



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

Reporting and Audience Member	Value of the PHDS to them	How you want them to use the PHDS findings	Information/resources partner can bring	How partner can ease administration, analysis, and/or dissemination	Best time to include partner	Impact on timeline, staffing, budget
#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
Health System	<ul style="list-style-type: none"> ➤ 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.
Office or Provider Groups	<ul style="list-style-type: none"> ➤ 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. ➤ 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.
Individual Health Care Providers	<ul style="list-style-type: none"> ➤ Provider team (see above) ➤ 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"> 1) Provider with whom the child is enrolled or "paneled" as a primary care provider. 2) Provider with whom the child had the most well-child visits in the last 12 months or since birth. <p>Tip from the Field: 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, CAHMI recommends 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>Specific Populations of Children</p>	<p>➤ Child-level variables: What variables will you use to identify specific children? Are these variables valid?</p> <p>Tip from the Field: 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, CAHMI recommends 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

	Comparison of individual providers^a	Comparison of offices or provider groups	Health-system level reporting	Comparison of health plans^e
Target number completed surveys	30 per health care provider ^b	30 per health care provider in each office	100 ^d	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 ^c	78 per health care provider	78 per health care provider in each office	253	632 per health plan

^a 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.

^b 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.

^c 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.

^d 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.

^e 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

	PHDS	ProPHDS	Difference Between the Tools?
<u>General Characteristics</u>			
Length of Survey	10 pages	5 pages	Yes
Time for Parent to Complete the Survey	10-15 minutes	5-10 minutes	Yes
<u>Survey Content</u>			
<u>Number of Items</u>			
<i>Rec. aspects of prev. and dev. care</i>			
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 ^a	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
<i>Child Health Care Characteristics</i>			
Access to Care, Use of Health Care	7	0	Yes
<i>Target Child Characteristics</i>			
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)

	PHDS	ProPHDS	Difference Between the Tools?
<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

^a 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.