sometimes have about their child.

4.* Do you have any concerns about . . .	Yes	A little	Not at all
a) Your child's learning, development or behavior	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b) How your child talks and makes speech sounds	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c) How your child understands what you say	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d) How your child uses his or her arms and legs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e) How your child behaves	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f) How your child gets along with others	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

5. Since your child was born, did your child's doctors or other health providers ask if you have concerns about you child's learning, development or behavior?

1   
Yes

2   
No

3   
I don't remember

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6. Since your child was born, did your child's doctors or other health providers give you specific information to address your concerns?

- Yes     
  No     
  I don't remember     
  I did not have any concerns

7. Since your child was born, did your child's doctors or other health providers:	Yes	No
a) Refer your child to another doctor or other health provider	<input type="checkbox"/>	<input type="checkbox"/>
b) Test your child's learning and behavior	<input type="checkbox"/>	<input type="checkbox"/>
c) Note a concern about your child that should be watched carefully	<input type="checkbox"/>	<input type="checkbox"/>
d) Refer your child for speech-language or hearing testing	<input type="checkbox"/>	<input type="checkbox"/>

8. Since your child was born, did your child's doctors or other health providers have your child pick up small objects, stack blocks, throw a ball or recognize different colors?

- Yes     
  No     
  I don't remember     
  My child is too young to do these kind of activities

9. Since your child was born, did your child's doctor or other health care provider have you fill out a questionnaire about specific concerns or observations you may have about your child's physical abilities, communication or social behaviors?

- Yes →Go to Question 9a     
  No →Go to question 10

9a. Did this questionnaire ask about your concerns or observations about how your child talks or makes speech sounds?

- Yes     
  No

9b. Did this questionnaire ask about your concerns or observations about how your child interacts with you and others?

- Yes     
  No

**SECTION IV: QUESTIONS ABOUT YOUR FAMILY**

A child's doctors or other health providers sometimes ask questions about a child's family. These questions help them provide the best care possible for your child. These questions can be asked in a survey that you fill out before the visit, in the waiting room or when you talked with your child's doctor or other health provider during your child's visit.

10. Since your child was born, did your child's doctors or other health providers <u>ask</u> you:	Yes	No
a) If you or someone in your household drinks alcohol or uses other substances	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b) If you ever feel depressed, sad or have crying spells	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c) If you have someone to turn to for emotional support	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d) To talk about any changes or stressors in your family or home	1 <input type="checkbox"/>	2 <input type="checkbox"/>
e) If you have any firearms in your home	1 <input type="checkbox"/>	2 <input type="checkbox"/>

**SECTION V: YOUR CHILD'S PERSONAL DOCTOR OR NURSE**

11. A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner or a physician assistant. Do you have one or more person(s) you think of as your child's personal doctor or nurse?

1   
Yes

2   
No → Go to Question 12

11 a. Which of these people do you think of as your child's personal doctor or nurse? Please mark one or more.

1   
Name #1

2   
Name 2

3   
Name 3

4   
Name 4

5   
Name 5

6   
Other Person

**SECTION VI: YOUR CHILD, YOU, AND YOUR FAMILY**

These last questions are about your child, you, and your family. We are asking these questions to better understand the children and families we care for so that we can improve our services. Remember this survey is **confidential** and results will be kept completely anonymous.

12. Is the child named in this survey your first child?

1  Yes      2  No      3  The question does not apply to me

13. Is your child of Hispanic or Latino origin or descent?

1   
Hispanic or Latino

2   
NOT Hispanic or Latino

14. What is your child's race? Please mark one or more.

1   
White

2   
Black or African American

3   
Asian

4   
American Indian or Alaskan Native

5   
Native Hawaiian or Other Pacific Islander

6   
Other

15. How long did you breastfeed your child?

- 1  My child was not breastfed      2  Less than a month      3  A month or more      4  I am still breastfeeding

16. How many days in a typical week do you or other family members read a book with your child?

- 1  No Days (0 days)      2  1-2 days      3  3-4 days      4  5-6 days      5  Everyday (7 days)

17. How many hours in a typical day does your child watch TV or watch videos?

- 1  0 hours      2  Less than 1 hour      3  1 -2 hours      4  More than 2 hours      5  We don't own a TV

18. What is the highest grade or level of school that you have completed?

- 1  8<sup>th</sup> grade or less      2  Some high school, but did not graduate      3  High school graduate or GED      4  Some college or 2-year degree      5  4-year college graduate      6  More than a 4-year college degree

19. How many days in the last week have you felt depressed?

- 1  0 days      2  1 day      3  2 days      4  3 days      5  4 days      6  5 days      7  6 days      8  All 7 days

20. In the last 12 months, have you had two weeks or more during which you felt sad, blue, depressed or lost pleasure in things you usually cared about or enjoyed?

- 1  Yes      2  No

21. How much trouble have you had paying for. . .

	A Lot of Trouble	Some Trouble	No Trouble
a) Child's health and medical expenses	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b) Supplies like formula, food, diapers, clothes and shoes	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c) Healthcare for yourself	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

**YOU'RE DONE!!**

**Thank you for completing the survey. Please put the survey in the envelope provided and drop it off in the "completed survey" box before you leave.**

**You have helped make a difference.**



## **Appendix 5**



### **Promoting Healthy Development Survey - Reduced-item Version (ProPHDS)**

**Version for Parents of Children 10-18 Months Old**



**(10 – 18 months)**

# Your Child's Health Care

- ❖ This survey is about discussions you may have had with your child's doctors or other health providers in the last 12 months.
- ❖ By completing this survey, you are indicating that you have given your consent to participate.
- ❖ This survey is confidential. Do not write your name or your child's name on this survey.
- ❖ If you choose to not answer the survey, the decision will have no effect on the health care you or your child receive or on your health care benefits.
- ❖ If you begin to answer the questions and then change your mind, you may stop at any time. Also, if there are particular questions that you don't want to answer, you may skip them. If you choose to skip or not answer any questions it will have no effect on the health care you or your child receive or on your health care benefits

---

## Instructions

1. Please use a BLUE or BLACK ink pen to complete this survey.
2. Answer all the questions by checking the box on top of your answer like this:

Yes

No

**SECTION I: DISCUSSIONS WITH YOUR CHILD'S DOCTORS OR OTHER HEALTH PROVIDERS**

A doctor or other health provider could be a general doctor, a specialist, a pediatrician, a nurse practitioner, a physician assistant, a nurse or any one else your child would see for health care.

1. In the <b>last 12 months</b> , did your child's doctors or other health providers talk with you about the following:	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) Things you can do to help your child grow and learn	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) The kinds of behaviors you can expect to see in your child as he/she gets older	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Vitamins and foods your child should eat	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Bed and naptime routines	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Words and phrases your child uses and understands	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Night waking and fussing	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Whether your child uses a bottle	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) How your child may start to explore away from you	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

2. In the <b>last 12 months</b> , did your child's doctors or other health providers talk with you about the following:	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) Guidance and discipline techniques to use with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Toilet training	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) What you should do if your child swallows certain kinds of poisons	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Using a car-seat	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) How to make your house safe	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Importance of reading with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Whether your child watches television (TV)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) Issues related to childcare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
i) Resources for parents and families in your community	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

## SECTION II: EXPERIENCE OF CARE

The next questions ask about your overall experiences with the health care your child has received from his or her doctors or other health providers in the last 12 months.

3. In the <u>last 12 months</u> , how often did your child's doctors or other health providers. . .	Never	Sometimes	Usually	Always
a) Take time to understand the specific needs of your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Respect you as an expert about your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Help you feel like a partner in your child's care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Explain things in a way that you can understand	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Show respect for your family's values, customs and how you prefer to raise your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

## SECTION III: HEALTH CONCERNS ABOUT YOUR CHILD

The next few questions ask about concerns parents or guardians sometimes have about their child.

4. * Do you have any concerns about . . .	Yes	A little	Not at all
a) Your child's learning, development or behavior	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b) How your child talks and makes speech sounds	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c) How your child understands what you say	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d) How your child uses his or her arms and legs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e) How your child behaves	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f) How your child gets along with others	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

5. In the last 12 months, did your child's doctors or other health providers ask if you have concerns about your child's learning, development or behavior?

1   
Yes

2   
No

3   
I don't remember

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6. In the **last 12 months**, did your child's doctors or other health providers give you specific information to address your concerns?

- Yes     
  No     
  I don't remember     
  I did not have any concerns

7. In the **last 12 months** did your child's doctors or other health providers:

	Yes	No
a) Refer your child to another doctor or other health provider	<input type="checkbox"/>	<input type="checkbox"/>
b) Test your child's learning and behavior	<input type="checkbox"/>	<input type="checkbox"/>
c) Note a concern about your child that should be watched carefully	<input type="checkbox"/>	<input type="checkbox"/>
d) Refer your child for speech-language or hearing testing	<input type="checkbox"/>	<input type="checkbox"/>

8. In the **last 12 months**, did your child's doctors or other health providers have your child pick up small objects, stack blocks, throw a ball or recognize different colors?

- Yes     
  No     
  I don't remember     
  My child is too young to do these kind of activities

9. In the **last 12 months**, did your child's doctor or other health care provider have you fill out a questionnaire about specific concerns or observations you may have about your child's physical ability, communication or social behaviors?

- Yes →Go to Question 9a     
  No →Go to Question 10

9a. Did this questionnaire ask about your concerns or observations about how your child **talks or makes speech sounds**?

- Yes     
  No

9b. Did this questionnaire ask about your concerns or observations about how your child **interacts with you and others**?

- Yes     
  No

**SECTION IV: QUESTIONS ABOUT YOUR FAMILY**

A child's doctors or other health providers sometimes ask questions about a child's family. These questions help them provide the best care possible for your child. These questions can be asked in a survey that you fill out before the visit, in the waiting room or when you talked with your child's doctor or other health provider during your child's visit.

10. In the <u>last 12 months</u> , did your child's doctors or other health providers <u>ask</u> you:	Yes	No
a) If you or someone in your household drinks alcohol or uses other substances	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b) If you ever feel depressed, sad or have crying spells	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c) If you have someone to turn to for emotional support	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d) To talk about any changes or stressors in your family or home	1 <input type="checkbox"/>	2 <input type="checkbox"/>
e) If you have any firearms in your home	1 <input type="checkbox"/>	2 <input type="checkbox"/>

**SECTION V: YOUR CHILD'S PERSONAL DOCTOR OR NURSE**

11. A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner or a physician assistant. Do you have one or more person(s) you think of as your child's personal doctor or nurse?

1

Yes

2

No → Go to Question 12

11 a. Which of these people do you think of as your child's personal doctor or nurse? Please mark one or more.

1

Name #1

2

Name 2

3

Name 3

4

Name 4

5

Name 5

6

Other Person

**SECTION VI: YOUR CHILD, YOU, AND YOUR FAMILY**

These last questions are about your child, you, and your family. We are asking these questions to better understand the children and families we care for so that we can improve our services. Remember this survey is **confidential** and results will be kept completely anonymous.

12. Is the child named in this survey your first child?

1

Yes

2

No

3

The question does not apply to me

13. Is your child of Hispanic or Latino origin or descent?

1

Hispanic or Latino

2

NOT Hispanic or Latino

14. What is your child's race? Please mark one or more.

- 1 White     
  2 Black or African American     
  3 Asian     
  4 American Indian or Alaskan Native     
  5 Native Hawaiian or Other Pacific Islander     
  6 Other

15. How many days in a typical week do you or other family members read a book with your child?

- 1 No Days (0 days)     
  2 1-2 days     
  3 3-4 days     
  4 5-6 days     
  5 Everyday (7 days)

16. How many hours in a typical day does your child watch TV or watch videos?

- 1 0 hours     
  2 Less than 1 hour     
  3 1 -2 hours     
  4 More than 2 hours     
  5 We don't own a TV

17. What is the highest grade or level of school that you have completed?

- 1 8<sup>th</sup> grade or less     
  2 Some high school, but did not graduate     
  3 High school graduate or GED     
  4 Some college or 2-year degree     
  5 4-year college graduate     
  6 More than a 4-year college degree

18. How many days in the last week have you felt depressed?

- 1 0 days     
  2 1 day     
  3 2 days     
  4 3 days     
  5 4 days     
  6 5 days     
  7 6 days     
  8 All 7 days

19. In the last 12 months, have you had two weeks or more during which you felt sad, blue, depressed or lost pleasure in things you usually cared about or enjoyed?

- 1 Yes     
  2 No

20. How much trouble have you had paying for . . .	A Lot of Trouble	Some Trouble	No Trouble
a) Child's health and medical expenses	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
b) Supplies like formula, food, diapers, clothes and shoes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
c) Healthcare for yourself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

**YOU'RE DONE!!**

**Thank you for completing the survey. Please put the survey in the envelope provided and drop it off in the "completed survey" box before you leave.**

**You have helped make a difference.**



## **Appendix 6**



### **Promoting Healthy Development Survey - Reduced-item Version (ProPHDS)**

**Version for Parents of Children 19-48 Months Old**

**(19 – 48 months)**

# Your Child's Health Care

- ❖ This survey is about discussions you may have had with your child's doctors or other health providers in the last 12 months.
- ❖ By completing this survey, you are indicating that you have given your consent to participate.
- ❖ This survey is confidential. Do not write your name or your child's name on this survey.
- ❖ If you choose to not answer the survey, the decision will have no effect on the health care you or your child receive or on your health care benefits.
- ❖ If you begin to answer the questions and then change your mind, you may stop at any time. Also, if there are particular questions that you don't want to answer, you may skip them. If you choose to skip or not answer any questions it will have no effect on the health care you or your child receive or on your health care benefits.

---

## Instructions

1. Please use a BLUE or BLACK ink pen to complete this survey.
2. Answer all the questions by checking the box on top of your answer like this:

Yes

No



**SECTION I: DISCUSSIONS WITH YOUR CHILD'S DOCTORS OR OTHER HEALTH PROVIDERS**

A doctor or other health provider could be a general doctor, a specialist, a pediatrician, a nurse practitioner, a physician assistant, a nurse or any one else your child would see for health care.

1. In the <b>last 12 months</b> , did your child's doctors or other health providers talk with you about the following:	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) Things you can do to help your child grow and learn	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) The kinds of behaviors you can expect to see in your child as he/she gets older	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Issues related to food and feeding	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Bedtime routines and how many hours of sleep your child needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Toilet training	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Words and phrases your child uses and understands	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) How your child is learning to get along with other children	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h) Guidance and discipline techniques to use with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

2. In the <b>last 12 months</b> , did your child's doctors or other health providers talk with you about the following:	YES, and my questions were answered	YES, but my questions were not answered completely	NO, but I wish we had talked about that	NO, but I already had information about this topic and did not need to talk about it any more
a) Ways to teach your child about dangerous situations, places and objects	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Using a car-seat	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) How to make your house safe	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) What you should do if your child swallows certain kinds of poisons	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Importance of reading with your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f) Whether your child watches television (TV)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g) Issues related to childcare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
i) Resources for parents and families in your community	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

### SECTION II: EXPERIENCE OF CARE

The next questions ask about your overall experiences with the health care your child has received from his or her doctors or other health providers in the last 12 months.

3. In the <b>last 12 months</b> , how often did your child's doctors or other health providers. . .	Never	Sometimes	Usually	Always
a) Take time to understand the specific needs of your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b) Respect you as an expert about your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c) Help you feel like a partner in your child's care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d) Explain things in a way that you can understand	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e) Show respect for your family's values, customs and how you prefer to raise your child	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

### SECTION III: HEALTH CONCERNS ABOUT YOUR CHILD

The next few questions ask about concerns parents or guardians sometimes have about their child.

4.* Do you have any concerns about . . .	Yes	A little	Not at all
a) Your child's learning, development or behavior	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b) How your child talks and makes speech sounds	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c) How your child understands what you say	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d) How your child uses his or her arms and legs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e) How your child behaves	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f) How your child gets along with others	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

5. In the **last 12 months**, did your child's doctors or other health providers ask if you have concerns about your child's learning, development or behavior?

1   
Yes

2   
No

3   
I don't remember

6. In the **last 12 months**, did your child's doctors or other health providers give you specific information to address your concerns?

- 1 Yes     
  2 No     
  3 I don't remember     
  4 I did not have any concerns

7. In the **last 12 months** did your child's doctors or other health providers:

	Yes	No
a) Refer your child to another doctor or other health provider	<input type="checkbox"/> 1	<input type="checkbox"/> 2
b) Test your child's learning and behavior	<input type="checkbox"/> 1	<input type="checkbox"/> 2
c) Note a concern about your child that should be watched carefully	<input type="checkbox"/> 1	<input type="checkbox"/> 2
d) Refer your child for speech-language or hearing testing	<input type="checkbox"/> 1	<input type="checkbox"/> 2

8. In the **last 12 months**, did your child's doctors or other health providers have your child pick up small objects, stack blocks, throw a ball or recognize different colors?

- 1 Yes     
  2 No     
  3 I don't remember     
  4 My child is too young to do these kind of activities

9. In the **last 12 months**, did your child's doctor or other health care provider have you fill out a questionnaire about specific concerns or observations you may have about your child's physical ability, communication or social behaviors?

- 1 Yes → Go to Question 9a     
  2 No → Go to Question 10

9a. Did this questionnaire ask about your concerns or observations about **words and phrases your child uses and understands**?

- 1 Yes     
  2 No

9b. Did this questionnaire ask about your concerns or observations about how your **child behaves and gets along with you and others**?

- 1 Yes     
  2 No

--

**SECTION IV: QUESTIONS ABOUT YOUR FAMILY**

A child's doctors or other health providers sometimes ask questions about a child's family. These questions help them provide the best care possible for your child. These questions can be asked in a survey that you fill out before the visit, in the waiting room or when you talked with your child's doctor or other health provider during your child's visit.

	Yes	No
10. In the <b>last 12 months</b> , did your child's doctors or other health providers <b>ask</b> you:		
a) If you or someone in your household drinks alcohol or uses other substances	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b) If you ever feel depressed, sad or have crying spells	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c) If you have someone to turn to for emotional support	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d) To talk about any changes or stressors in your family or home	1 <input type="checkbox"/>	2 <input type="checkbox"/>
e) If you have any firearms in your home	1 <input type="checkbox"/>	2 <input type="checkbox"/>

**SECTION V: YOUR CHILD'S PERSONAL DOCTOR OR NURSE**

11. A **personal doctor or nurse** is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner or a physician assistant. Do you have one or more person(s) you think of as your child's personal doctor or nurse?

1   
Yes

2   
No → Go to Question 12

11 a. Which of these people do you think of as your child's personal doctor or nurse? Please mark one or more.

1   
Name #1

2   
Name 2

3   
Name 3

4   
Name 4

5   
Name 5

6   
Other Person

**SECTION VI: YOUR CHILD, YOU, AND YOUR FAMILY**

These last questions are about your child, you, and your family. We are asking these questions to better understand the children and families we care for so that we can improve our services. Remember this survey is **confidential** and results will be kept completely anonymous.

12. Is the child named in this survey your first child?

1   
Yes

2   
No

3   
The question does not  
apply to me

13. Is your child of Hispanic or Latino origin or descent?

1   
Hispanic or Latino

2   
NOT Hispanic or Latino

14. What is your child's race? Please mark one or more.

- 1 White     
  2 Black or African American     
  3 Asian     
  4 American Indian or Alaskan Native     
  5 Native Hawaiian or Other Pacific Islander     
  6 Other

15. How many days in a typical week do you or other family members read a book with your child?

- 1 No Days (0 days)     
  2 1-2 days     
  3 3-4 days     
  4 5-6 days     
  5 Everyday (7 days)

16. How many hours in a typical day does your child watch TV or watch videos?

- 1 0 hours     
  2 Less than 1 hour     
  3 1 -2 hours     
  4 More than 2 hours     
  5 We don't own a TV

17. What is the highest grade or level of school that you have completed?

- 1 8<sup>th</sup> grade or less     
  2 Some high school, but did not graduate     
  3 High school graduate or GED     
  4 Some college or 2-year degree     
  5 4-year college graduate     
  6 More than a 4-year college degree

18. How many days in the last week have you felt depressed?

- 1 0 days     
  2 1 day     
  3 2 days     
  4 3 days     
  5 4 days     
  6 5 days     
  7 6 days     
  8 All 7 days

19. In the last 12 months, have you had two weeks or more during which you felt sad, blue, depressed or lost pleasure in things you usually cared about or enjoyed?

- 1 Yes     
  2 No

20. How much trouble have you had paying for. . .

	A Lot of Trouble	Some Trouble	No Trouble
a) Child's health and medical expenses	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
b) Supplies like formula, food, diapers, clothes and shoes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
c) Healthcare for yourself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

**YOU'RE DONE!!**

**Thank you for completing the survey. Please put the survey in the envelope provided and drop it off in the "completed survey" box before you leave.**

**You have helped make a difference.**



## Appendix 7



### **Example Data Dictionary of Supplemental Variables Collected for the Starting Sample of the PHDS for Which the Primary Units of Analysis were 10 Pediatric Offices and 56 Individual Health Care Providers**

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- **Data Set #1:** Information about the starting sample for the survey administration based on administrative, enrollment and health care utilization information.

This is a **child-level data set**. It includes the following information:

- ✓ Child-specific general and enrollment information: **Table 1** provides an overview of the data file elements to be collected about the child and child's enrollment.
  - ✓ Child-specific health care utilization information- **Table 2** provides an overview of the data file elements that will be collected about the child's health care utilization. Examples of variables include the following: Count variable of the number of well-child visits the child has had in the last 12 months, count variable of the number of non-well-child visits the child has had in the last 12 months, count variable of the number of emergency room visits the child has had in the last 12 months, categorical, blinded variable of the visits the child has had in each office the child has received care.
- **Data Set #2:** Information about the pediatric offices . This database will include the office level ID codes that will allow the CAHMI team to link Data Set #1 with Data Set #2.

This is an **office-level database**. It includes the following information:

- ✓ Office-specific characteristics- **Table 3** provides an overview of the data to be collected for each office. An example of a variable in this data set is a categorical variable of the number of FTE physicians in the office.
- **Data Set #3:** Information about the 56 pediatric providers. This data set will include the provider and office level ID codes that will allow the CAHMI team to link Data Set #3 with Data Sets #1 and #2.

This is a **provider-level database**. It includes the following information:

- ✓ Provider-specific characteristics- **Table 4** provides an overview of the data to be collected for each office. An example of a variable in this data set is a variable showing the clinical FTE for the specific provider.

## Part 1: Data Set #1 (Child-Level Data Base)

Table 1 and Table 2 describe the key data file elements to be included in this database.

**Table 1: Data file elements related child-specific general and enrollment information**

Variable	Description of Variable	Response Code
<b>Study ID</b>	Study unique identifier	
<b>GENDER</b>	Gender of the child	1=Male 2=Female
<b>CHDAGE</b>	Child's age in months, at the time the survey will be mailed out.	Variable between 3 and 40.99 months.
<b>CHDAGEC</b>	Child's age in months, at the time the survey will be mailed out. Categorical variable.	1=3 – 9 months; 2=10 – 18 months; 3= 19-35 months 4=36– 40.99 months 5= 41-45.99 months
<b>langcat</b>	Language spoken at home or on record for the child. Not a reliable code for language. Often entered in when a patient actively request transcription services.	Two digit code. Weiming will provide a dictionary for the response codes.
<b>payor</b>	Type of insurance the child has	1= Private 2= Public (Medicaid or SCHIP)
<b>mocont</b>	Number of months the child has been continuously enrolled with KPNW.	Count variable.
<b>moconto</b>	Number of months the child has been continuously enrolled with the office the child is currently enrolled in.	Count variable.
<b>mocontp</b>	Number of months the child has been continuously enrolled with the provider the child is currently enrolled in.	Count variable.
<b>offenroll</b>	The number of offices the child has been enrolled with in the last 12 month or since the child was born. (Office enrollment will be based on the provider the child is enrolled with)	1= 1 office 2= 2 offices 3= 3 offices 4= 4 or more offices
<b>provenroll</b>	The number of providers the child has been enrolled with in the last 12 month or since the child was born.	1= 1 provider 2= 2 providers 3= 3 providers 4= 4 or more providers
<b>office</b>	Office the child is current enrolled with. (Office enrollment will be based on the provider the child is enrolled with)	Numeric value. Office specific codes values. Weiming will provide definitions for each response code.
<b>Provider_ce</b>	Provider the child is current enrolled with.	Blinded provider codes. Numeric value. (e.g. Provider A, Provider B). The provider code that indicates an office-level provider allocation will end with i.
<b>provfte_tot</b>	The FTE of the provider the child is currently enrolled. Total FTE	Number.
<b>provfte_clin</b>	The FTE of the provider the child is currently enrolled. Clinical FTE ONLY	Number.
<b>Office_l</b>	Office the child has been enrolled with for the longest time over the last 12 months. (Office enrollment will be based on the provider the child is enrolled with)	Numeric value. Office specific codes values. Weiming will provide definitions for each response code.
<b>provider_cel</b>	Provider to which the child has been enrolled with for the longest time over the last 12 months.	Blinded provider codes. Numeric value. (e.g. Provider A, Provider B). The provider code that indicates an office-level provider allocation will end with i.
<b>Provcelfte_tot</b>	The FTE of the provider the child has been enrolled with for the longest time. Total FTE	Number.
<b>Provcelfte_clin</b>	The FTE of the p the child has been enrolled with for the longest time. Clinical FTE ONLY	Number.
<b>Age_samp</b>	Age group the child was assigned to at the time of sampling	1. 3-7.99 months 2. 10-16.99 months 3. 19-40.99 months 4. 41-46 months old (2 <sup>nd</sup> sample only)
<b>office_bn</b>	Whether the child is enrolled in an office in the ten pediatric offices of focus.	1= Child is enrolled in the ten pediatric offices



		2= child is enrolled in a office that is outside the ten pediatric office
prov_bn	Whether the child is enrolled in with a provider who located in an office in the ten pediatric offices of focus.	1= Child is enrolled with a provider located in the ten pediatric offices 2= Child is enrolled with a provider located in an office that is outside the ten pediatric offices
prov_p_o	Whether the child is enrolled with a pediatric department provider	1= Child is enrolled with a pediatric provider located in the ten pediatric offices 2= Child is enrolled in a pediatric provider that is outside the ten pediatric offices 3= Child is enrolled with a non-pediatrics provider

**Table 2: Data file elements related child-specific health care utilization**

Variable	Description of Variable	Response Code
<b>Study ID</b>	Study unique identifier	
WVISITCNT	Number of well-child visits in the last 12 months. A well-visit will be defined using the National Committee for Quality Assurance's (NCQA) definition of a well-child visit.	Numeric value – total of numbers in well-child visits for each child
SVISITCNT	Number of problem visits in the last year. These are all outpatient visits that are not well-child care. Emergency room, urgent care, and hospital care is NOT included in this variable. Note to Weiming – Send Colleen a frequency output of the non-well child visits that are represented and the proportion of the visits that each type of visit represents.	Numeric value – total of numbers in SICKVISITS for each child
TWC_LAST	Months (at the time of sampling) since the child's last well-child visit.	Numeric value between 0-12.
REFERCNT	Total number of referrals to a non-primary care provider.	Numeric value – Total number of referrals to a non-primary care provider.
ERVISIT	Number of emergency room visits including urgent care visit.	1. 0 er visits 2. 1 er /urgent care visits 3. 2 er /urgent care visits 4. 3 or more er /urgent care Visits
HOSPVIS	Number of overnight hospital stays the child had.	1. 0 overnight hospital stays 2. 1 overnight hospital stay 3. 2 overnight hospital stays 4. 3 or more overnight hospital stays
offwcv	The number of offices the child received well-child care from the last 12 months..	1= 1 office 2= 2 offices 3= 3 offices 4= 4 or more offices
offanyvis	The number of offices the child received any kind of visit the last 12 months.	1= 1 office 2= 2 offices 3= 3 offices 4= 4 or more offices
provwcv	The number of providers the child received well-child care from the last 12 months.	1= 1 provider 2= 2 providers 3= 3 providers 4= 4 or more providers
Office_WC	Offices the child has received well-child care from the last 12 months. IF there multiple offices then create office_wc_1, office_wc_2, etc.	Numeric value. Office specific codes values. Weiming will provide definitions for each response code.
Prov_WC	Providers the child has received well-child care from the last 12 months. IF there multiple offices then create prov_wc_1, prov_wc_2, etc.	Blinded provider codes. Numeric value. (e.g. Provider A, Provider B). The provider code that indicates an office-level provider allocation will end with i.
Office_MWC	Office the child received a majority of their well-child care in the last 12 months.	Numeric value. Office specific codes values. Weiming will provide definitions for each response code.
Prov_MWC	Provider the child received a majority of their well-child care in the last 12 months	Blinded provider codes. Numeric value. (e.g. Provider A, Provider

		B). The provider code that indicates an office-level provider allocation will end with i.
<b>Prvfte_wc</b>	The FTE of the provider the child received the most well-child care from. Total FTE.	Number
<b>Prvfte_wc_clin</b>	The FTE of the provider the child received the most well-child care from. Clinical FTE	Number
<b>Office_any</b>	Office the child received any kind of care from. IF there multiple offices then create office_any_1, office_any_2, etc.	1= Office A 2= Office B 3= Office C 4= Office D 5= Office E 6= Office F 7= Office G 8= Office H 9= Office I 10= Office J
<b>Provider_any</b>	Provider s to which the child has received any type of care..	Blinded provider codes. Numeric value. (e.g. Provider A, Provider B)
<b>Office_samp</b>	Office the child was assigned to at the time of sampling	Blinded office codes. Numeric value. (e.g. Provider A, Provider B)

## Part 2: Data Set #2 (Office-Level Data Base)

For each ten pediatric offices the following data elements should be provided.

**Table 3: Data file elements related office-specific information**

<b>Office ID</b>	Office ID	
<b>Office_prov</b>	Number of providers in the office	Number
<b>OfficeAfte_T</b>	Number of FTE in Office A. Total FTEI	number
<b>OfficeApte_C</b>	Number of FTE in Office A. – CLINICAL FTE	Number

## Part 3: Data Set #3 (Provider-Level Data Base)

For each of the 56 participating pediatric providers the following data elements should be provided.

**Table 4: Data file elements related provider-specific information**

<b>Provider ID</b>	Office ID	
<b>FTE_TOTAL</b>	Total FTE	Number
<b>FTE_CLINICAL</b>	Clinical FTE	number
<b>OfficeID</b>	Offices the provider works in. If multiple do Office_1, Office_2, Office 3 where 1 is the office they work in the majority of the child.	Number
<b>Prov_Degree</b>	Type of health care provider	MD MD-resident NP PA etc.
<b>Prov_spec</b>	Specialty of the provider.	2 character code
<b>Prov_sex</b>	Gender of the provider.	F Female M Male
<b>prov_agec</b>	Age of the provider in years at the time the survey was mailed (October 27 <sup>th</sup> )`	Number in years



## Appendix 8



### Example Survey Administration Materials

#### Template for Pre-notification letter:

Date

Dear Parent or Guardian **[insert child's name]**,

You have been chosen to answer questions in a survey that will help the **[insert health system]** improve the health care services your child gets.

If you are willing to help us (and we hope you will), this is how it will work:

- In a few days you will get the survey in the mail.
- The parent or guardian who takes your child to the doctor most often should be the person who fills out the survey so we can get as much information as possible.
- When you are done, send it back in the postage paid envelope within two weeks.

All of the information you give us will be kept private and will be joined with many other parents or guardians being asked to fill out the survey.

A private company called **[insert company]**, will be adding the answers together and giving the results of all the completed surveys back to the **[insert your health system]**.

If you have any questions about the survey or how your answers will be used, call **[insert contact person]** at **[company]** on this toll-free number **[insert number]** or e-mail **[insert address]**.

Thank you for your time and your help in making our health care system better.

Sincerely,

Template for Cover Letter:

Date

Dear Parent or Guardian of **[insert child's name]**,

You are invited to participate in a survey that will help improve the health care services your child receives at **[insert health system]**. This survey is part of a research study to measure the quality of health care provided to young children.

We have asked the **[insert company]** to conduct this survey.

This is how it works:

- With this letter you received a survey.
- The parent or guardian who takes your child to the doctor most often should be the person who fills out the survey so we can get as much information as possible.
- This survey should take about 5 minutes to complete.
- When you are done, send it back in the postage paid envelope within two weeks.

Your participation in the survey is **voluntary**. All the information you give us will be kept private and will never be matched to your name or your child's name. Your child's doctor or nurse will not see your individual responses or know who completed the survey.

Staff from the **[insert company]** will be adding the answers together, combining them with information about your child's health care visits, and giving a summary report back to health care providers at **[insert health system]**. **[Insert company]** is helping us analyze the data in order to protect your confidentiality.

If you have any questions about the survey or how your answers will be used, call **[insert contact person]** of the **[insert company]** at **[phone number]** or e-mail her at **[insert address]**.

Thank you for your effort to improve health care for young children at **[insert health system]**.

Your opinion is important and will help us improve the health care we provide.

Sincerely,

Template for Thank you/ Reminder Post card:

From Practice

Dear Parent or Guardian of **[child's name]**,

Two weeks ago we sent you an important survey about your child's health care. If you have mailed it, please accept our sincere thanks. If you haven't mailed this important survey, please take the time now to complete and mail it, or fill it out on the internet at the web site provided in the survey cover letter.

If you have any questions or need another copy, please call **[contact name]** at our toll free number **[insert number]**.

Your opinion is valuable and will help us here at **[insert practice name]** in the health care services we provide for young children.

Thanks again for your help.

Sincerely,

### Template for telephone reminder phone call:

Hello, can I speak to parent/guardian of **[Insert Child's name]**?

#### **If Yes, or This Is:**

- I am **[insert your name]** calling from the **[insert health system]**. Recently, we sent you a survey titled “**Your Child’s Health Care**” that is about the health care your child gets. Did you receive the survey? Is a white survey with green/teal writing on it - It was in a booklet form?”

Have you sent it back in the last few days?

- If they **yes**, Say “We are just calling to remind parents to please fill out the survey. It is part of an effort the **[insert department/health system]** is doing to improve well-child care for young children and they think the best way to get feedback is to hear from parents like yourself. Do you think you sent it back in the last few days?”
  - If they say **yes** – Thank you, and have a great day!
  - If they say **no** - Your participation in the survey is **voluntary**. However, only parents like you can provide the important feedback needed in the survey. All the information you give us will be kept confidential and will never be matched to your name or your child's name. Your child's doctor or nurse will not see your individual responses or know who completed the survey. We hope you reconsider and will take the time to complete the survey. Thank you for your time, have a good morning, night, afternoon.
- If they say “**No**,” say “Did you receive the survey in the mail? It was in a booklet form?”
  - If they say **No**: If we send another survey to your home, would you be willing to complete it?
    - If yes – they want another survey: Thank you. We will send it to you as soon as possible. Can I please CHECK Your ADDRESS? (Check address)

Thank you, in advance, for the time you take to complete the survey. The information you provide will help improve health care for children in **[insert health system]**.

- If no- they don't want another survey: Your participation in the survey is **voluntary**. Only parents like you can provide the important feedback needed in the survey. All the information you give us will be kept confidential and will never be matched to your name or your child's name. Your child's doctor or nurse will not see your individual responses or know who completed the survey. We hope you reconsider and will take the time to complete the survey. Thank you for your time, have a good morning, night, afternoon.
  
- If they say **Yes**: "I know parents like yourself are busy and it may be hard to find time to complete the survey but your feedback is very important. The information you give us will help improve health care for children in **[insert health system]**. Do you think you could take the time either today or tomorrow?"
  - ◆ If they **say yes** "Thank you so much, we look forward to your feedback. Remember to send it back in as soon as possible and have a good afternoon, morning, night."
  - ◆ If they **say no**, say "....."
  - ❖ If they don't want to do it: Your participation in the survey is **voluntary**. Only parents like you can provide the important feedback needed in the survey. All the information you give us will be kept confidential and will never be matched to your name or your child's name. Your child's doctor or nurse will not see your individual responses or know who completed the survey. We hope you reconsider and will take the time to complete the survey. Thank you for your time, have a good morning, night, afternoon.

- ❖ If they say they have questions before they will fill out: You can contact **[insert contact name]** at the following toll-free line with any questions that you have about the survey or how your responses will be used: **[insert phone number]**. Thank you for your time.

**If No,**

May I please speak to the parent or guardian of **[insert child's name]**?

If Yes, (go to the back to the top)

If No, they are not here: Ok, thank you. We will call back. (Enter Call Back Code)

If no, they don't live here or they refuse to pass the phone on:

Thank you for the time. (Enter Refusal Code – Don't Call Back)

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If it is a Message Machine:

Hello, I am calling from the **[insert health system]**. Recently, we sent you a survey titled "**Your Child's Health Care**" about the health care **[Insert child's name]** gets. Our records show that we haven't received the survey yet. I know parents like yourself are busy, but your feedback is very important. The information you give us will help improve health care for children in **[insert health system/city]**. All responses will be kept confidential. We are calling to remind you to please send back the survey as soon as possible. If you have questions about the survey or how you responses will be used, you can call **[insert contact person]** at the following toll-free number: **[insert phone number]**. Have a good day.





## Appendix 9



### 3-9 Month Old Example Data Dictionary of ProPHDS Survey Dataset

VARIABLE NAME	Question in the Practice Level PHDS	Response Codes
<b>STUDY ID</b>	Study, unique identifier	
<b>SURVDISP</b>	Survey disposition	<ol style="list-style-type: none"> <li>1. Survey received</li> <li>2. Survey not received</li> <li>3. Survey returned due to bad address</li> <li>4. Survey returned but parent refused to answer the survey. Survey completely blank.</li> <li>5. Survey returned-Child not in age range and parent thought it was for too young a child.</li> </ol>
<b>SURVDATE</b>	Date survey was received	YYYY-MM-DD
<b>SURVRAGE</b>	Age of the child, in months, at the time the survey was received.	Age of child in months.
<b>SURVSTEP</b>	Stage of survey administration during which survey was received.	<ol style="list-style-type: none"> <li>1. After the 1st Mailing</li> <li>2. After the Post Card Reminder</li> <li>3. After the 2nd Mailing</li> <li>4. After the Phone Call Reminder</li> <li>5. After the 2nd Post Card</li> <li>6. Survey was not returned</li> <li>7. Survey not applicable</li> </ol>
<b>AGPE3_1A</b>	Q1a. In the last 12 months, did your child's doctors or other health providers talk with you about things you can do to help your CHILD grow and learn?	<ol style="list-style-type: none"> <li>1. Yes, and my questions were answered</li> <li>2. Yes, but my questions were not answered completely</li> <li>3. No, but I wish we had talked about that</li> <li>4. No, but I already had information about this topic and did not need to talk about it anymore.</li> <li>5. Multiple response; Yes/No</li> <li>99. Missing</li> </ol>

<b>AGPE3_1B</b>	Q1b. In the last 12 months, did your child's doctors or other health providers talk with you about the kinds of behaviors you can expect to see as your CHILD gets older?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_1C</b>	Q1c. In the last 12 months, did your child's doctors or other health providers talk with you about breastfeeding?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_1D</b>	Q1d. In the last 12 months, did your child's doctors or other health providers talk with you such as introduction of solid foods?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_1E</b>	Q1e. In the last 12 months, did your child's doctors or other health providers talk with you about the importance of placing your CHILD on his/her back when going to sleep?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>

<b>AGPE3_1F</b>	Q1f. In the last 12 months, did your child's doctors or other health providers talk with you about where your child sleeps (such as the location and type of crib your child may sleep in)?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_1G</b>	Q1g. In the last 12 months, did your child's doctors or other health providers talk with you about night waking and fussing?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_1H</b>	Q1h. In the last 12 months, did your child's doctors or other health provider's talk with you about how your child communicates his/her needs?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_2A</b>	Q2a. In the last 12 months, did your child's doctors or other health providers talk with you about what your child is able to understand?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>

<b>AGPE3_2B</b>	Q2b. In the last 12 months, did your child's doctors or other health providers talk with you about how your child responds to you, other adults, and caregivers?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_2C</b>	Q2c. In the last 12 months, did your child's doctors or other health providers talk with you about how to avoid burns to your child such as changing the hot water temperature in your home?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_2D</b>	Q2d. In the last 12 months, did your child's doctors or other health providers talk with you about using a car seat?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_2E</b>	Q2e. In the last 12 months, did your child's doctors or other health providers talk with you about how to make your house safe?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>

<b>AGPE3_2F</b>	Q2f. In the last 12 months, did your child's doctors or other health providers talk with you about the importance of showing a picture book and reading with your child?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_2G</b>	Q2g. In the last 12 months, did your child's doctors or other health providers talk with you about whether you child watches TV?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_2H</b>	Q2h. In the last 12 months, did your child's doctors or other health providers talk with you about issues related to childcare?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>
<b>AGPE3_2I</b>	Q2i. In the last 12 months, did your child's doctors or other health providers talk with you about resources for parents and families in your community?	<p>1. Yes, and my questions were answered</p> <p>2. Yes, but my questions were not answered completely</p> <p>3. No, but I wish we had talked about that</p> <p>4. No, but I already had information about this topic and did not need to talk about it anymore.</p> <p>5. Multiple response; Yes/No</p> <p>99. Missing</p>

<b>FC3A</b>	Q3a. In the last 12 months how often did your child's doctors or other health providers take time to understand the specific needs of CHILD?	1. Never 2. Sometimes 3. Usually 4. Always 99. Missing
<b>FC3B</b>	Q3b. In the last 12 months how often did your child's doctors or other health providers respect you as an expert about CHILD?	1. Never 2. Sometimes 3. Usually 4. Always 99. Missing
<b>FC3C</b>	Q3c. In the last 12 months how often did your child's doctors or other health providers help you feel like a partner in your child's care?	1. Never 2. Sometimes 3. Usually 4. Always 99. Missing
<b>FC3D</b>	Q3d. In the last 12 months how often did your child's doctors or other health providers explain things in a way that you can understand?	1. Never 2. Sometimes 3. Usually 4. Always 99. Missing
<b>FC3E</b>	Q3e. In the last 12 months how often did your child's doctors or other health providers show respect for your family's values, customs and how you prefer to raise your child?	1. Never 2. Sometimes 3. Usually 4. Always 99. Missing
<b>PEDS4A</b>	Q4a. Do you have any concerns about your child's learning, development, or behavior?	1. Yes 2. A little 3. Not at All 99. Missing
<b>PEDS4B</b>	Q4b. ....how your child talks and make speech sounds?	1. Yes 2. A little 3. Not at All 99. Missing
<b>PEDS4C</b>	Q4c..... how your child understands what you say?	1. Yes 2. A little 3. Not at All 99. Missing
<b>PEDS4D</b>	Q4d..... how your child uses his/her arms and legs?	1. Yes 2. A little 3. Not at All 99. Missing
<b>PEDS4E</b>	Q4e..... how your child behaves?	1. Yes 2. A little 3. Not at All 99. Missing
<b>PEDS4F</b>	Q4f..... how your child gets along with others?	1. Yes 2. A little 3. Not at All 99. Missing
<b>DEV5</b>	Q5. In the last 12 months, did your child's doctors or other health providers ask if you have concerns about CHILD'S learning, development, or behavior?	1. Yes 2. No 3. I don't remember 99. Missing
<b>DEV6</b>	Q6. In the last 12 months, did your child's doctors or other health providers give you specific information to address your concerns?	1. Yes 2. No 3. I don't remember 4. I did not have any concerns 99. Missing

<b>FU7A</b>	Q7a. In the last 12 months did your child's doctors or other health providers refer your CHILD to another doctor or other health provider?	1. Yes 2. No 99. Missing
<b>FU7B</b>	Q7b. In the last 12 months did your child's doctors or other health providers test child's learning and behavior?	1. Yes 2. No 99. Missing
<b>FU7C</b>	Q7c. In the last 12 months did your child's doctors or other health providers note a concern about your CHILD that should be watched carefully?	1. Yes 2. No 99. Missing
<b>FU7D</b>	Q7d. In the last 12 months did your child's doctors or other health providers refer your CHILD to speech-language or hearing testing?	1. Yes 2. No 99. Missing
<b>DA8</b>	Q8. In the last 12 months did your child's doctors or other health providers have your child pick up small objects, stack blocks, throw a ball or recog. Different colors?	1. Yes 2. No 3. I don't remember 4. My child is too young to do these kind of activities 99. Missing
<b>DA9</b>	Q9. In the <b>last 12 months</b> , did your child's doctor or other health care provider have you fill out a questionnaire about <u>specific concerns</u> or <u>observations</u> you may have about your child's physical ability, communication or social behaviors?	1. Yes 2. No 99. Missing
<b>DA9A</b>	Q9a. Did this questionnaire ask about your concerns or observations about how your child talks or makes speech sounds?	1. Yes 2. No 99. Missing
<b>DA9B</b>	Q9b. Did this questionnaire ask about your concerns or observations about how your child interacts with you and others?	1. Yes 2. No 99. Missing
<b>AF10A</b>	Q10a. In the last 12 months did your child's doctors or other health providers ask you if you or someone in your household drinks alcohol or uses other substances?	1. Yes 2. No 99. Missing
<b>AF10B</b>	Q10b. In the last 12 months did your child's doctors or other health providers ask you if you ever feel depressed, sad, or have crying spells?	1. Yes 2. No 99. Missing
<b>AF10C</b>	Q10c. In the last 12 months did your child's doctors or other health providers ask if you have someone to turn to for emotional support?	1. Yes 2. No 99. Missing
<b>AF10D</b>	Q10d. In the last 12 months did your child's doctors or other health providers ask you to talk about any changes or stressors in your family or home?	1. Yes 2. No 99. Missing
<b>AF10E</b>	Q10e. In the last 12 months did your child's doctors or other health providers ask you if you have any firearms in your home?	1. Yes 2. No 99. Missing
<b>PD11</b>	Q11. Do you have one or more person(s) that you think of as your child's personal doctor or nurse?	1. Yes 2. No 99. Missing
<b>PD11A</b>	Q11A. Which of these people do you think of as your child's personal doctor or nurse?	Provider name(s)
<b>FRSTCH12</b>	Q12. Is the child named in the survey your first child?	1. Yes 2. No 3. This question does not apply to me 99. Missing

<b>HISLAT13</b>	Q13. Is your child of Hispanic or Latino origin?	<b>1.</b> Hispanic or Latino <b>2.</b> Not Hispanic or Latino <b>99.</b> Missing
<b>white_14</b>	Q14. What is your child's race. Please mark one or more	1=Name Checked
<b>black_14</b>	Q14. What is your child's race. Please mark one or more	1=Name Checked
<b>asian_14</b>	Q14. What is your child's race. Please mark one or more	1=Name Checked
<b>amind_14</b>	Q14. What is your child's race. Please mark one or more	1=Name Checked
<b>nathi_14</b>	Q14. What is your child's race. Please mark one or more	1=Name Checked
<b>other_14</b>	Q14. What is your child's race. Please mark one or more	1=Name Checked
<b>PB_BF</b>	Q15. How long did you breastfeed your child	<b>1.</b> My child was not breastfed <b>2.</b> Less than a month <b>3.</b> A month or more <b>4.</b> I am still breastfeeding <b>99.</b> Missing
<b>PB_READ</b>	Q16. How many days in a typical week do you or other family members read a book with your child?	<b>1.</b> No days ( 0 days) <b>2.</b> 1-2 days <b>3.</b> 3-4 days <b>4.</b> 5-6 days <b>5.</b> Everyday (7 days) <b>99.</b> Missing
<b>PB_TV</b>	Q17. How many hours in a typical day does your child watch TV or watch videos?	<b>1.</b> 0 hours <b>2.</b> Less than 1 hour <b>3.</b> 1-2 hours <b>4.</b> More than 2 hours <b>5.</b> We don't own a tv <b>99.</b> Missing
<b>RESPED</b>	Q18. What is the highest grade or level of school that you have completed?	<b>1.</b> 8 <sup>th</sup> grade or less <b>2.</b> Some high school, but did not graduate <b>3.</b> High school graduate or GED <b>4.</b> Some college or 2 year degree <b>5.</b> 4 year college graduate <b>6.</b> More than a 4 year college graduate <b>99.</b> Missing
<b>DEP_1</b>	Q19. How many days in the last week have you felt depressed?	<b>1.</b> 0 days <b>2.</b> 1 day <b>3.</b> 2 days <b>4.</b> 3 days <b>4.</b> 4 days <b>5.</b> 5 days <b>6.</b> 6 days <b>7.</b> All 7 days <b>99.</b> Missing



<b>DEP_2</b>	Q20. In the last 12 months, have you had two weeks or more during which you felt sad, blue, depressed, or lost pleasure in things that you usually cared about or enjoyed?	<b>1.</b> Yes <b>2.</b> No <b>99.</b> Missing
<b>PTRB_A</b>	Q21a. How much trouble have you had paying for.....CHILD'S health and medical expenses?	<b>1.</b> A lot of Trouble <b>2.</b> Some Trouble <b>3.</b> No Trouble <b>99.</b> Missing
<b>PTRB_B</b>	Q21b. How much trouble have you had paying for.....Supplies like formula, food, diapers, clothes and shoes?	<b>1.</b> A lot of Trouble <b>2.</b> Some Trouble <b>3.</b> No Trouble <b>99.</b> Missing
<b>PTRB_C</b>	Q21c. How much trouble have you had paying for.....Healthcare for yourself?	<b>1.</b> A lot of Trouble <b>2.</b> Some Trouble <b>3.</b> No Trouble <b>99.</b> Missing



## Appendix 10



### **Office Systems Inventory** **Derived From the *A Practical Guide for Improving Child Developmental Services***

# OFFICE SYSTEMS INVENTORY

**Instructions:** To complete this tool, we recommend including your lead clinician, lead nurse, office administrator, and one or two other clinicians and staff. This tool will help you assess the degree to which systems exist in your office that make it possible for your practice to:



- Meet parents' informational needs and address their concerns about their child's learning, development, and behavior,
- Identify children at risk through the use of structured developmental and psychosocial assessments and screening at appropriate visits,
- Provide a strong and streamlined link to community resources for families who need or want them, and
- Promote optimal parent/child relationships.

## 1. Eliciting Parents' Informational Needs

Check off each office system your practice *currently* uses or has in place.

- We utilize a formal and informal survey to focus the visit on the parents' informational needs (e.g., a formal survey such as the *Promoting Healthy Development Survey* or an informal survey, such as questions routinely asked at beginning of visit).
- We have established practice-wide guidelines on anticipatory guidance and parent education topics.
- We have embedded practice guidelines into a clinical tool, such as a preventive services summary/flow sheet, health maintenance record, or a well-child care record.
- We have established practice-wide guidelines for annually updating and reviewing anticipatory guidance and parent education guidelines.
- We have implemented an annual chart review or parent survey to measure performance of anticipatory guidance and parent education.
- We have circulated results of the chart review to clinicians to plan for system changes.

**SCORE:** \_\_/6

## 2. Identifying Children at Risk

- We use standardized structured screening tools to identify children at risk for developmental delays (e.g., ASQ, PEDS).
- We identify high-risk families through psychosocial screening for maternal depression, substance abuse and domestic violence.
- We elicit parent/family strengths at well-child visits.
- We use tools at each well-child visit that alert the physician to needed preventive and developmental services and risk screenings (e.g., chart screening prior to visit, flag on chart).

- We utilize a screening and prompting system for needed preventive and developmental services at both well-child and non-well child visits.
- We train and utilize office staff to prompt practitioners to use preventive and developmental screening systems routinely.
- We have established a registry to monitor the care of high-risk patients (e.g., developmentally delayed, at-risk family).
- We utilize a recall system to follow up with children who have missed well-child appointments.

**SCORE: \_\_/8**

### **3. Linking Families to Community Resources for Additional Care**

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- We identify and utilize community resources to meet the needs of the practice population.
- We identify and train a staff person to regularly update a community resources listing.
- We organize and make accessible a listing of community resources.
- We identify and utilize a central contact and referral source in the community for needed referrals.
- We have created/adapted a standard referral form to send information to community agencies.
- We have created/adapted a standard referral form to request information from community agencies.
- We utilize a tracking system to follow up on referrals to community agencies.

**SCORE: \_\_/7**

### **4. Promoting Optimal Parent/Child Relationships**

---

- We designate a clinical staff person to train office staff about anticipatory guidance and parent education guidelines.
- We train and utilize clinic personnel (other than the physician) to conduct problem-focused counseling on specific topics (e.g., car seat safety, toilet training).
- We provide patient goal setting and/or written plans to facilitate behavior change.
- We provide patient education materials about specific topics (e.g., toilet training, sleep) that are consistent with the practice guidelines.
- We organize and make accessible patient education materials.
- We have created/adapted a standardized way to document anticipatory guidance and patient education (e.g., flow sheet, computerized record).

**SCORE: \_\_/6**

	Score	Possible Total	Rating Your Office Systems
Section 1		6	Above 20 points: Your practice likely has a

Section 2	8	number of well-developed office systems in place.
Section 3	7	10-20 points: It is likely there are some systems within your office that need improvement. The sub-scores for each system will help you identify specific opportunities for improvement.  Lower than 10 points: Your office probably does not have a large number of systems in place.
Section 4	6	
Total	27	

---



## APPENDIX 11: OFFICE POSTER, HANDOUT, AND/OR MEDICAL CHART EXTRACTION TOOL



The list of topics in column A are the topics asked about in the PHDS.

- Directions: 1) Create a column for each provider, office or other unit of analysis of focus.  
 2) Put a "1" in each corresponding cell if the office has a corresponding parent education material  
 3) Create separate counts for office posters/handouts versus the medical chart  
 4) Count within each topic area and then count across all topic areas

	PHDS Version
<b>Development and Behavior</b>	
Things to help child grow and learn	All Ages
Behaviors you can expect 2 see in child	All Ages
Reading	All Ages
TV	All Ages
How child communicates his/her needs	3-9 Month
What child is able to understand	3-9 Month
How child responds to you	3-9 Month
How child responds to others, including caregivers	3-9 Month
Night waking and fussing	3-9 Month, 10-18 Month
Explore away from you	10-18 Month
Guidance and discipline techniques	10-18 Month, 19-48 Month
Toilet training	10-18 Month, 19-48 Month
Words and phrases child uses	10-18 Month, 19-48 Month
Words and phrases child understands	10-18 Month, 19-48 Month
How child gets along with other children	19-48 Month

<b>Physical Care</b>	
Childcare Issues	All Ages
Issues related to food and feeding	3-9 Month, 19-48 Month
Breastfeeding	3-9 Month
Introduction to solid food	3-9 Month
Importance of placing child on his or her back	3-9 Month
Child's crib and location	3-9 Month
Vitamins and foods child should eat	10-18 Month
Bedtime routines	10-18 Month, 19-48 Month
Naptime routines	10-18 Month
Child sleeping with a bottle	10-18 Month
Weaning child from a bottle	10-18 Month
Issues related to feeding (power issues)	19-48 Month
Number of hours of sleep child needs	19-48 Month

<b>Injury Prevention</b>	
Car Seats	All Ages
House safety	All Ages
How to avoid burns to child	3-9 Month
Turning down hot water temperature	3-9 Month
What you should do if child swallows certain kinds of poisons	10-18 Month, 19-48 Month
Ways to teach child about dangerous situations	19-48 Month



## Appendix 12



### Example Executive Summary of the PHDS Findings

**EXECUTIVE SUMMARY:**  
**Opportunities to Improve Preventive and Developmental Health Care for Young Children in HEALTH PLAN X:**  
**Promoting Healthy Development Survey (PHDS) Findings in Kaiser Permanente Northwest**



**Background:**

Over the last two years the Child and Adolescent Health Measurement Initiative (CAHMI) has worked collaboratively with the Pediatrics department to implement the Promoting Healthy Development Survey (PHDS) to measure the quality of preventive and developmental health care provided in the ten pediatric offices located in the Portland metropolitan region. The PHDS was administered, via a subcontract with the Center for Health Research, during October 2004-January 2005 to a sample of eligible children meeting the enrollment and well-child visit criteria. A total of 2,166 completed surveys were obtained. Office- and provider-level reports have been shared with the pediatric providers.

**Key Findings:**

Across the six aspects of care measured in the PHDS, the scores ranged from 25-93 (out of 100). The chart below shows the findings for each aspect of care measured.

**PHDS Measure of Care Scores in Health Plan X**

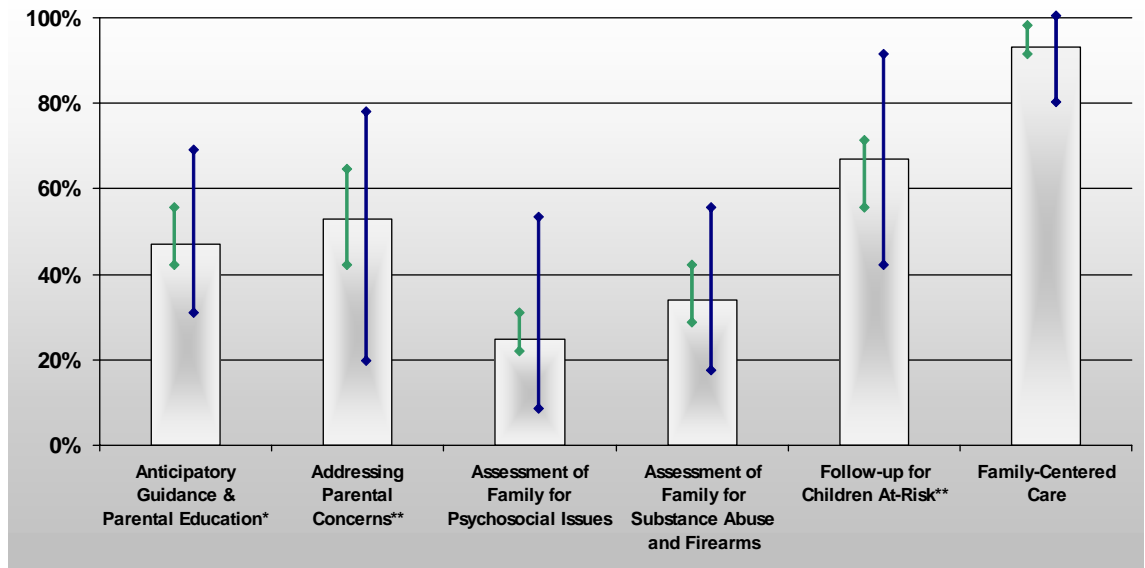
**Office-Level Variation:**

- Significant variation was observed on 4/6 of the PHDS measures across the *ten pediatric offices* located in the Portland Metropolitan region.
- No one office scored the highest OR lowest on every measure.

**Provider-Level Variation:**

- Significant variation was observed on all six PHDS measures for the 51 pediatric providers with N=15 or more PHDS surveys.
- No one provider scored the highest or lowest on every measure.

The average percent of recommended topics addressed:



Source: 2004 CAHMI PHDS Data, Health Plan X (N=2,116)

\*This is the average percent of recommended topics discussed with the child's health care provider. The chart in the office-level report shows the average percent of topics for which the parent had their informational needs met either through a discussion with their health care provider OR they already had information.

\*\* These measures of care are based on one item or concept. Therefore, the number shown is the percent of children receiving the aspect of care.

**Opportunities for Improvement in HEALTH PLAN X:**

**OPPORTUNITY #1: MEETING PARENTS' INFORMATIONAL NEEDS ON RECOMMENDED ANTICIPATORY GUIDANCE & PARENTAL EDUCATION**

The PHDS asks about whether approximately 18 recommended anticipatory guidance and parental education topics were discussed. The response option allows the parent to indicate whether, if the topic was not discussed, they wished it had been or if he/she already had information and did not need to discuss the topic with their child's health care provider.

- On average, 47% of the recommended topics were discussed.
- 6 out of 10 children had parents with *one or more UNMET informational needs* on a recommended topic (e.g. parent responded that the topic was not discussed and they wished it had been).





*Top Topics for Which At Least 1 out of 4 Children Had Parents With UNMET Information Needs  
(% of Children Whose Parent Responded "No, but I Wish We Had Discussed")*

Children 3-9 months old	Children 10-18 months old	Children 19-48 months old
<ul style="list-style-type: none"> <li>• What child is able to understand (39%)</li> <li>• Issues related to TV and video watching (35%)</li> <li>• How child responds to you and other caregivers (30%)</li> <li>• Night waking and fussing (28%)</li> </ul>	<ul style="list-style-type: none"> <li>• What to do if child swallows poisons (41%)</li> <li>• Guidance and discipline techniques (34%)</li> <li>• Anticipatory guidance about toilet training (at the 18 month visit) (29%)</li> <li>• How child may start to explore away from the parent (26%)</li> <li>• Words and phrases child uses and understands (25%)</li> </ul>	<ul style="list-style-type: none"> <li>• What to do if child swallows poisons (35%)</li> <li>• Ways to teach child about dangerous situations and places (28%)</li> <li>• Guidance and discipline techniques (26%)</li> </ul>

**OPPORTUNITY #2: ASKING ABOUT AND ADDRESSING PARENTAL CONCERNS ABOUT THEIR CHILD**

Items from the Parents Evaluation of Developmental Status® (PEDS) tool are in the PHDS. The PEDS asks parents about specific concerns they may have about their child's learning development and behavior and identifies children at risk for delays. The PHDS also includes items that focus on whether health care providers ask about and address parental concerns.

- 1 out of 2 children had a parent who reported being asked by their child's health care provider about their concerns.
  - 53.8% of children had parents with one more concerns about their child
 

*Of these children, 53.5% were asked about their concerns and 69% received information to address their concerns*
- 3 out of 10 children were identified at significant risk for social, emotional or behavioral delays.
 

*Of these children, 3 out of 5 received some level of follow-up care*

**OPPORTUNITY #3: SCREENING THE FAMILY FOR RISKS**

The PHDS includes five items asking about whether the child's health care providers screened the parent for psychosocial, safety and substance abuse issues in the family.

- On average, children's parents were asked about 1 out of 5 items: (*% asked by child's health care provider*)

○ Alcohol or substance abuse -49%	○ Ever feel depressed, sad or have crying spells - 21%	○ Someone to turn to for emotional support- 27%	○ Changes or stressors in the family -27%	○ Firearms in the home - 20%
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**Why is screening families for risks a pediatric issue? An applied example in parental depression**

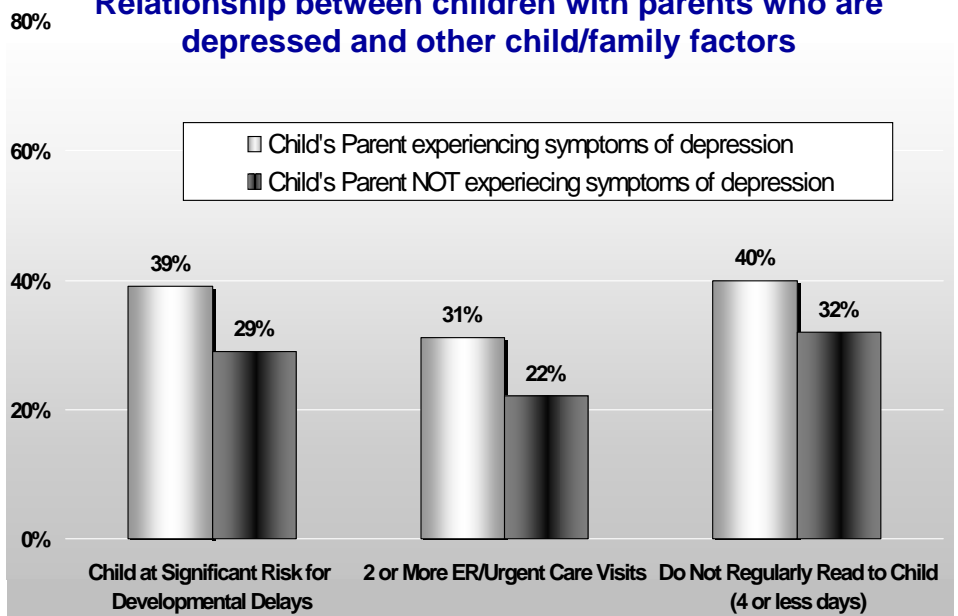
The PHDS includes the Kemper depression screening tool that asks the parent whether they are experiencing symptoms of depression.

- 1 out of 10 children (0-3 years old) in HEALTH PLAN X have parents experiencing symptoms of depression.

Children of depressed parents in HEALTH PLAN X were:

- More likely to visit the emergency room or urgent care clinic more often
- More likely to be at risk for developmental, behavioral delays
- Less likely to be read to by their parents

**Relationship between children with parents who are depressed and other child/family factors**



Source: 2004 CAHMI PHDS Data, Health Plan X (N=2,116)

This report was created by the Child and Adolescent Health Measurement Initiative (www.cahmi.org). The data presented is confidential and should not be cited, reproduced or copied without written permission from the CAHMI. For more information please contact Colleen Peck Reuland at reulandc@ohsu.edu or 503-494-0456.





## Appendix 13



### Sample Communication Template to Frontline Healthcare Providers

# QUALITY OF CARE FINDINGS FOR [Office X]

Date

Dear [insert group] pediatric providers,

During [Date], the [insert company], in collaboration with the [insert health system], implemented a survey to parents of young children (0-3 years old). This survey, the Provider-Level Promoting Healthy Development Survey (Pro-PHDS), assesses whether or not national recommendations for health promotion and developmental services are provided by pediatric clinicians.

We've since compiled the data, analyzed it by a number of variables, and are now sharing some of the office-level findings. **All information included in this report is confidential.**

**[Sample size]** parents or guardians of children who received well-child care at [Office X] in the last 12 months completed this survey in your office.

This report details key findings in Beaverton related to the following measures of care:

	Pg
1. <b>Anticipatory Guidance and Parental Education</b> .....	1
2. <b>Addressing Parental Concerns</b> .....	3
3. <b>Follow-up for Children At-Risk</b> .....	4
4. <b>Assessment of the Family</b> .....	5
5. <b>Family-Centered Care</b> .....	6
6. <b>Quality of Care Findings by Select Child Characteristics</b> .....	7
7. <b>Conclusions and Implications</b> .....	8

Throughout this report you will find charts that display your office's findings compared to two groups: (1) Other [Office] pediatric offices, and (2) Pro-PHDS benchmark data. More information about the comparative data presented can be found on **Page 8**.

A summary of the key findings, additional information about the PHDS, and quality improvement resources can also found on Page 8.

If you have questions about the findings presented in this report please contact [insert contact person] at XXX-XXX-XXXX or email him/her at [insert email address].

[Insert Name]  
[Insert Title]

[Insert Name]  
[Insert Title]



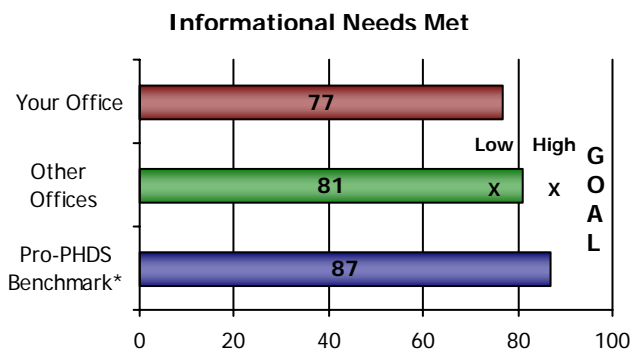
**MEASURE:**

# ANTICIPATORY GUIDANCE AND PARENTAL EDUCATION

**DESCRIPTION:** National recommendations for well-child care call for health care providers to provide anticipatory guidance and parental education about a number of topics related to children's development, growth, behavior and safety. In the PHDS, parents are asked whether their child's doctor or other health care providers discussed approximately 15 recommended age-specific anticipatory guidance and parental education topics. The response choices allow parents to indicate whether their informational needs on each topic were met:

- ✓ Yes, and my questions were answered (*Informational need met*)
- ✓ Yes, but my questions were not answered completely (*Informational need unmet*)
- ✓ No, but I wish we had talked about that (*Informational need unmet*)
- ✓ No, but I already had information about that and did not need to talk about it any more (*Informational need met*)

## OVERALL RESULTS FOR [Office X]



The chart above shows, on average, the percentage of topics for which parents had their informational needs met. (Parent responded "Yes, and my questions were answered" OR "No, but I already had information about that and did not need to talk about it any more".)

### All Recommended Topics Discussed

- **4%** of parents reported that their child's doctors or other health care providers talked with them about all of the age-appropriate topics.

### Average Number of Recommended Topics Discussed

- On average, **44%** of the recommended topics asked about in the PHDS are discussed with parents.

### Informational Needs Unmet

- **64%** of parents noted at least once "No, but I wish we had talked about that" OR "Yes, but my questions were not answered".

## TOPIC-SPECIFIC RESULTS FOR [Office X]

	Physical Care	Development & Behavior	Injury Prevention
<b>Keep up the good work!</b>	<ul style="list-style-type: none"> <li>- Breastfeeding</li> <li>- Back to sleep</li> </ul>	<ul style="list-style-type: none"> <li>- Reading with child</li> <li>- Behaviors you can expect in child</li> </ul>	<ul style="list-style-type: none"> <li>- Car seats</li> <li>- House safety</li> </ul>
<b>Room for improvement</b>	<ul style="list-style-type: none"> <li>- Bed and naptime routines</li> <li>- Weaning child from a bottle/breastmilk</li> </ul>	<ul style="list-style-type: none"> <li>- Guidance and discipline techniques</li> <li>- Toilet training</li> </ul>	<ul style="list-style-type: none"> <li>- What to do if child swallows certain kinds of poisons</li> <li>- Ways to teach child about dangerous situations</li> </ul>

## RELATED PARENTING BEHAVIORS

To provide you with descriptive information about your patients, we asked parents to report about key parenting behaviors. Following each topic is the percentage of parents who report they did NOT do the activity:

- Did not breastfeed their child OR breastfed less than a month<sup>1</sup> – **7%**
- In a typical week: Read 0-2 days – **18%**    Read 3-4 days – **14%**    Read 5-7 days – **69%**
- In a typical day: Number of hours child watched TV or Videos:

### Younger than 2 years old

- 0 hours<sup>2</sup> – **32%**    • Less than 1 hour – **41%**
- 1-2 hours – **23%**    • More than 2 hours – **5%**

### Two years and older

- 0 hours<sup>2</sup> – **3%**    • Less than 1 hour – **23%**
- 1-2 hours – **47%**    • More than 2 hours – **28%**

<sup>1</sup>Only asked in 3-9 month old version of the survey.

<sup>2</sup>Includes parents who do not own a TV.

## TOPIC-SPECIFIC FINDINGS FOR [Office X]

The figures listed after each topic represent, respectively, the percentage of children whose parents who responded: **Yes, topic was discussed**; **No, but I already had information about that topic**; **No, but I wished we had talked about that OR Yes, but I still had questions**.

	3 - 9 MONTHS OLD N= 72	10 - 18 MONTHS OLD N= 80	19 - 48 MONTHS OLD N= 162
<b>DISCUSSIONS ABOUT PHYSICAL CARE</b>	<ul style="list-style-type: none"> <li>• Things you can do to help child grow and learn – 72, 11, 17 (%)</li> <li>• Breastfeeding – 90, 6, 4 (%)</li> <li>• Issues related to food such as the introduction of solid foods – 79, 6, 15 (%)</li> <li>• Importance of placing child on back – 88, 7, 6 (%)</li> <li>• Where your child sleeps (location, type of crib) – 42, 46, 13 (%)</li> <li>• Whether your child watches television (TV) or videos – 13, 52, 35 (%)</li> <li>• Issues related to childcare – 36, 43, 21 (%)</li> </ul>	<ul style="list-style-type: none"> <li>• Things you can do to help child grow and learn – 62, 15, 23 (%)</li> <li>• Vitamins and foods your child should eat – 67, 6, 27 (%)</li> <li>• Bed and naptime routines – 33, 38, 29 (%)</li> <li>• Whether child sleeps with a bottle – 51, 37, 12 (%)</li> <li>• Weaning your child from a bottle – 29, 44, 27 (%)</li> <li>• Whether your child watches television (TV) or videos – 17, 55, 28 (%)</li> <li>• Issues related to childcare – 17, 58, 25 (%)</li> </ul>	<ul style="list-style-type: none"> <li>• Things you can do to help child grow and learn – 57, 23, 19 (%)</li> <li>• Issues related to food and feeding – 65, 19, 16 (%)</li> <li>• Bedtime routines and how many hours of sleep child needs – 30, 44, 26 (%)</li> <li>• Whether your child watches television (TV) or videos – 22, 57, 21 (%)</li> <li>• Issues related to childcare – 19, 64, 16 (%)</li> </ul>
<b>DISCUSSIONS ABOUT DEVELOPMENT AND BEHAVIOR</b>	<ul style="list-style-type: none"> <li>• Kinds of behaviors you can expect to see in child as he/she gets older – 71, 10, 19 (%)</li> <li>• Night waking and fussing – 39, 34, 27 (%)</li> <li>• How child communicates his/her needs – 52, 28, 20 (%)</li> <li>• What your child is able to understand – 44, 24, 32 (%)</li> <li>• How your child responds to you and other caregivers – 53, 26, 21 (%)</li> <li>• Importance of showing a picture book to or reading with your child – 35, 45, 20 (%)</li> </ul>	<ul style="list-style-type: none"> <li>• Kinds of behaviors you can expect to see in child as he/she gets older – 58, 20, 22 (%)</li> <li>• Words and phrases child uses and understands – 44, 23, 32 (%)</li> <li>• Night waking and fussing – 35, 31, 34 (%)</li> <li>• How your child may start to explore away from you – 19, 51, 29 (%)</li> <li>• Guidance and discipline techniques – 13, 35, 52 (%)</li> <li>• Anticipatory guidance about toilet training – 7, 49, 44 (%)</li> <li>• Importance of reading with child – 34, 48, 18 (%)</li> </ul>	<ul style="list-style-type: none"> <li>• Kinds of behaviors you can expect to see in child as he/she gets older – 60, 22, 19 (%)</li> <li>• Toilet training – 35, 35, 29 (%)</li> <li>• Words and phrases child uses and understand – 60, 25, 14 (%)</li> <li>• How child is learning to get along with other children – 35, 37, 27 (%)</li> <li>• Guidance and discipline techniques – 25, 42, 33 (%)</li> <li>• Importance of reading with child – 44, 45, 12 (%)</li> </ul>
<b>DISCUSSIONS ABOUT INJURY PREVENTION</b>	<ul style="list-style-type: none"> <li>• How to avoid burns to your child, such as changing the hot water temperature in your home – 30, 50, 20 (%)</li> <li>• Using a car seat – 57, 33, 10 (%)</li> <li>• How to make your house safe – 32, 45, 23 (%)</li> </ul>	<ul style="list-style-type: none"> <li>• What you should do if your child swallows certain kinds of poisons – 14, 34, 52 (%)</li> <li>• Using a car seat – 37, 46, 18 (%)</li> <li>• How to make your house safe – 41, 42, 18 (%)</li> </ul>	<ul style="list-style-type: none"> <li>• What to do if your child swallows certain kinds of poisons – 28, 40, 32 (%)</li> <li>• Using a car seat – 36, 55, 9 (%)</li> <li>• How to make your house safe – 29, 62, 9 (%)</li> <li>• Ways to teach child about dangerous situations, places and objects – 22, 44, 34 (%)</li> </ul>

**MEASURE:**

# ADDRESSING PARENTAL CONCERNS

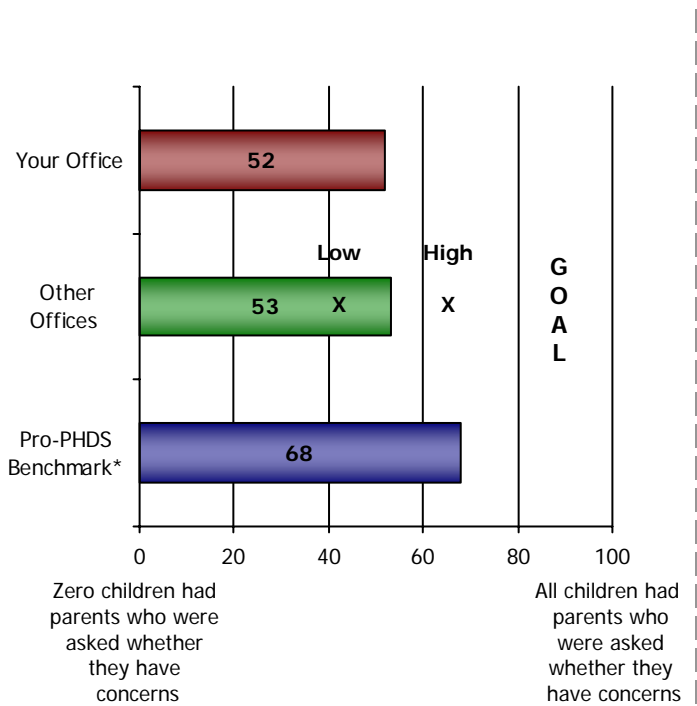
**DESCRIPTION:**

Research with health care providers and parents consistently finds that asking about and addressing parent concerns is one of the most important and valuable aspects of well-child care. Two items in the PHDS focus on addressing parent concerns:

- ✓ Whether or not their child's doctors or other health care providers asked the parent if he/she has concerns about the child's learning, development or behavior
- ✓ Whether or not parents with concerns received specific information to address those concerns

Six items derived from the Parent's Evaluation of Developmental Status (PEDS)<sup>®\*</sup> are also included in the PHDS. These items ask parents about specific concerns they may have about their child's learning, development or behavior.

## OVERALL RESULTS FOR [Office X]



### Parents With Concerns Who Were Asked About Their Concerns

- **55%** of children have parents with one or more concerns about their child's learning, development or behavior. Of this group, **50%** of children have parents who reported that their child's doctors or other health care providers asked whether or not they had any concerns about their child.

### Parents With Concerns Who Received Information to Address Their Concerns

- **64%** of children have parents with concerns who reported that their child's doctors or other health care providers gave them specific information to address their concerns.

## PARENTAL CONCERNS

The following percentages of children have parents who reported having "a lot" or "a little" concern about:

- The child's learning, development or behavior – **39%**
- How the child talks and makes speech sounds – **33%**
- How the child understands what parents say – **25%**
- How the child uses his or her arms and legs – **17%**
- How the child behaves – **34%**
- How the child gets along with others – **29%**

\*Glascoe FP. Parents' Evaluation of Developmental Status. Nashville, TN: Ellsworth & Vandermeer Press, Ltd; 1998

**MEASURE:**

# FOLLOW-UP FOR CHILDREN AT-RISK

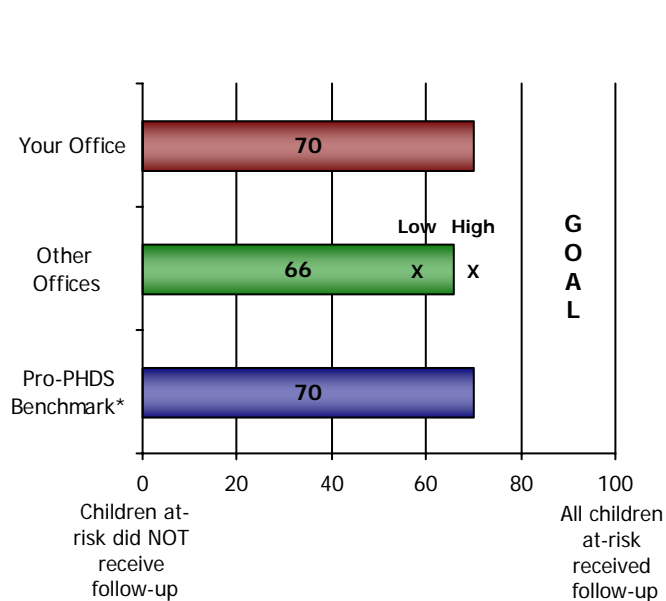
**DESCRIPTION:**

Parent concerns can be an indication of their child's risk for developmental, behavioral or social delays. The PHDS includes items adapted from the PEDS<sup>®</sup>\* to identify a group of children "at risk" for a developmental/behavioral delay who should have received some level of follow-care care. The PEDS uses an age- and concern-specific scoring algorithm to identify this group of children.

The PHDS asks a series of four questions to assess whether or not children at risk for developmental/behavioral delays received follow-up care from their doctors or other health care providers. Parents were asked if their child's doctors or other health care providers:

- ✓ Tested the child's learning and behavior
- ✓ Referred the child to another doctor or health care provider
- ✓ Referred the child for speech-language or hearing testing
- ✓ Noted a concern about the child that should be watched

## OVERALL RESULTS FOR [Office X]



### Children Identified At-Risk

- 35% of children have parents with concerns that indicate their child is **at risk** for developmental, behavior or social delays.

### Children At-Risk Who Received Follow-Up Care

- 70% of children identified at risk for developmental/behavioral delays received some form of follow-up care (according to parental report).

## LEVEL OF FOLLOW-UP RECEIVED BY AT-RISK GROUP

Listed below are the percentages of children identified as "at-risk" by the PEDS items whose parents reported that their child's doctor or other health care providers did one or more of the follow-up actions:

- Tested their child's learning and behavior – **24%**
- Referred their child to another doctor or health care provider – **38%**
- Referred their child for speech-language or hearing testing – **27%**
- Noted a concern about their child that should be watched – **26%**

\*Glascoe FP. Parents' Evaluation of Developmental Status. Nashville, TN: Ellsworth & Vandermeer Press, Ltd; 1998

**MEASURE:**

# ASSESSMENT OF THE FAMILY

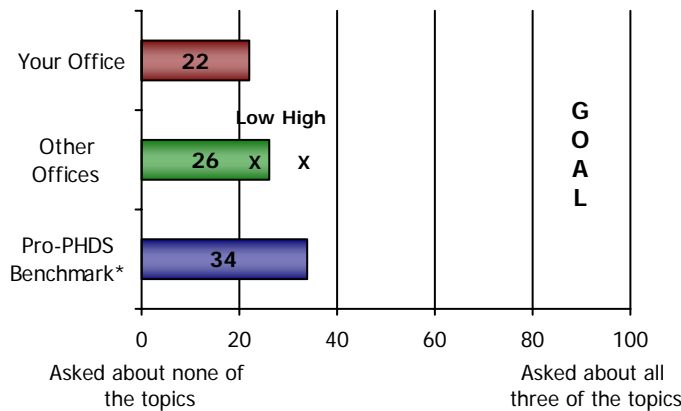
**DESCRIPTION:**

Parental well-being and the home environment are major determinants of the health and well-being of young children. National guidelines recommend that pediatric clinicians annually assess for the well-being of parents and safety within the family. Five items in the PHDS ask about whether the child's doctors or other health care providers assess the parent and family for risks to the child's health.

## OVERALL RESULTS FOR [Office X]

### PSYCHOSOCIAL ISSUES

- ✓ If the parent ever feels depressed, sad or has crying spells
- ✓ If the parent has someone to turn to for emotional support
- ✓ Changes or stressors in the home



#### Asked About All Topics

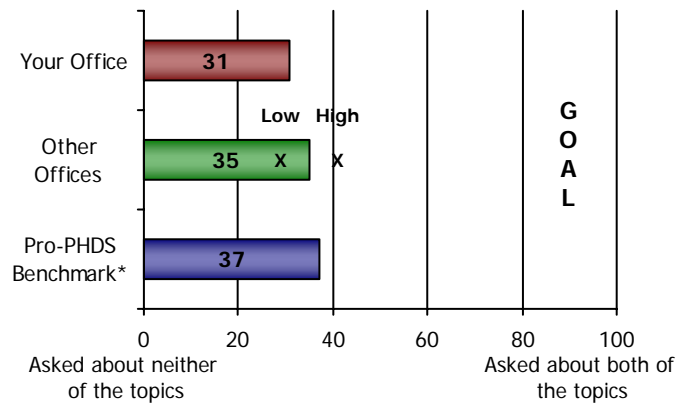
- **10%** of children have parents who reported that their child's doctors or other health care providers asked about all three topics.

#### Not Asked About ANY Topic

- **66%** of children have parents who reported that their child's doctors or other health care providers did NOT ask about ANY of the three topics.

### SUBSTANCE ABUSE/FIREARMS

- ✓ Alcohol and other substance abuse in the household
- ✓ Firearms in the home



#### Asked About Both Topics

- **11%** of children have parents who reported that their child's doctors or other health care providers asked about both topics.

#### Not Asked about EITHER Topic

- **50%** of children have parents who reported that their child's doctors or other health care providers did NOT ask about EITHER topic.

## ITEM-SPECIFIC FINDINGS

The percentage of children whose parents reported that their child's doctors or other health care provider asked about the following topics in the last 12 months:

- If parent feels depressed, sad or has crying spells – **17%**
- If parent has someone to turn for emotional support – **25%**
- If there are changes or stressors in their life or home – **23%**
- If someone in the household drinks alcohol or uses other substances – **45%**
- If there are firearms in the home – **17%**

## RELATED ISSUES IN THE FAMILY

**15%** of children have parents who reported experiencing symptoms of depression in the last 12 months. Of this group...



...**21%** were asked by their child's doctors or other health care providers if they have felt depressed, sad or had experienced crying spells.



**MEASURE:**

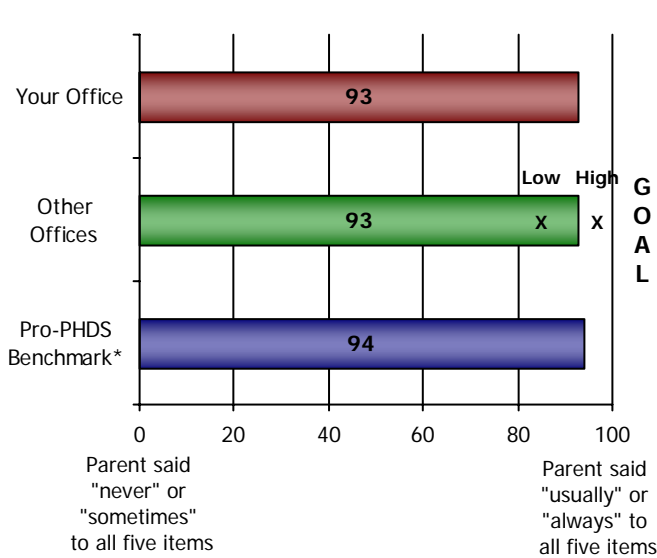
# FAMILY-CENTERED CARE

**DESCRIPTION:**

Research demonstrates that a positive partnership with a child's doctors or other health care providers is one of the most important factors for ensuring parents get the information and support they need to promote the healthy development of their child. Five items in the PHDS assess the degree to which the care provided is family-centered by asking parents how often the child's doctor or other health care providers do the following:

- ✓ Respect the parent as an expert about their child
- ✓ Take time to understand the specific needs of the child
- ✓ Help the parent feel like partner in their child's care
- ✓ Explain things in a way that the parent can understand
- ✓ Show respect for the family's values, customs and how they prefer to raise their child

## OVERALL RESULTS FOR [Office X]



- **84%** of children have parents who reported "usually" or "always" to all of the family-centered care items.
- **16%** of children have parents who reported "never" or "sometimes" to one or more of the family-centered care items.

## ITEM-LEVEL RESULTS FOR [Office X]

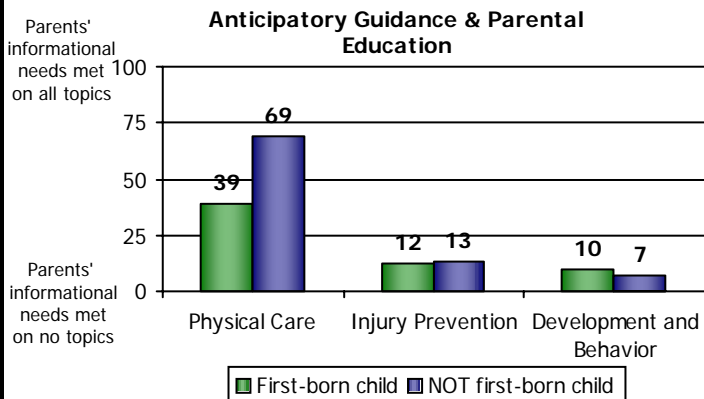
Percentage of children whose parents reported that their child's doctors and other health care providers "usually" or "always":

- Respect the parent as an expert about the child – **91%**
- Take the time to understand the specific needs of the child – **89%**
- Help the parent feel like a partner in their child's care – **93%**
- Explain things in a way the parent can understand – **97%**
- Show respect for the family's values, customs and how they prefer to raise the child – **93%**

# VARIATIONS IN QUALITY OF CARE FINDINGS BY CHILD CHARACTERISTICS

## Variations in Care by *Birth Order of the Child*

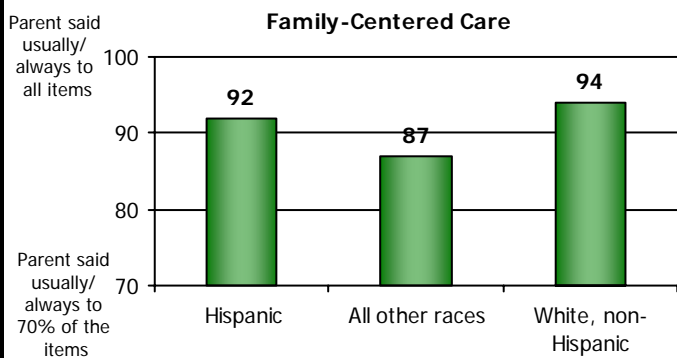
- In your office, **59%** of children whose parents completed the survey were first-born children.



### Key Findings in [Office X]

- Children who were not a family's first-born child had parents who were **JUST AS LIKELY** to report that they wanted more guidance and information on selected topics as compared to children who were the family's first born. For example, when compared to parents who completed the survey for their *first-born child*, these parents were just as likely to want more information and guidance than they received on topics related to their child's **development, behavior and injury prevention**.
- On the other hand, parents who completed the survey for a child who was not their first-born were significantly less likely to report wanting information and guidance about topics focused on the **physical care of the child** – such as issues related to food and feeding or number of hours of sleep a child needs.

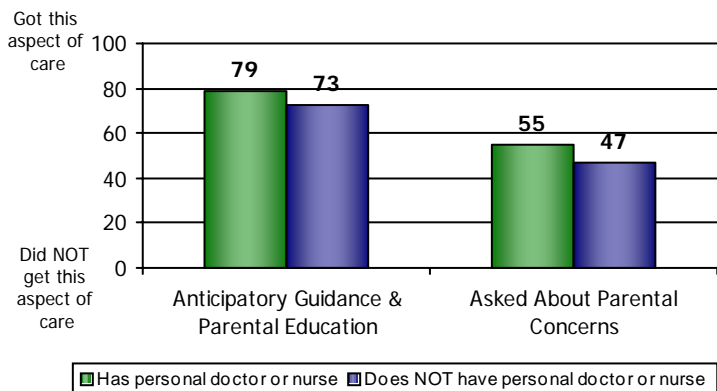
## Variations in Care by Child's *Race/Ethnicity*



### Key Findings in [Office X]

- In your office, **9%** of children were reported by parents to be Hispanic, **69%** were reported to be white, **14%** Asian, and **9%** as another race.
- Parents of non-white children were significantly less likely to report **positive partnerships and communication** with their child's health care providers.

## Quality Higher for Children with a *Personal Doctor or Nurse*



### Key Findings in [Office X]

- In your office, **78%** of children have parents who report that their child has one or more personal doctor(s) or nurse(s) who knows him/her and his/her health history well.
- For a majority of the PHDS quality measures, scores were significantly higher for children who had a personal doctor or nurse, when compared to those who did not have a personal doctor or nurse.

# CONCLUSIONS AND IMPLICATIONS OF THE FINDINGS

Parents in your office indicated many areas where your office is doing very well. They also noted areas where there are opportunities for improvement. Listed below is a selection of the findings.

## Areas of Excellence in [Office X]

### Meeting Parents' Informational Needs

Parents are getting the information and guidance they need on:

- Breastfeeding
- Back to sleep
- Car seats

### Family-Centered Care

Parents Report Positive Communication and Partnerships

- **84%** of parents in your office report receiving all aspects of family-centered care.

## Improvement Opportunities

Parents want more information and guidance on:

- Guidance and discipline techniques
- What to do if child swallows certain kinds of poisons
- Toilet training

Ideas you can use:

- ✓ Add text about adding these topics to your after-visit summaries.
- ✓ Get topic-specific parent education hand-out materials.
- ✓ Get topic-specific posters and put them in your office.

## Asking About and Addressing Parental Concerns

- **55%** of children had parents who reported one or more concerns about their child's learning, development or behavior. Of these, **50%** were asked about their concerns and **64%** received information to address their concerns.

Ideas you can use:

- ✓ Research has shown that asking parents a general question such as "Do you have any concerns?" does not elicit reliable parent responses to indicate a child's risk for delays.
- ✓ To standardize this activity in your office, incorporate items from the PEDS tool into your well-child visit dot phrases.
- ✓ Consider having the parent complete a standardized developmental screening tool in the waiting room or have your office staff help parents complete the tool before they see you. Current tools recommended by the AAP include the PEDS or the Ages and Stages Questionnaire (ASQ).

## Assessing the Parent for Risks to the Child's Healthy Development

- **15%** of children had parents who reported symptoms of depression.
  - Of these, only **21%** had parents who were asked if she/he felt depressed, sad or has crying spells.

Ideas you can use:

- ✓ Consider having the parent complete a standardized depression screener in the waiting room.
- ✓ Tools are available on the KP website. Kathi Kemper, MD has also developed a 3-item tool shown to be feasible in primary care offices.

**IMPORTANT NOTE ABOUT THE FINDINGS:** These survey results present a "best case" scenario due to an inherent positivity bias caused by two factors: 1) The survey was conducted only in English, and 2) Only parents whose children had at least one well-child visit in the last 12 months were eligible to receive the survey.

**\*DATA PRESENTED IN THE CHARTS:** The second bar labeled "Other Offices" is based on data from all other pediatric offices (NOT including your office) in [office x] that are located in [insert city]. The X under the word "high" indicates the highest office-level score observed while the X under the word "low" indicates the lowest office-level score observed. The comparison data presented in the charts is based on Provider-Level PHDS (ProPHDS) data gathered between 2001-2005 by the Child and Adolescent Health Measurement Initiative.

**ADDITIONAL INFORMATION ABOUT THE CAHMI AND THE PROMOTING HEALTHY DEVELOPMENT SURVEY (PHDS):** The PHDS was created by the CAHMI and has been proven to be a reliable and valid tool for assessing health care quality. To date, over 45,000 PHDS surveys have been collected and analyzed. Additional information about the CAHMI and the PHDS can be found on the CAHMI website at [www.cahmi.org](http://www.cahmi.org).

**ADDITIONAL RESOURCES ABOUT PREVENTIVE AND DEVELOPMENTAL HEALTH CARE:**

[www.aap.org](http://www.aap.org) • [brightfutures.aap.org/web/](http://brightfutures.aap.org/web/) • [www.zerotothree.org](http://www.zerotothree.org) • [www.nichq.org](http://www.nichq.org) • [www.cincinnatichildrens.org/health-quality](http://www.cincinnatichildrens.org/health-quality) • [www.cmwf.org](http://www.cmwf.org)

**QUESTIONS? CONCERNS?** If you have questions about the findings presented in this report, please contact [insert contact info] or email him/her at [insert address].



## Appendix 14



### Example of a Topic-Specific Issue Brief on the PHDS Findings Focused Parental Depression

# Screening for Parental Depression in Pediatric Practices:

## MISSED OPPORTUNITIES & Why This is a Pediatric Issue



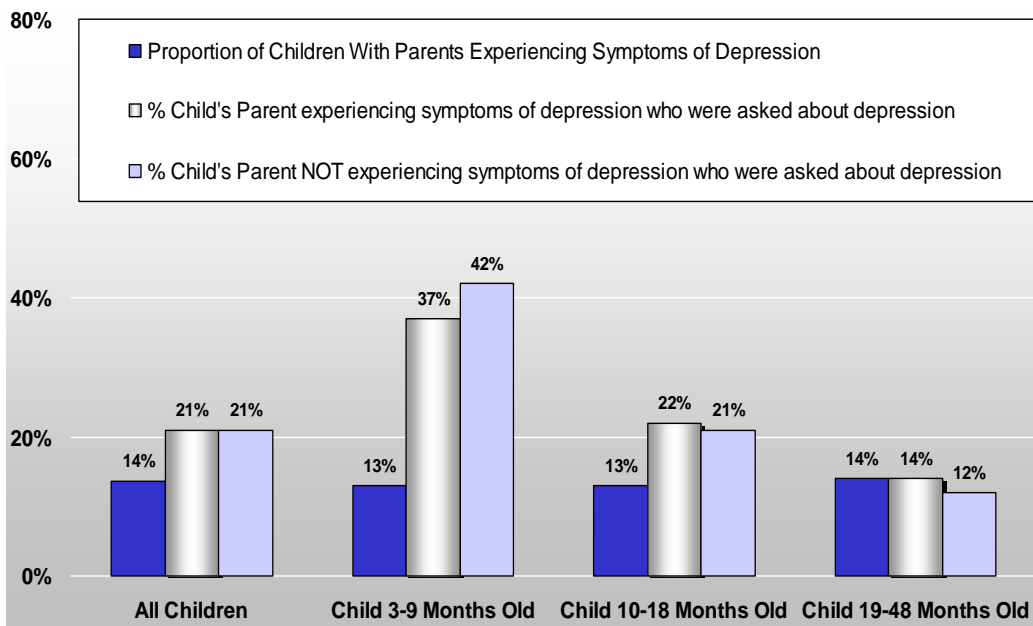
Findings and Recommendations from the CAHMI<sup>1</sup>: The Pediatrics Department in Health System X recently collaborated with the Child and Adolescent Health Measurement Initiative to implement the Promoting Healthy Development Survey. This memo highlights some of the findings related to parental depression and highlights why it is an important issue for pediatric health care providers to consider.

Authors: Child and Adolescent Health Measurement Initiative (CAHMI): Colleen Peck Reuland, Christina Bethell, Danielle Hermann, Molly Skarphol and Nicole Hinckley-Hines, MD. More information about the CAHMI can be found at [www.cahmi.org](http://www.cahmi.org).

### In Health System X

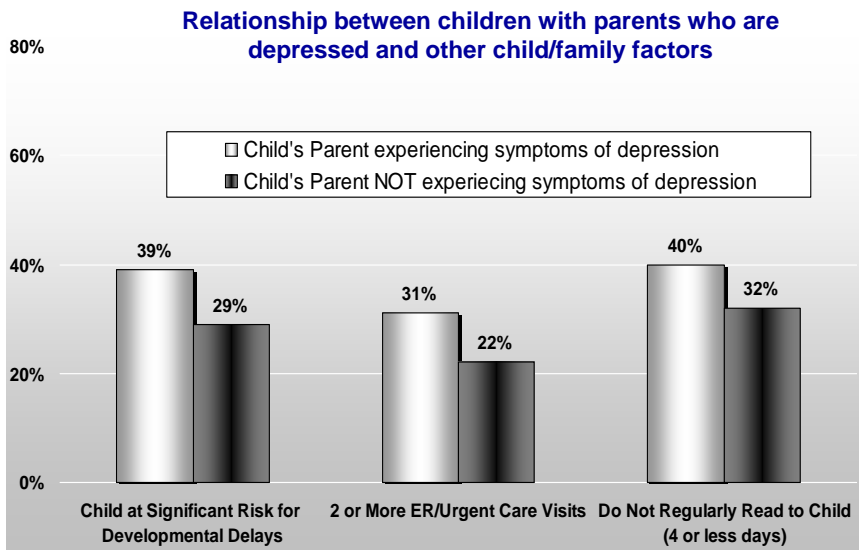
- **1 out of 10 children** (0-3 years old) have parents experiencing symptoms of depression
  - Infants (3-9 months) were NOT more likely to have parents experiencing symptoms of depression as compared to older children (10 months- 3 years old).
- **1 out of 5 children** have parents who were asked about depression by their child's health care providers
  - Children whose parents are experiencing symptoms of depression were NOT more likely to have been asked about depression.
  - Infants were more likely to have their parents screened for depression as compared to toddlers.

**Relationship between children with parents who are depressed and whether or not they were asked about depression**



**MISSED OPPORTUNITY:** In the first three years of life there are ten well-child visits. This represents at least 10 opportunities to screen parents for depression.

## In Health System X: Why is Parental Depression a Pediatric Issue?



Children whose parents are experiencing symptoms of depression are significantly more likely to:

### Cost More-

- More likely to visit the emergency room or urgent care clinic more often

### Are at Risk-

- More likely to be at risk for developmental, behavioral delays
- More likely to be read to less by their parents

### FACTS ABOUT PARENTAL DEPRESSION:

- Maternal depression, or depressive symptoms, was found to be related to lower birthweight, increased emotional lability among infants and toddlers, behavior problems, increased rate of injuries or accidents, failure to thrive among preschoolers and symptoms of mental illness and behavioral problems in school age children (Zuckerman 1987).
- Maternal depression often slips through the cracks of the medical community as women bounce back and forth for support between psychiatric, obstetric, pediatric and general family disciplines (Kleinman, 1994).
- While medical professionals have been taught to expect a certain degree of emotional upheaval during the postpartum period, there is a tendency to normalize such response and not take the woman's concerns seriously (Kleinman 1994).
- Postpartum depression, for many women does not last just a few months after birth but can continue throughout their child's first years.

## What can pediatric health care providers do?

**Simple and validated screening tools** can identify parents who may be experiencing depression, and if identified, prescription medication and psychological intervention can effectively treat depression.

- Computers or the "black boxes" could be utilized to administer screening tools to parents in the waiting room.
- Medical assistants can ask the 1-3 screening questions as part of their pre-screening during well-child visits.

### EXAMPLE: KEMPER DEPRESSION SCREENER:

- How many days in the last week have you felt depressed?
- In the past year, have you had two weeks or more during which you felt sad, blue, depressed, or lost pleasure in things that you usually cared about or enjoyed?
- Have you had two or more years in your life when you felt depressed or sad most days, even if you felt okay sometimes?

## Antidepressant Medication Management Screening

- A high-priority HEDIS measure is related to antidepressant medication management.
- KPNW has created systems for adults to focus on this important aspect of care.
- Pediatric health care providers need a link to these systems.
- Opportunity to Address An Aspect of Care Measured in HEDIS: Remember: Pediatric health care providers see parents of young children ten times in the first year. This is ten times to assure that people with depressive symptoms are linked into systems that assure that their symptoms and medications are managed.

<sup>1</sup>Data Source: The data presented is based on the 2004-2005 implementation of the Promoting Healthy Development Survey (PHDS). Parents of children who were between 3-45 months old, had at least one well-child visit, had been continuously enrolled in X for 12 months or since the time of birth completed the survey and who were able to complete the mailed survey in English completed the survey. For more information about the PHDS and X project, please contact Colleen Peck Reuland at



## Appendix 15



### Sample Communication Template to Parents of Young Children





# Be a partner in your child's health care!

## Your Child's Developmental Needs & Behavior

### Areas of excellence:

Number of parents who talked with their child's health care provider about:

- Behaviors you can expect to see in your child — 9 out of 10
- The importance of reading to your child — 8 out of 10

### Room for improvement:

Number of parents who did not talk with their child's doctor or other health care provider and wished they had talked about:

- Guidance and discipline techniques — 1 out of 4
- Toilet training — 1 out of 5

Talk to your child's health care providers about:

- o Behaviors to expect from your child
- o Words or phrases your child may use
- o How often you should read to your child
- o Toilet training
- o Guidance and discipline techniques



## Preventing Injury & Keeping Your Child Safe

### Areas of excellence:

Number of parents who talked with their child's health care provider about:

- Car seat safety — 8 out of 10
- House safety — 8 out of 10

### Room for improvement:

Number of parents who did not talk with their child's doctor or other health care provider and wished they had talked about:

- What to do if your child swallows something poisonous — 1 out of 4
- Teaching your toddler about dangerous situations, places, and objects — 1 out of 4

Talk to your child's health care providers about:

- o Safety in your home and car
- o Poison prevention
- o Teaching your child about dangerous situations, places, and objects



## Do You Have Concerns about Your Child's Learning, Development, or Behavior?

Before your child's office visit, think about if you have these concerns:

- o How your child talks and makes speech sounds
- o How your child understands what you say
- o How your child uses his or her arms and legs
- o How your child behaves or gets along with others

Voicing these concerns can help your child's health care provider assess your child's risk for learning, developmental, and behavioral delays.

Parents are often the first to notice delays in their child's growth and development. Voicing your concerns can help your child's health care providers identify issues early.



## We Care about Your Entire Family!

Your child's doctor or other health care provider should ask about family issues that affect your child's health and well-being.

Your child's health care provider should ask:

- If anyone in your household smokes
- If anyone in your household abuses alcohol or other substances
- If you feel safe at home
- If you ever feel depressed, sad, or have crying spells



You can talk to your doctor or other health care provider about these issues.