

December 2007

# **Manual of Operations for the MCAN Common Data Elements Survey**

Prepared for

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# Introduction

The Common Data Elements and Demographic survey instruments were created to collect standardized outcome information from patients enrolled in the five MCAN sites. The Manual of Operations provides instructions for administering the surveys, data entry and coding, formatting and storage, delivery of the data to RTI International, and the schedule for data delivery. Appendix A provides English and Spanish versions of the instrument and Appendix B provides an example of coded data.

## 1. Instrument Administration Instructions

This section presents the instructions for administering the Common Data Elements survey instrument and the Demographic survey instrument. Both survey instruments are reprinted in Appendix A.

### 1.1 Common Data Elements

All questions in the MCAN Common Data Elements instrument questionnaire (Questions 1–14) must be administered exactly as written, including prompts. There are some questions (for example, the income question in the demographic section of the instrument) that have different wording for in-person versus phone interviews, and sites must use the applicable wording as described below.

Each site may add its own introduction and instructions at the beginning of the interview or at the beginning of the MCAN Common Data Elements section. The MCAN Common Data Elements instrument may be combined with existing site-specific instruments or administered on its own.

#### 1.1.1 Interview Information

<b>Interview information</b>	
Patient ID _____	Survey (check one):
Date ____/____/____ [E.G., 12/31/1999] M M/ D D/ Y Y Y Y	1 <input type="checkbox"/> Baseline
Survey Administration Method	2 <input type="checkbox"/> 6 month follow-up
1 <input type="checkbox"/> Telephone	3 <input type="checkbox"/> 12 month follow-up
2 <input type="checkbox"/> In-person by Interviewer	4 <input type="checkbox"/> Other, _____
3 <input type="checkbox"/> Mail	
4 <input type="checkbox"/> Self-Administered	
5 <input type="checkbox"/> Other, _____	

The Interview Information section at the beginning of the MCAN Common Data Elements must be completed at the beginning or end of the interview by the interviewer. If the survey is self-administered (administered by the respondent), then the site must fill in this information upon receipt of the survey.

Each site may use its own protocol for assigning patient ID numbers. These numbers are to be assigned in a logical manner and not repeated across respondents. Each respondent must have a unique patient ID number that must be identical at baseline, 6-month follow-up, and 12-month follow-up. This unique ID should be used again if the same patient enters a program multiple times. RTI may

reassign ID numbers when pooling data across sites for the cross-site analysis to ensure consistency in format across sites.

Although parents/caregivers may be completing interviews for more than one child at a sitting, it is important to keep the patient information separate. A separate instrument should be completed for each child.

The date required in the Interview Information section includes the date the interview was completed. If the survey takes place over multiple interview sessions the date provided in the dataset should be the date of the final session for that follow-up period (e.g., baseline, 6-month follow-up, 12-month follow-up).

RTI has listed several potential survey administration methods in the Interview Information section. Ideally the administration method will be consistent across the survey periods but the sites' budget constraints may make that difficult. RTI expects the majority of surveys will be administered over the telephone or in person. In-person interviews may be administered by an interviewer reading questions from a paper or computerized instrument. Interviewers administering a paper version of the survey must pay close attention to the skip instructions and skip questions when instructed. If the survey is administered in a method not listed in the Interview Information section sites should specify how the interview is administered. The coding section of this document (Appendix B) will provide an example of how this response should be entered in the data file.

MCAN expects sites to administer surveys at baseline, 6 months, and 12 months. The sites may have trouble reaching an individual between interviews, resulting in a gap larger than 6 months between interviews. Sites should make every effort to collect follow-up information from patients even if the follow-up survey occurs outside of the 6-month or 12-month window. Sites conducting 3-month follow-ups should enter the data as "other" in the Interview Information section.

### **1.1.2 Intervention Inventory**

A separate box listing the interventions for each site is included at the start of the survey form. The purpose of the intervention inventory is to record the interventions each patient received. Patients may receive different sets of interventions either by design or because they refused a particular intervention or were not able to participate in it. Where possible, the interviewer should check the interventions in which each child/family has participated during the course of the program. This section should be completed at baseline if the patient has received any interventions and at each follow-up. See the coding section for detailed instructions on data recording (Appendix B). RTI assembled the list of interventions from site materials. Please let RTI know if there are interventions for your site that are not included or if your site is not participating in an intervention listed under your name.

### **1.1.3 Questions for Caregivers**

The section of the interview comprising the common data elements should begin with the medication questions. There is a short description of the questions that should be read to the parent/caretaker at each interview. Insert the child's name in the text for [CHILD's NAME] wherever it appears.

1. Does [CHILD's NAME] currently take medication for asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

- 1  Yes [GO TO QUESTION 2]
- 2  No [SKIP TO QUESTION 4]
- 994  Don't Know [SKIP TO QUESTION 4]
- 997  Refused [SKIP TO QUESTION 4]

Question 1 asks about asthma medication use. The question should be read exactly as written and the information in brackets following the question should not be read aloud. This question specifies that the interviewer is not to read any possible answer responses aloud but should wait for the respondent to answer the question without prompting. For all responses except "Yes," the interviewer should proceed to Question 4. If the respondent answers "Yes" the interviewer should proceed to Question 2. The interviewer should mark the appropriate response on the paper or computerized instrument and proceed accordingly.

2. Please tell us the names of those medications and whether it is taken every day or as needed: [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT; ADD MORE LINES IF CHILD TAKES MORE THAN SIX (6) MEDICATIONS FOR ASTHMA]

[PROMPT: THESE COULD BE OVER-THE-COUNTER OR DOCTOR PRESCRIBED MEDICATIONS]  
 [PROMPT: IF RESPONDENT ANSWERS INHALER, ASK IF THEY KNOW THE NAME OF THE INHALER]

- |                         |      |                                      |                                      |
|-------------------------|------|--------------------------------------|--------------------------------------|
| 2.1M Medication 1 _____ | 2.1T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed |
|                         | 994  | <input type="checkbox"/> Don't Know  | 997 <input type="checkbox"/> Refused |
| 2.2M Medication 2 _____ | 2.2T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed |
|                         | 994  | <input type="checkbox"/> Don't Know  | 997 <input type="checkbox"/> Refused |
| 2.3M Medication 3 _____ | 2.3T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed |
|                         | 994  | <input type="checkbox"/> Don't Know  | 997 <input type="checkbox"/> Refused |
| 2.4M Medication 4 _____ | 2.4T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed |
|                         | 994  | <input type="checkbox"/> Don't Know  | 997 <input type="checkbox"/> Refused |
| 2.5M Medication 5 _____ | 2.5T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed |
|                         | 994  | <input type="checkbox"/> Don't Know  | 997 <input type="checkbox"/> Refused |
| 2.6M Medication 6 _____ | 2.6T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed |
|                         | 994  | <input type="checkbox"/> Don't Know  | 997 <input type="checkbox"/> Refused |

- 994  Don't Know
- 997  Refused

[PROMPT: ASK RESPONDENT IF THERE ARE ANY ADDITIONAL MEDICATIONS THEY CAN THINK OF BEFORE MOVING ON TO THE NEXT QUESTION]

Question 2 asks for the names of asthma medications and frequency of use. The interviewer should not read the information in brackets aloud—the question is open ended. If the respondent is having trouble responding or doesn't understand the question the interviewer can read the [PROMPT: THESE COULD BE OVER-THE-COUNTER OR DOCTOR PRESCRIBED MEDICATIONS] aloud. The respondent may not know the names of any medications. If so, the interviewer should mark the “Don't Know” option below the list of medications and move on to Question 3. The respondent should have at least one answer to this question since the answer to Question 1 was “Yes.” The interviewer may need to remind the respondent of his or her answer to Question 1 or ask the respondent if he or she would like to change the answer to Question 1.

The interviewer should make sure to collect frequency information for each medication. If the parent/caretaker names a list of medications, the interviewer should record the names of the medications and record for each one whether it is taken every day or as needed. This may require additional prompting on the part of the interviewer. The interviewer should not make judgment calls on what qualifies as an asthma medication and what does not. If a respondent lists, for example, “Advil” as a medication the interviewer should record the response and the frequency of use. Additionally, the interviewer should probe for a specific drug name if a general name is given. If the respondent says that the child uses an inhaler the interviewer should ask the respondent if he or she knows the name of the inhaler.

Before moving on to Question 3, the interviewer should ask the respondent the prompt given at the end of the question.

3. During the past 14 days, how many days did [CHILD'S NAME] use [HIS/HER] quick-relief or rescue medication for asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: THINK OF A DAY AS BEING A 24-HOUR PERIOD. IF THE CHILD HAD MULTIPLE EPISODES DURING EITHER THE DAY OR NIGHT OF A 24-HOUR PERIOD, PLEASE COUNT THAT AS ONE (1) DAY]

\_\_\_\_\_ Days [RANGE 0-14]

992  Does not apply [CHILD DOES NOT TAKE RESCUE MEDICATIONS]

994  Don't Know

997  Refused

Question 3 should be asked of all respondents who answered “yes” to Question 1, regardless of their response to Question 2. The interviewer should not read the information in brackets or the answer choices aloud. If participant has trouble answering the question the interviewer can read the prompt that specifies how a day is to be defined. The answer to this question should be a number between 0 and 14, inclusive. If the respondent says the child does not take a rescue medication then the interviewer should select “does not apply” rather than answering “0.” Please see coding instructions for more detailed coding information for this question (Appendix B).

4. An asthma action or management plan is a printed form that tells when to increase medicine, when to take other medicine, when to call the doctor for advice, and when to go to the emergency room. Has a doctor or other health professional ever given [CHILD's NAME] or [CHILD's NAME]'s parent/caregiver/guardian an asthma management plan? *[ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]*

- 1  Yes
- 2  No
- 994  Don't Know
- 997  Refused

Question 4 should be asked of all respondents, regardless of their answers to previous questions. Some sites may create an asthma management/action plan as part of the intervention but this question should still be asked. The interviewer should not assume an answer to this question, even if the interviewer was the one to develop an asthma action plan with the caregiver. Although sites may not expect the answer to this question to change across interview periods the question should be asked every time this survey is administered. If the interviewer knows that the parent/caregiver has an asthma action plan for the child but he or she answers "No," the interviewer may not prompt the parent/caregiver to change his or her answer and must record the answer given.

There is a text box after Question 4 that gives instructions for the completion of the next section of the survey. The information in this box must be read verbatim by the interviewer. This requires the interviewer to calculate the date that was 14 days prior to the date of the interview. The sites should prepare a chart for interviewers to use in the field as reference. MCAN will provide such a chart if the sites request it.



5. In the last 14 days, how many days did [CHILD's NAME] have wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD MULTIPLE EPISODES DURING THE DAY, PLEASE COUNT THAT AS ONE (1) DAY]

\_\_\_\_\_ Days [RANGE 0-14]

994  Don't Know

997  Refused

6. In the last 14 nights, how many nights did [CHILD's NAME] wake up because of asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD MULTIPLE EPISODES DURING THE NIGHT, PLEASE COUNT THAT AS ONE (1) NIGHT]

\_\_\_\_\_ Nights [RANGE 0-14]

994  Don't Know

997  Refused

7. In the last 14 days, how many days did [CHILD's NAME] have to slow down or stop [HIS/HER] play or activities because of asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD TO SLOW DOWN OR STOP HIS PLAY MULTIPLE TIMES IN ONE DAY, PLEASE COUNT THAT AS ONE (1) DAY]

\_\_\_\_\_ Days [RANGE 0-14]

994  Don't Know

997  Refused

Questions 5, 6, and 7 all refer to asthma events occurring in the past 14 days. Question 6 refers ONLY to asthma problems during the day, not at night. All three questions should be asked of all respondents. The interviewer should not read the information in brackets or the answer choices aloud. If a participant has trouble answering the question, the interviewer can read the prompt that specifies how a day/night is to be defined. The answer to this question should be a number between 0 and 14, inclusive.

There is a small text box following Question 7 that must be read to respondents before the completion of Questions 8–11. This requires the interviewer to calculate the date that was 1 year prior to the date of the interview. Although it is not anticipated that interviewers will have difficulty calculating the correct date, sites may create or request a chart for interviewers to use as a reference.

8. During the past twelve (12) months, how many days did [CHILD's NAME] miss school for any reason?  
[ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: PLEASE INCLUDE ONLY DAYS WHEN SCHOOL (OR DAYCARE/PRE-SCHOOL, DEPENDING ON AGE OF THE CHILD) WAS IN SESSION]

\_\_\_\_\_ Days [RANGE 0-365]

- 992  Does not apply [CHILD NOT IN SCHOOL; SKIP TO QUESTION 10]  
994  Don't Know  
997  Refused

Questions 8 and 9 deal with school absences. Question 8 should be asked of all respondents, regardless of the age of the child. The interviewer should not read the information in brackets or the answer choices aloud, but may read the prompt if the respondent has trouble answering the question. If the child is not of school age but attends preschool or a daycare program the days of these programs missed should be considered school absences. Question 8 asks about absences for any reason, however, school not being in session is not a reason for missing school (e.g., Saturdays and Sundays should not be counted as absences).

Numerical answers to Question 8 should be between 0 and 365, inclusive. Realistically, answers should not be as high as 365, but interviewers should record the response given by the respondent. If the respondent says the child is not in school/preschool/daycare the interviewer should mark "does not apply" rather than "0" and proceed to Question 10. If the respondent gives a numerical answer, does not know, or refuses to answer, the interviewer should proceed to Question 9.

9. During the past twelve (12) months, how many days did [CHILD's NAME] miss school due to asthma?  
[ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: PLEASE INCLUDE ONLY DAYS WHEN SCHOOL (OR DAYCARE/PRE-SCHOOL, DEPENDING ON AGE OF THE CHILD) WAS IN SESSION]

\_\_\_\_\_ Days [RANGE 0-365; NUMBER SHOULD NOT EXCEED THE ANSWER IN QUESTION 8]

- 992  Does not apply [CHILD NOT IN SCHOOL]  
994  Don't Know  
997  Refused

Question 9 is similar to Question 8 but only addresses absences due to asthma. The interviewer should not read the information in brackets or the answer choices aloud, but may read the prompt if the respondent has trouble answering the question. If the child is not of school age but attends preschool or a daycare program, the days of these programs missed should be considered school absences. Question 9 asks about absences for asthma, however, school not being in session is not a reason for missing school (e.g., Saturdays and Sundays should not be counted as absences).

Numerical answers to Question 9 should be between 0 and 365, inclusive. Realistically, answers should not be as high as 365, but interviewers should record the response given by the respondent. A numerical answer to Question 9 should be equal to or lower than a numerical answer to Question 8. The interviewer should review Questions 8 and 9 with the respondent if the number of days given in Question 9 exceeds the number of days given in Question 8.

Although there is a “does not apply” answer choice for Question 9, it is not expected that it will be used. According to the skip pattern defined in Question 8, parents/caretakers of children not in school should not be asked Question 9.

10. In the past twelve (12) months, how many times has [CHILD's NAME] been treated in the Emergency Room or ER for asthma (without hospitalization)? *[ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]*

*[PROMPT: DO NOT INCLUDE TIMES WHEN YOUR CHILD WAS ADMITTED TO THE HOSPITAL FOR AN OVERNIGHT STAY RIGHT AFTER BEING TREATED AT THE EMERGENCY ROOM OR ER]*

\_\_\_\_\_ Times *[RANGE 0-365]*

994  Don't Know

997  Refused

Question 10 should be asked of all respondents. Interviewers should not read the information in brackets following the question and should not read possible answer choices. Interviewers can read the prompt aloud if the respondent has trouble answering or understanding the question.

11. In the past twelve (12) months, how many times has [CHILD's NAME] had to stay overnight in a hospital for asthma? *[ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]*

*[PROMPT: THIS NUMBER WOULD NOT INCLUDE VISITS TO THE ER THAT DID NOT RESULT IN AN OVERNIGHT HOSPITAL STAY]*

\_\_\_\_\_ Times *[RANGE 0-365]*

994  Don't Know

997  Refused

Question 11 is similar to Question 10, but deals with times the child has had to stay overnight in a hospital. These times should be when the child has been admitted to the hospital, not kept overnight in the ER for observation. If the child stayed in the hospital for multiple nights, this should be counted as 1 time and reported as “1.”

Numerical answers to Questions 10 and 11 should be between 0 and 365, inclusive. Realistically, answers should not be as high as 365, but interviewers should record the response given by the respondent. The sum of the answers to Questions 10 and 11 should not be greater than 365.

12. Asthma triggers are things that may start or set off an asthma attack in your child. Cigarette smoke, pets and dust are triggers that set off asthma attacks in some children. Have you taken any steps to reduce asthma triggers for [CHILD'S NAME] in your home? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: TRIGGERS MAY ALSO MAKE YOUR CHILD'S ASTHMA WORSE]

- 1  Yes [GO TO QUESTION 13]
- 2  No [SKIP TO QUESTION 14]
- 994  Don't Know [SEE PROMPT BELOW; IF STILL DON'T KNOW, SKIP TO QUESTION 14]
- 997  Refused [SKIP TO QUESTION 14]

[PROMPT IF ANSWER IS DON'T KNOW: STEPS CAN BE THINGS LIKE DUSTING MORE OFTEN OR NOT ALLOWING SMOKING IN YOUR HOME]

There is a small bit of text preceding Question 12 that gives an introduction to the next few questions. Please read this before reading Question 12. Ask Question 12 as an open-ended question and do not read the options to the respondent. If the respondent does not understand the question or is having trouble coming up with an answer, read the prompt following the question. For any answer except "Yes," skip to Question 14.

13. What steps have you taken to reduce asthma triggers in your home? [ASK THIS QUESTION OPEN-ENDED AND SEPARATELY RECORD EACH STEP MENTIONED BY THE RESPONDENT]

- 1  \_\_\_\_\_
- 2  \_\_\_\_\_
- 3  \_\_\_\_\_
- 4  \_\_\_\_\_
- 5  \_\_\_\_\_
- 6  \_\_\_\_\_
- 7  \_\_\_\_\_
- 8  \_\_\_\_\_
- 9  \_\_\_\_\_
- 10  \_\_\_\_\_
- 994  Don't Know
- 997  Refused

Question 13 is asked only of respondents who answered "Yes" to Question 12. The interviewer should record the responses verbatim and not attempt to categorize or summarize the actions. Each site may follow its own internal coding for this question but the dataset given to RTI should record each action exactly as described by the respondent. Respondents should be able to list at least one step they have taken to reduce asthma triggers in their home. The interviewer should review Question 12 if the respondent does not have an answer to Question 13.

14. I am going to read you a list of options from strongly agree to strongly disagree to answer this next question. How would you rate your agreement with the following statement; I have control over [CHILD's NAME] asthma. [READ OPTIONS TO RESPONDENT AND SELECT APPROPRIATE ANSWER]

- 1  Strongly agree
- 2  Agree
- 3  Disagree
- 4  Strongly disagree
- 994  Don't Know [DO NOT READ]
- 997  Refused [DO NOT READ]

Question 14 should be asked of all participants. For this question the interviewer should read the first the answer options (“Strongly agree,” “Agree,” “Disagree,” “Strongly disagree”) aloud before the respondent gives his or her answer. The interviewer may need to reread the statement if the respondent has trouble answering the question.

## 1.2 Demographics

Sites may ask the demographic questions as a separate instrument or as part of a larger instrument. **If the demographic questions are asked separately, the questions from the Interview Information section (see Section 1.1.1 above) must be completed at the beginning or end of the interview by the interviewer.** These questions need to be asked only at the baseline interview. Sites not asking the race and income questions need to refer to the end of this section for instructions on collecting race and income information using Census tracts.

The text at the beginning of the demographic section is optional and sites may replace or revise it as appropriate. The information contained in the text may help explain the intent of the demographic questions to communities or populations especially sensitive to these topics.

1. [CHILD's NAME] date of birth? [MONTH RANGE 0-12; DAY RANGE 1-31; YEAR RECORDED AS 4 DIGITS]

\_\_\_\_/\_\_\_\_/\_\_\_\_ [E.G., 12/31/1999]  
M M / D D / Y Y Y Y

- 994  Don't Know
- 997  Refused

This question may be asked of the respondent or recorded from another source. See the coding section for instructions on reporting data for this question (Appendix B).

2. What is [CHILD's NAME] gender? [NO NEED TO ASK, JUST MARK APPROPRIATE RESPONSE]

- 1  Male
- 2  Female

Interviewers do not need to ask this question if the child's gender is clear through conversation with

**3. What is your relationship to [CHILD'S NAME]? [MOTHER, FATHER, GRANDMOTHER, ETC]**

\_\_\_\_\_ Relationship

994  Don't Know

997  Refused

the respondent.

Question 3 is an open-ended question although the interviewer may read the prompt or offer examples of relationships if the respondent has trouble answering the question. The interviewer should not assume a relationship unless it has been explicitly stated elsewhere. Sites should send RTI the responses to this question as given. Do not attempt to code responses in the dataset sent to RTI.

**4. How would you describe [CHILD'S NAME]'s race, nationality, or ethnic background? [ASK OPEN-ENDED AND USE CODES BELOW]**

1  Hispanic [IF PERSON SAYS HISPANIC, PROMPT BY READING THROUGH THE OPTIONS: WOULD YOU SAY, PUERTO RICAN? DOMINICAN? MEXICAN? AND USE CODES BELOW]

11  Puerto Rican

12  Dominican

13  Mexican

14  South American

15  Central/Latin American

16  Cuban

17  Other Hispanic

2  Black/African American

3  White

4  Asian

5  Mixed, [SPECIFY] \_\_\_\_\_

6  Native American \_\_\_\_\_

7  Other, [SPECIFY] \_\_\_\_\_

994  Don't Know

997  Refused

[NOTE ON CODING: HISPANIC IS CODED AS 1 IF NO MORE DETAIL IS PROVIDED. PUERTO RICAN IS CODED 11, ETC.]

Question 4 asks for the race and ethnicity of the child and is required for all sites not providing Census data. The question should be asked open-ended. The interviewer should prompt the respondent for more information if the respondent gives Hispanic, Mixed, or Other as answers. For Hispanic answers, prompt the respondents for a specific country or region of origin. If the respondent does not know or will not give more detail, code the answer as "1." For answers of Mixed or Other, prompt the respondents to be more specific. Record the answer as given and report to RTI as a text string. See the coding section for more information (Appendix B).

**5.** How many people live in your household, including yourself?

*[PROMPT: INCLUDE [CHILD'S NAME] AND YOURSELF IN THE COUNT]*

\_\_\_\_\_ People  
994  Don't Know  
997  Refused

Some sites have a question similar to Question 5 on existing instruments. They may use the answer to the similar question to fill in this answer. Other sites should ask Question 5, making it clear that the respondent should include him- or herself and the child in the answer.

**6.** How many children live in your household?

*[PROMPT: WE ARE ASKING ABOUT CHILDREN LESS THAN 18 YEARS OLD. INCLUDE [CHILD'S NAME] IN THE COUNT]*

\_\_\_\_\_ Children *[NOT TO EXCEED ANSWER GIVEN IN QUESTION 5]*  
994  Don't Know  
997  Refused

Question 6 is a follow-up to Question 5. The interviewer should specify that children are less than 18 years old and that the child should be included in the count. The answer given to Question 6 should be at least 1 if the child lives with the respondents. Additionally, the answer to Question 6 should be less than the answer given for Question 5.

**7.** Does *[CHILD'S NAME]* primary caregiver speak a language other than English at home?

1  Yes *[GO TO QUESTION 8]*  
2  No *[SKIP TO QUESTION 9]*  
994  Don't Know *[SKIP TO QUESTION 9]*  
997  Refused *[SKIP TO QUESTION 9]*

Question 7 may be omitted in the Spanish version of the instrument if the respondent is the child's primary caregiver. In these cases, interviewers should mark the answer as "1." This question should be asked of all other respondents. For all answers except "1" the interviewer should skip to Question 9.

8. If yes, what language do they speak?

\_\_\_\_\_ Language

994  Don't Know

997  Refused

Question 8 may be omitted in the Spanish version of the instrument if the respondent is the child's primary caregiver. In these cases, interviewers should mark the answer as "Spanish" and proceed to Question 9. The answer to this question should not be "English."

9. What is the highest degree or level of school [CHILD'S NAME]'s primary caregiver has COMPLETED?

*[IF THE QUESTION IS ASKED OVER THE PHONE OR IF IT IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE. IF QUESTION IS ASKED IN-PERSON BY AN INTERVIEWER, CONSIDER USING A SHOWCARD WITH THE OPTIONS LISTED AND ASK THE RESPONDENTS TO POINT TO THEIR CATEGORY]*

- 1  Never attended/ kindergarten only
- 2  1<sup>st</sup> grade
- 3  2<sup>nd</sup> grade
- 4  3<sup>rd</sup> grade
- 5  4<sup>th</sup> grade
- 6  5<sup>th</sup> grade
- 7  6<sup>th</sup> grade
- 8  7<sup>th</sup> grade
- 9  8<sup>th</sup> grade
- 10  9<sup>th</sup> grade
- 11  10<sup>th</sup> grade
- 12  11<sup>th</sup> grade
- 13  12<sup>th</sup> grade, NO DIPLOMA
- 14  GED or equivalent
- 15  HIGH SCHOOL GRADUATE – high school DIPLOMA
- 16  Some college credit, but no degree
- 17  Associate degree: occupational, technical, or vocational program
- 18  Associate degree: academic program
- 19  Bachelor's degree (for example: BA, AB, BS)
- 20  Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
- 21  Professional degree (for example: MD, DDS, DVM, LLB, JD)
- 22  Doctorate degree (for example: PhD, EdD)
- 994  Don't Know
- 997  Refused

Interviewers should ask Question 9 differently for phone and in-person interviews. For interviews over the phone the interviewer should read the question as written. Interviewers should then tell respondents they will read the possible answer choices one by one and the respondent should stop them when they reach the correct category. Record the answer as the category where the respondent tells the interviewer to stop reading.



For in-person interviews the interviewer should show the possible answer options to the respondent and have the respondent point to the correct one. Sites should use the format in the instrument to create a card specifically for that purpose. If the interviewer does not feel comfortable with this method he or she may use the instructions for administering the question over the telephone.

*[IF THE INCOME QUESTION IS ASKED OVER THE PHONE OR IF IT IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE.]*

**10.** For the last month, what was your total household income from all sources? Include income from everyone in your home. Give amount before taxes and other deductions. If monthly income is unknown, estimate your income per year.

- 1  Less than \$833 per month (less than \$10,000 per year)
- 2  \$834 to \$1,666 per month (\$10,000 to \$19,999 per year)
- 3  \$1,667 to \$2,500 per month (\$20,000 to \$29,999 per year)
- 4  \$2,501 to \$3,333 per month (\$30,000 to \$39,999 per year)
- 5  \$3,334 to \$3,750 per month (\$40,000 to \$49,999 per year)
- 6  More than \$4,166 per month (more than \$50,000 per year)
- 994  Don't Know
- 997  Refused

*[IF THE INCOME QUESTION IS ASKED IN PERSON BY AN INTERVIEWER, USE THIS QUESTION AND CONSIDER SHOWING THE TABLE AND ASKING RESPONDENTS TO POINT TO THEIR CATEGORY, THEN ENTER THE INCOME CODE, RATHER THAN THE DOLLAR AMOUNT]*

**10.** For the last month, what was the total household income from all sources? Include income from everyone in your home. Please point to the answer closest to your total household income.

Income code \_\_\_\_\_

- 994  Don't Know
- 997  Refused

<b>Monthly</b>	<b>Income Code</b>	<b>Yearly</b>
Less than \$833 per month	<b>1</b>	less than \$10,000 per year
\$834 - \$1,666 per month	<b>2</b>	\$10,000 - \$19,999 per year
\$1,667 - \$2,500 per month	<b>3</b>	\$20,000 - \$29,999 per year
\$2,501 - \$3,333 per month	<b>4</b>	\$30,000 - \$39,999 per year
\$3,334 - \$3,750 per month	<b>5</b>	\$40,000 - \$49,999 per year
More than \$4,166 per month	<b>6</b>	more than \$50,000 per year
<ul style="list-style-type: none"> <li>- Include all sources of income</li> <li>- If monthly income is unknown, estimate income per year</li> <li>- Give amount before taxes and other deductions.</li> </ul>		

The administration of Question 10 also depends on the survey administration method. The responses for both administration methods include monthly and annual income as it may be easier for the respondents to provide one or the other. The monthly and yearly income amounts for a single income

code are equivalent. Sites not asking this question should provide Census information. Please see the Census section of this document for instructions.

Interviewers should use the first version of Question 10 if the survey is administered over the phone. The interviewer should read the possible answer choices and ask the respondent to stop him or her when he or she reaches the correct category.

For in-person interviews, the interviewer should read the second version of the question and show the respondent the income card. The respondent should point to the correct category.

**11. Does child have health or medical insurance?**

- 1  Yes
- 2  No
- 994  Don't Know
- 997  Refused

Sites may ask this question elsewhere or in a different format. These answers may be transferred to this question and the question can be skipped. Sites that do not ask a similar question elsewhere should use this question.

**12. How many years have you lived at your current residence?**

- 1  Less than 1 year
- 2  1 to 2 years
- 3  3 to 5 years
- 4  More than 5 years
- 994  Don't Know
- 997  Refused

Question 12 should be asked of all respondents. Sites may ask this question elsewhere or in a different format. These answers may be transferred to this question and the question can be skipped. Sites that do not ask a similar question elsewhere should use this question.

### **1.3 Census Data as a Substitute for Race and Income Questions**

Some sites have chosen not to ask the race and income questions to study participants. These sites have agreed to provide Census data for the participant addresses instead of individual data.

For each address the site is responsible for identifying and recording the correct Census tract. This can be done via the Census website at:

[http://factfinder.census.gov/servlet/AGSGeoAddressServlet?\\_lang=en&\\_programYear=50&\\_treeId=420](http://factfinder.census.gov/servlet/AGSGeoAddressServlet?_lang=en&_programYear=50&_treeId=420)

Alternately:

1. Go to [www.census.gov](http://www.census.gov).
2. Click on “American Fact Finder” on the menu on the left side of the screen.
3. Click on “street address” in the “Address Search...” box on the left side of the screen.

In addition to the tract number, sites are responsible for collecting and reporting the following variables from the Census 2000 Summary File 3 – Sample Data file.

- P1. Total Population
- P6. Race
- P7. Hispanic or Latino by Race
- P52. Household Income in 1999
- P53. Median Household Income in 1999 (Dollars)

These data can be found by using the American Fact Finder. Detailed instructions are below.

1. Go to [www.census.gov](http://www.census.gov).
2. Click on “American Fact Finder” on the menu on the left side of the screen.
3. Click on “Data Sets” on the menu on the left side of the screen.
4. Select the radio button next to “Census 2000 Summary File 3 (SF 3) – Sample Data.”
5. Select “Detailed Tables” from the menu at right.
6. Set the “Geographic Type” to “Census Tract.”
7. Select the appropriate state, county, and tract. You may select more than one tract at a time.
8. Once the tracts are selected and added as current selections, click on the “Next” button at the bottom of the screen.
9. Select the five variables above and add them to the current selection. Click on the “Show Result” button at the bottom of the screen.
10. Copy or download the data.

Sites using Census data will send RTI a data file with each child’s ID number, the Census tract of their residence, and the corresponding data listed above.

## **2. Expectations for Administration**

### **2.1 Administration**

The interview will be completed entirely in English using the English instrument or entirely in Spanish using the Spanish instrument. Interviewers will follow the script exactly, including prompts. Computerized instruments should be programmed with appropriate prompts and skip patterns.

**Sites will train all interviewers on how to administer the survey instruments to obtain as much uniformity in data collection as possible.**

Sites are expected to have an established protocol for contacting participants and generating follow-up interviews. Sites should provide information about this protocol to RTI when they deliver their first round of data.

#### **2.1.1 Recontact Attempts**

Sites are expected to make a reasonable effort based on industry standards to contact respondents. The industry standard, presented below, represents the **minimum** number of contact attempts required. Sites that already follow protocols requiring more contact attempts should continue using their site’s protocol. These practices are detailed for phone interviews but may be adapted for in-person interviews.

### Industry standard and minimum MCAN requirements:

- Number of initial contact attempts: Complete a minimum of 10 call attempts for all participants. Call attempts beyond 10 should be made if the call history indicates that further attempts may be productive. The maximum number of call attempts to any households is expected to be no more than 30 calls, except for unusual circumstances.
- After initial contact with a household, the Table 2.1 specifies the procedure to follow depending on the type of initial contact.

**Table 2.1. Initial Contact and Follow-up Protocol**

Type of Initial Contact	Follow-up Protocol
Hung up during introduction	2 refusals before finalization
Refusal by unknown person (mild or firm refusal)	3 refusals before finalization
Refusal by eligible adult (mild or firm refusal)	2 refusals before finalization
Hostile refusal or “Take me off your list” by unknown or by eligible respondent	1 refusal before finalization (do not call back)

**Mild refusal**—A mild refusal is when someone refuses “politely” or without providing a direct statement. For example, “please don’t call here again,” “I just don’t want to participate,” “I really don’t have time for this, not interested.”

**Firm Refusal**—A firm refusal is when someone refuses and their *tone of voice* is stern and direct. For example, “DO NOT call my house again,” “I am NOT interested in participating in X survey,” “I have spoken with several people from your organization and do NOT want to participate.” The biggest difference between mild and firm is the person’s tone of voice and direct “statement” of their refusal.

**Hostile Refusal**—A hostile refusal is when someone uses profanity, threatens to contact their lawyer, Attorney General’s office, Better Business Bureau, or claims harassment.

## 2.2 Sample Size

In their original proposals, the sites set expected sample sizes that would provide each site with enough power to conduct their proposed site-level analysis. However, because the new Common Data Elements survey instrument will not be implemented until late 2007, the sample size available for the cross-site analysis will be smaller.

Based on calculations for before-after comparisons of both binary variables and continuous variables, a total, final sample size for the pooled analysis (combining data from all 5 sites) of between 100 and 125 should provide enough power to detect at least a 30% change in the binary variables and a 2-day decrease in variables such as number of symptom days or nighttime wakings with a 95% confidence interval and power of 80%.<sup>1</sup> A total sample size of 100 to 125 implies at least 20 to 25 observations per site. However, to compare sites to each other, each site would need 100 to 125 respondents. Note

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<sup>1</sup> Sample size calculations for binary variables are based calculated for a McNemar’s test, a statistical procedure used to compare two proportions that are dependent or correlated.

that the final sample size is the number of complete and valid observations after accounting for respondents who did not complete follow-up interviews, missing data or invalid responses.

By way of comparison, analyses from the *Yes We Can* program and from *NICAIS* reported 30% to 80% improvement for variables similar to some of the variables in the MCAN common instrument. The *Yes We Can* program reported a sample size of 65 children for their calculations.<sup>2,3</sup>

### **3. Data Entry and Coding**

#### **3.1 Coding Data**

Table 3.1 displays the data directory with variable names, definitions, and coding information. Data should be coded as specified in Table 3.1 and in the Common Data Elements and Demographics survey instruments. In the survey instruments, the numeric codes for each response category are listed to the left of the response categories for each question. Please note that “994” is always the code for “Don’t know” and “997” is always the code for “Refused.” Missing data should be entered as “.”

We provide an example of coding in Appendix B. The appendix includes the survey instruments marked with sample responses. Following the survey instruments is a table with the variables’ names and the coding for the sample responses marked in the survey instruments.

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<sup>2</sup> Thyne, S., Rising, J., Legion, V., and M. Love. 2006. “The *Yes We Can* Urban Asthma Partnership: A Medical/Social Model for Childhood Asthma Management.” *Journal of Asthma*, 43: 667-673.

<sup>3</sup> [http://www.cdc.gov/asthma/interventions/inner\\_city\\_asthma.htm](http://www.cdc.gov/asthma/interventions/inner_city_asthma.htm)

**Table 3.1 Data Directory**

Variable Name	Definition	Possible Values	Data Type	Notes
patientid	Site-assigned patient ID number		text or numeric	Should be unique for each patient
date	Date of survey completion		text	Entered as "03/17/2008"
method	Method of survey administration	1-5	numeric	
method_t	Method of "Other" survey administration		text	Only used if method=5
survey	Period of survey	1-4	numeric	
survey_t	"Other" period of survey		text	Only used if survey=4
intervention1	Indicates whether child/parent participated in 1st intervention listed under site name	0,1	numeric	=0 if child/parent did not participate, =1 if parent/child did participate
intervention2	Indicates whether child/parent participated in 2nd intervention listed under site name	0,1	numeric	=0 if child/parent did not participate, =1 if parent/child did participate
intervention3	Indicates whether child/parent participated in 3rd intervention listed under site name	0,1	numeric	=0 if child/parent did not participate, =1 if parent/child did participate
intervention4	Indicates whether child/parent participated in 4th intervention listed under site name	0,1	numeric	=0 if child/parent did not participate, =1 if parent/child did participate
intervention5	Indicates whether child/parent participated in 5th intervention listed under site name	0,1	numeric	=0 if child/parent did not participate, =1 if parent/child did participate
intervention6	Indicates whether child/parent participated in 6th intervention listed under site name	0,1	numeric	=0 if child/parent did not participate, =1 if parent/child did participate; leave blank if site does not have 6th intervention
intervention7	Indicates whether child/parent participated in 7th intervention listed under site name	0,1	numeric	=0 if child/parent did not participate, =1 if parent/child did participate; leave blank if site does not have 7th intervention
intervention8	Indicates whether child/parent participated in 8th intervention listed under site name	0,1	numeric	=0 if child/parent did not participate, =1 if parent/child did participate; leave blank if site does not have 8th intervention
Q1	Answer to Question 1	1, 2, 994, 997	numeric	
Q2	Don't Know/Refused answer to Question 2	994, 997	numeric	Used only if Q1=1 and answer to Q2 is "Don't Know" or "Refused"
Q2_1M	Name of 1st asthma medication		text	Used only if Q1=1
Q2_1T	Frequency of 1st asthma medication	1, 2, 994, 997	numeric	Used only if Q1=1 and Q2.1M has answer
Q2_2M	Use if needed, see Q2.1M			

**Table 3.1 Data Directory (continued)**

Variable Name	Definition	Possible Values	Data Type	Notes
Q2_2T	Use if needed, see Q2.1T			
Q2_3M	Use if needed, see Q2.1M			
Q2_3T	Use if needed, see Q2.1T			
Q2_3M	Use if needed, see Q2.1M			
Q2_3T	Use if needed, see Q2.1T			
Q2_4M	Use if needed, see Q2.1M			
Q2_4T	Use if needed, see Q2.1T			
Q2_5M	Use if needed, see Q2.1M			
Q2_5T	Use if needed, see Q2.1T			
Q2_6M	Use if needed, see Q2.1M			
Q2_6T	Use if needed, see Q2.1T			
Q3	Answer to Question 3	0-14, 992, 994, 997	numeric	Used only if Q1=1
Q4	Answer to Question 4	1, 2, 994, 997	numeric	
Q5	Answer to Question 5	0-14, 994, 997	numeric	
Q6	Answer to Question 6	0-14, 994, 997	numeric	
Q7	Answer to Question 7	0-14, 994, 997	numeric	
Q8	Answer to Question 8	0-365, 992, 994, 997	numeric	
Q9	Answer to Question 9	0-365, 992, 994, 997	numeric	Used only if Q8 not equal to 992, answer not greater than Q8
Q10	Answer to Question 10	0-365, 994, 997	numeric	
Q11	Answer to Question 11	0-365, 994, 997	numeric	
Q12	Answer to Question 12	1, 2, 994, 997	numeric	
Q13	Don't Know/Refused answer to Question 13	994, 997	numeric	Used only if Q12=1 and answer to Q13 is "Don't Know" or "Refused"
Q13_1	First step taken to reduce asthma triggers		text	Used only if Q12=1
Q13_2	Use if needed, see Q13_1			

**Table 3.1 Data Directory (continued)**

Variable Name	Definition	Possible Values	Data Type	Notes
Q13_3	Use if needed, see Q13_1			
Q13_4	Use if needed, see Q13_1			
Q13_5	Use if needed, see Q13_1			
Q13_6	Use if needed, see Q13_1			
Q13_7	Use if needed, see Q13_1			
Q13_8	Use if needed, see Q13_1			
Q13_9	Use if needed, see Q13_1			
Q13_10	Use if needed, see Q13_1			
Q14	Answer to Question 14		numeric	
D1	Child's date of birth		text	Entered as "03/17/2008"
D2	Child's gender	1, 2	numeric	
D3	Answer to Demographic Question 3	text or 994, 997	text	
D4	Answer to Demographic Question 4	1-7, 11-17, 994, 997	numeric	
D4_t	Answer to "Other" or "Mixed" Demographic Question 4		text	Used only if D4=5 or D4=7
D5	Answer to Demographic Question 5	1-100, 994, 997	numeric	
D6	Answer to Demographic Question 6	0-100, 994, 997	numeric	Should not be greater than or equal to D5
D7	Answer to Demographic Question 7	1, 2, 994, 997	numeric	
D8	Answer to Demographic Question 8	text or 994, 997	text	Used only if D7=1
D9	Answer to Demographic Question 9	1-22, 994, 997	numeric	
D10	Answer to Demographic Question 10	1-6, 994, 997	numeric	
D11	Answer to Demographic Question 11	1, 2, 994, 9997	numeric	
D12	Answer to Demographic Question 12	1-4, 994, 997	numeric	



## 3.2 Data Entry

### 3.2.1 Create Two Data Files

Using the data from the Common Data Elements survey and the Demographics survey, sites should create two data files – one file for responses to the Common Data Elements survey and one file for the Demographic data.

**The Demographic data file should include the data from the “Interview Information” section (see Section 1.2 and example in Appendix B).**

### 3.2.2 Double-Enter Data

RTI recommends that all data entered from paper-and-pencil survey forms be entered twice to prevent data entry errors. If all the data will not be double entered, then a sample of the data should be double entered and checked for errors. If the data are entered incorrectly for a particular variable, all data should be double entered.

Data quality is extremely important to the validity of the pooled data analysis. It is expected that the sites will program checks into their data entry system to ensure out-of-range values or improper response codes can not be entered.

### 3.2.3 Each Interview is a Separate Observation

Ideally, each patient caregiver will be interviewed three times: at baseline, at a 6-month follow-up and at a 12-month follow-up. The Demographic survey instrument will be administered once at baseline. The Common Data Elements survey will be administered three times.

In the Demographic data file, each respondent will have one observation with the data from the baseline Demographic survey. **The Demographic data file should include the interview information and the responses to the Demographic survey questions.**

For the Common Data Elements, the data from each of the three interviews should be entered as a separate observation (or row) in the data file. The observations will be linked by the patient’s unique ID number. A patient who completes all three rounds of the interviews will have three observations in the Common Data Elements data file (or three rows). Data from the interview information section at the beginning of the Common Data Elements should be included for each interview and will be used to identify baseline, 6-month, and 12-month follow-up interviews.

### 3.2.4 Patients with Missing Interviews

Some patient caregivers will not complete either or both of the 6- and 12-month follow-up interviews. The baseline data and whatever follow-up data, if any, are available for these patients should be retained as part of the data set. **Do not drop patients from the data file just because there are no follow-up data for them.** Often, respondents and nonrespondents have different characteristics and these differences can be accounted for in the data analysis.

## 4. Format/Storage

The data should be entered into an electronic database from which data files can be created for delivery to RTI. Sites should tell RTI what type of file they will use when they deliver their data. The following file types are preferred for data delivered to RTI:

- ASCII text file
- Microsoft Office Excel spreadsheet
- SAS data file
- STATA data file

Sites are expected to adhere to their IRB requirements regarding data security.

## 5. Data Cleaning

**Data provided to RTI should not contain any identifying personal information including but not limited to name, address, and phone number. Patients should be identified by a unique ID number only.**

Prior to sending data to RTI, sites will clean the data to ensure that the data are complete, coded correctly, and any problems have been resolved.

Before sending data to RTI, and preferably on a more frequent internal schedule, check data:

- Sections filled out by the interviewer should be complete and coded correctly.
- Child's unique ID should be verified.
- Data from follow-up interviews should be matched with baseline data to check for errors in coding the ID number and consistency.
- Verify data are coded according to the coding instructions (no data outside the established range, the data are properly formatted as text or numeric).
- Resolve any issues with the data internally before sending to RTI.

If the data files contain numerous errors or inconsistent information, RTI will work with the sites to identify the problem. If the problems cannot be resolved, the sites may be required to double enter their data again and RTI may request hardcopies of the original surveys, de-identified, for paper-based surveys.

### 5.1 What if the Sites or RTI Make Changes to a Data File After It is Delivered?

Section 6 provides guidance on delivering the data files. In cases where the sites discover problems with data files that have already been delivered, the sites should contact RTI to discuss the problems. Together, RTI and the sites can determine whether a new data file should be delivered immediately or whether the corrected data can be delivered at the next scheduled time. Similarly, RTI will contact sites with questions about data files and together RTI and the sites will resolve any problems.

Each time a data file is delivered it should contain all the data collected to date and an explanation of any changes to the data since the last delivery. This provides RTI with the most recent data from the sites.

## 6. Delivering Data to RTI

### 6.1 Quarterly Progress Updates

At the end of each quarter starting with the fourth quarter of 2007, the sites will provide RTI with a progress update on data collection. The quarterly updates are needed to track sample size, identify data problems, plan for data delivery, and plan for data analysis. **Sites do not need to send any data as part on the progress update.**

The quarterly progress update can be sent to RTI in an e-mail. The progress report will include the following:

- The target and actual number of baseline, 6-month, and 12-month follow-up surveys completed in the quarter and cumulatively.
- A summary of any issues or problems that came up during the quarter related to the cross-site evaluation data collection.

### 6.2 Data Files

Data files will be delivered twice a year according to the schedule in Section 6.3. The following information will be submitted along with the data files.

1. Data file containing all the baseline Demographic data collected to date (not just new observations). [NOTE: Sites using Census data for race and/or income will send RTI a data file with each child's ID number, the Census tract of their residence, and the corresponding data listed above.]
2. Data file containing all the Common Data Elements data collected to date from baseline, 6-month, and 12-month follow-ups (not just new observations).
3. Data directory listing variable names and location in data file.
4. Summary statistics for data file including variable names, variable format (text or numeric), number of observations for each variable, if numeric mean, minimum and maximum values. Summary statistics should be provided for the entire data file and for baseline, 6-month, and 12-month follow-up interviews separately.
5. Description of changes to data previously delivered or problems encountered during interviews or data entry/cleaning.
6. Response rate for follow-up interviews separately for 6-month and 12-month follow-ups, both cumulative and for new data.
7. Summary of protocols used to collect data including maximum number of contact attempts, refusal conversion approach, incentives offered, and other details. *This information only needs to be provided once unless changes are made to the protocol.*

### 6.3 Schedule

#### 6.3.1 Schedule for Sites

Quarterly updates will be delivered at the end of each quarter. The delivery schedule for data files is based on the timing for MCAN's National Advisory Board meeting in April and the Board of Trustees meeting in October. In early January 2008, the sites will deliver to RTI a sample of

observations from the two data files. RTI will use the sample to set up the data input programs and identify any problems.

### **Quarterly Progress Reports**

December 28, 2007

March 31, 2008

June 30, 2008

September 30, 2008

December 22, 2008

### **Data Files**

January 31, 2008: Delivery of samples of both data files (5-10 observations)

February 15, 2008: Deliver both data files for update provided at April meeting (optional)

July 25, 2008: Deliver updates of both data files

January 20, 2009: Deliver updates of both data files

July 31, 2009: Deliver final data files

**Appendix A: Common Data Elements and Demographic Survey Instruments, English and Spanish Language Versions**

## A.1 English Version

### MCAN Common Data Elements

#### SITE-SPECIFIC INTRODUCTION AND INSTRUCTIONS

#### **Interview information**

Patient ID \_\_\_\_\_

Date \_\_\_/\_\_\_/\_\_\_ [E.G., 12/31/1999]  
M M/ D D/ Y Y Y Y

Survey Administration Method

- 1  Telephone
- 2  In-person by Interviewer
- 3  Mail
- 4  Self-Administered
- 5  Other, \_\_\_\_\_

Survey (check one):

- 1  Baseline
- 2  6 month follow-up
- 3  12 month follow-up
- 4  Other, \_\_\_\_\_

#### PLEASE CHECK INTERVENTIONS IN WHICH CHILD/FAMILY HAS PARTICIPATED

#### **Chicago**

- 1  School Screening with Yes We Can
- 2  Mobile Pediatric Van
- 3  Open Airways
- 4  Home Visitation
- 5  BPAS+ Asthma Screening
- 6  Freedom From Smoking (parents)

#### **Los Angeles**

- 1  Breathmobile
- 2  Received Materials/Instructions from Nurse Case Manager
- 3  Health Insurance Outreach, Enrollment, and Retention
- 4  Open Airways
- 5  Starbright Asthma Kit used in school curriculum
- 6  Tobacco Use Prevention Education Program
- 7  Home Visitation by Nurse Case Manager using CASA Teaching Manual
- 8  Received Home Mitigation Materials

#### **New York**

- 1  NCICAS or Modified NCICAS Intervention (modified has no home visit)
- 2  Enroll children in health insurance plan
- 3  Modified NCICAS asthma prevalence screening survey (in schools)
- 4  Wee Wheezers
- 5  Asthma Basics for Children
- 6  Open Airways
- 7  Received modified NCICAS asthma information materials through schools
- 8   NCICAS Integrated Pest Management Home Environmental Assessment & Trigger Reduction

## A.1 English Version

### Activities

#### ***Philadelphia***

- 1  School BPAS Screening
- 2  Asthma Awareness Days
- 3  Open Airways
- 4  Door to Door Screening
- 5  Home Visits using Modified NCICAS
- 6  Link Line
- 7  ACT Asthma Education
- 8  You Can Control Asthma Community Class

#### ***Puerto Rico***

- 1  Yes We Can home treatment protocol
- 2  Yes We Can clinical recruitment protocol
- 3  Clinical Risk Assessment
- 4  Open Airways
- 5  ICAS home educational module

*WE WOULD LIKE TO ASK YOU A FEW QUESTIONS ABOUT MEDICATIONS [CHILD'S NAME] MAY TAKE FOR [HIS/HER] ASTHMA. THESE COULD BE OVER-THE-COUNTER MEDICATIONS OR A DOCTOR MAY HAVE PRESCRIBED OR GIVEN THEM TO YOU FOR [CHILD'S NAME] ASTHMA.*

1. Does [CHILD'S NAME] currently take medication for asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

- 1  Yes [GO TO QUESTION 2]
- 2  No [SKIP TO QUESTION 4]
- 994  Don't Know [SKIP TO QUESTION 4]
- 997  Refused [SKIP TO QUESTION 4]

## A.1 English Version

2. Please tell us the names of those medications and whether it is taken every day or as needed: *[ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT; ADD MORE LINES IF CHILD TAKES MORE THAN SIX (6) MEDICATIONS FOR ASTHMA]*

*[PROMPT: THESE COULD BE OVER-THE-COUNTER OR DOCTOR PRESCRIBED MEDICATIONS]*

*[PROMPT: IF RESPONDENT ANSWERS INHALER, ASK IF THEY KNOW THE NAME OF THE INHALER]*

2.1M Medication 1 _____	2.1T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
	994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.2M Medication 2 _____	2.2T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
	994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.3M Medication 3 _____	2.3T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
	994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.4M Medication 4 _____	2.4T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
	994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.5M Medication 5 _____	2.5T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
	994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.6M Medication 6 _____	2.6T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
	994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused

994  Don't Know

997  Refused

*[PROMPT: ASK RESPONDENT IF THERE ARE ANY ADDITIONAL MEDICATIONS THEY CAN THINK OF BEFORE MOVING ON TO THE NEXT QUESTION]*

3. During the past 14 days, how many days did *[CHILD'S NAME]* use *[HIS/HER]* quick-relief or rescue medication for asthma, wheezing or tightness in the chest, or cough? *[ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]*

*[PROMPT: THINK OF A DAY AS BEING A 24-HOUR PERIOD. IF THE CHILD HAD MULTIPLE EPISODES DURING EITHER THE DAY OR NIGHT OF A 24-HOUR PERIOD, PLEASE COUNT THAT AS ONE (1) DAY]*

\_\_\_\_\_ Days *[RANGE 0-14]*

992  Does not apply *[CHILD DOES NOT TAKE RESCUE MEDICATIONS]*

994  Don't Know

997  Refused



## A.1 English Version

4. An asthma action or management plan is a printed form that tells when to increase medicine, when to take other medicine, when to call the doctor for advice, and when to go to the emergency room. Has a doctor or other health professional ever given [CHILD's NAME] or [CHILD's NAME]'s parent/caregiver/guardian an asthma management plan? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

- 1  Yes  
2  No  
994  Don't Know  
997  Refused

NOW WE WANT TO TALK WITH YOU ABOUT HOW ASTHMA AFFECTS YOU AND [CHILD's NAME] EACH DAY.

THE NEXT FEW QUESTIONS ARE ABOUT [CHILD's NAME] HEALTH IN THE LAST TWO WEEKS, THAT IS, THE PAST 14 DAYS, SINCE [GIVE RESPONDENT THE DATE 14 DAYS PRIOR TO TODAY]. SOME QUESTIONS ARE ABOUT YOUR CHILD'S ASTHMA DURING THE DAY AND SOME QUESTIONS ARE ABOUT YOUR CHILD'S ASTHMA DURING THE NIGHT.

5. In the last 14 days, how many days did [CHILD's NAME] have wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD MULTIPLE EPISODES DURING THE DAY, PLEASE COUNT THAT AS ONE (1) DAY]

\_\_\_\_\_ Days [RANGE 0-14]

- 994  Don't Know  
997  Refused

6. In the last 14 nights, how many nights did [CHILD's NAME] wake up because of asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD MULTIPLE EPISODES DURING THE NIGHT, PLEASE COUNT THAT AS ONE (1) NIGHT]

\_\_\_\_\_ Nights [RANGE 0-14]

- 994  Don't Know  
997  Refused

7. In the last 14 days, how many days did [CHILD's NAME] have to slow down or stop [HIS/HER] play or activities because of asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD TO SLOW DOWN OR STOP HIS PLAY MULTIPLE TIMES IN ONE DAY, PLEASE COUNT THAT AS ONE (1) DAY]

\_\_\_\_\_ Days [RANGE 0-14]

- 994  Don't Know  
997  Refused

## A.1 English Version

THE NEXT FEW QUESTIONS ARE ABOUT THE PAST YEAR, THAT IS, SINCE [GIVE RESPONDENT THE DATE ONE YEAR PRIOR TO TODAY'S DATE]

8. During the past twelve (12) months, how many days did [CHILD'S NAME] miss school for any reason? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: PLEASE INCLUDE ONLY DAYS WHEN SCHOOL (OR DAYCARE/PRE-SCHOOL, DEPENDING ON AGE OF THE CHILD) WAS IN SESSION]

\_\_\_\_\_ Days [RANGE 0-365]

992  Does not apply [CHILD NOT IN SCHOOL; SKIP TO QUESTION 10]

994  Don't Know

997  Refused

9. During the past twelve (12) months, how many days did [CHILD'S NAME] miss school due to asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: PLEASE INCLUDE ONLY DAYS WHEN SCHOOL (OR DAYCARE/PRE-SCHOOL, DEPENDING ON AGE OF THE CHILD) WAS IN SESSION]

\_\_\_\_\_ Days [RANGE 0-365; NUMBER SHOULD NOT EXCEED THE ANSWER IN QUESTION 8]

992  Does not apply [CHILD NOT IN SCHOOL]

994  Don't Know

997  Refused

10. In the past twelve (12) months, how many times has [CHILD'S NAME] been treated in the Emergency Room or ER for asthma (without hospitalization)? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: DO NOT INCLUDE TIMES WHEN YOUR CHILD WAS ADMITTED TO THE HOSPITAL FOR AN OVERNIGHT STAY RIGHT AFTER BEING TREATED AT THE EMERGENCY ROOM OR ER]

\_\_\_\_\_ Times [RANGE 0-365]

994  Don't Know

997  Refused

11. In the past twelve (12) months, how many times has [CHILD'S NAME] had to stay overnight in a hospital for asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: THIS NUMBER WOULD NOT INCLUDE VISITS TO THE ER THAT DID NOT RESULT IN AN OVERNIGHT HOSPITAL STAY]

\_\_\_\_\_ Times [RANGE 0-365]

994  Don't Know

997  Refused

## A.1 English Version

NOW I'D LIKE TO ASK YOU ABOUT THINGS YOU MAY HAVE DONE TO MANAGE [CHILD'S NAME] AT HOME. SOME PARENTS FIND THESE THINGS HELPFUL; OTHERS FIND THEY ARE NOT HELPFUL.

12. Asthma triggers are things that may start or set off an asthma attack in your child. Cigarette smoke, pets and dust are triggers that set off asthma attacks in some children. Have you taken any steps to reduce asthma triggers for [CHILD'S NAME] in your home? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: TRIGGERS MAY ALSO MAKE YOUR CHILD'S ASTHMA WORSE]

- 1  Yes [GO TO QUESTION 13]  
2  No [SKIP TO QUESTION 14]  
994  Don't Know [SEE PROMPT BELOW; IF STILL DON'T KNOW, SKIP TO QUESTION 14]  
997  Refused [SKIP TO QUESTION 14]

[PROMPT IF ANSWER IS DON'T KNOW: STEPS CAN BE THINGS LIKE DUSTING MORE OFTEN OR NOT ALLOWING SMOKING IN YOUR HOME]

13. What steps have you taken to reduce asthma triggers in your home? [ASK THIS QUESTION OPEN-ENDED AND SEPARATELY RECORD EACH STEP MENTIONED BY THE RESPONDENT]

- 1  \_\_\_\_\_  
2  \_\_\_\_\_  
3  \_\_\_\_\_  
4  \_\_\_\_\_  
5  \_\_\_\_\_  
6  \_\_\_\_\_  
7  \_\_\_\_\_  
8  \_\_\_\_\_  
9  \_\_\_\_\_  
10  \_\_\_\_\_

- 994  Don't Know  
997  Refused

14. I am going to read you a list of options from strongly agree to strongly disagree to answer this next question. How would you rate your agreement with the following statement; I have control over [CHILD'S NAME] asthma. [READ OPTIONS TO RESPONDENT AND SELECT APPROPRIATE ANSWER]

- 1  Strongly agree  
2  Agree  
3  Disagree  
4  Strongly disagree  
994  Don't Know [DO NOT READ]  
997  Refused [DO NOT READ]

## A.1 English Version

### Demographics

Suggested text to preface demographic questions – each site may use or not use this text as they want

*SOME OF THE QUESTIONS WE ARE NOW GOING TO ASK YOU MAY SEEM PERSONAL TO SOME PEOPLE. YOU DO NOT HAVE TO ANSWER ANY QUESTIONS THAT YOU FEEL UNCOMFORTABLE ANSWERING. YOUR NAME WILL NOT BE LINKED WITH ANY OF YOUR ANSWERS.*

*HOWEVER, YOUR ANSWERS TO THESE QUESTIONS WILL HELP [NAME OF SITE'S PROGRAM] TO LEARN MORE ABOUT ASTHMA AND ABOUT THE HEALTH AND WELL-BEING OF CHILDREN LIVING IN OUR COMMUNITY.*

*YOUR ANSWERS WILL ALSO HELP US BETTER SERVE CHILDREN WITH ASTHMA IN OUR COMMUNITY AND CAN HELP OTHER COMMUNITIES LIKE OURS IMPROVE THEIR ASTHMA SERVICES.*

1. [CHILD's NAME] date of birth? [MONTH RANGE 0-12; DAY RANGE 1-31; YEAR RECORDED AS 4 DIGITS]

\_\_\_\_/\_\_\_\_/\_\_\_\_ [E.G., 12/31/1999]  
MM/DD/YYYY

994  Don't Know

997  Refused

2. What is [CHILD's NAME] gender? [NO NEED TO ASK, JUST MARK APPROPRIATE RESPONSE]

1  Male

2  Female

3. What is your relationship to [CHILD's NAME]? [MOTHER, FATHER, GRANDMOTHER, ETC]

\_\_\_\_\_ Relationship

994  Don't Know

997  Refused

## A.1 English Version

4. How would you describe [CHILD's NAME]'s race, nationality, or ethnic background? [ASK OPEN-ENDED AND USE CODES BELOW]

- 1  Hispanic [IF PERSON SAYS HISPANIC, PROMPT BY READING THROUGH THE OPTIONS: WOULD YOU SAY, PUERTO RICAN? DOMINICAN? MEXICAN? AND USE CODES BELOW]
- 11  Puerto Rican
- 12  Dominican
- 13  Mexican
- 14  South American
- 15  Central/Latin American
- 16  Cuban
- 17  Other Hispanic
- 2  Black/African American
- 3  White
- 4  Asian
- 5  Mixed, [SPECIFY] \_\_\_\_\_
- 6  Native American
- 7  Other, [SPECIFY] \_\_\_\_\_
- 994  Don't Know
- 997  Refused

[NOTE ON CODING: HISPANIC IS CODED AS 1 IF NO MORE DETAIL IS PROVIDED. PUERTO RICAN IS CODED 11, ETC.]

5. How many people live in your household, including yourself?

[PROMPT: INCLUDE [CHILD's NAME] AND YOURSELF IN THE COUNT]

- \_\_\_\_\_ People
- 994  Don't Know
- 997  Refused

6. How many children live in your household?

[PROMPT: WE ARE ASKING ABOUT CHILDREN LESS THAN 18 YEARS OLD. INCLUDE [CHILD's NAME] IN THE COUNT]

- \_\_\_\_\_ Children [NOT TO EXCEED ANSWER GIVEN IN QUESTION 5]
- 994  Don't Know
- 997  Refused

7. Does [CHILD's NAME] primary caregiver speak a language other than English at home?

- 1  Yes [GO TO QUESTION 8]
- 2  No [SKIP TO QUESTION 9]
- 994  Don't Know [SKIP TO QUESTION 9]
- 997  Refused [SKIP TO QUESTION 9]

## A.1 English Version

8. If yes, what language do they speak?

\_\_\_\_\_ Language

994  Don't Know

997  Refused

9. What is the highest degree or level of school [*CHILD'S NAME*]'s primary caregiver has COMPLETED?

*[IF THE QUESTION IS ASKED OVER THE PHONE OR IF IT IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE. IF QUESTION IS ASKED IN-PERSON BY AN INTERVIEWER, CONSIDER USING A SHOWCARD WITH THE OPTIONS LISTED AND ASK THE RESPONDENTS TO POINT TO THEIR CATEGORY]*

1  Never attended/ kindergarten only

2  1<sup>st</sup> grade

3  2<sup>nd</sup> grade

4  3<sup>rd</sup> grade

5  4<sup>th</sup> grade

6  5<sup>th</sup> grade

7  6<sup>th</sup> grade

8  7<sup>th</sup> grade

9  8<sup>th</sup> grade

10  9<sup>th</sup> grade

11  10<sup>th</sup> grade

12  11<sup>th</sup> grade

13  12<sup>th</sup> grade, NO DIPLOMA

14  GED or equivalent

15  HIGH SCHOOL GRADUATE – high school DIPLOMA

16  Some college credit, but no degree

17  Associate degree: occupational, technical, or vocational program

18  Associate degree: academic program

19  Bachelor's degree (for example: BA, AB, BS)

20  Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)

21  Professional degree (for example: MD, DDS, DVM, LLB, JD)

22  Doctorate degree (for example: PhD, EdD)

994  Don't Know

997  Refused

## A.1 English Version

*Note: Sites choosing not to ask about income need to provide the Census tract for each respondent*

*[IF THE INCOME QUESTION IS ASKED OVER THE PHONE OR IF IT IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE.]*

- 10.** For the last month, what was your total household income from all sources? Include income from everyone in your home. Give amount before taxes and other deductions. If monthly income is unknown, estimate your income per year.
- 1  Less than \$833 per month (less than \$10,000 per year)  
 2  \$834 to \$1,666 per month (\$10,000 to \$19,999 per year)  
 3  \$1,667 to \$2,500 per month (\$20,000 to \$29,999 per year)  
 4  \$2,501 to \$3,333 per month (\$30,000 to \$39,999 per year)  
 5  \$3,334 to \$3,750 per month (\$40,000 to \$49,999 per year)  
 6  More than \$4,166 per month (more than \$50,000 per year)  
 994  Don't Know  
 997  Refused

*[IF THE INCOME QUESTION IS ASKED IN PERSON BY AN INTERVIEWER, USE THIS QUESTION AND CONSIDER SHOWING THE TABLE AND ASKING RESPONDENTS TO POINT TO THEIR CATEGORY, THEN ENTER THE INCOME CODE, RATHER THAN THE DOLLAR AMOUNT]*

- 10.** For the last month, what was the total household income from all sources? Include income from everyone in your home. Please point to the answer closest to your total household income.

Income code \_\_\_\_\_

- 994  Don't Know  
 997  Refused

<b>Monthly</b>	<b>Income Code</b>	<b>Yearly</b>
Less than \$833 per month	<b>1</b>	less than \$10,000 per year
\$834 - \$1,666 per month	<b>2</b>	\$10,000 - \$19,999 per year
\$1,667 - \$2,500 per month	<b>3</b>	\$20,000 - \$29,999 per year
\$2,501 - \$3,333 per month	<b>4</b>	\$30,000 - \$39,999 per year
\$3,334 - \$3,750 per month	<b>5</b>	\$40,000 - \$49,999 per year
More than \$4,166 per month	<b>6</b>	more than \$50,000 per year
- Include all sources of income - If monthly income is unknown, estimate income per year - Give amount before taxes and other deductions.		

- 11.** Does child have health or medical insurance?

- 1  Yes  
 2  No  
 994  Don't Know  
 997  Refused

## A.1 English Version

12. How many years have you lived at your current residence?

- 1  Less than 1 year
- 2  1 to 2 years
- 3  3 to 5 years
- 4  More than 5 years
- 994  Don't Know
- 997  Refused



## A.2 Spanish Version

### Red de Asma Infantil Merck (MCAN, por sus siglas en inglés) Elementos comunes de información

#### SITE-SPECIFIC INTRODUCTION AND INSTRUCTIONS

#### **Interview information**

Patient ID \_\_\_\_\_

Date \_\_\_/\_\_\_/\_\_\_ [E.G., 12/31/1999]  
M M/ D D/ Y Y Y Y

Survey Administration Method

- 1  Telephone
- 2  In-person by Interviewer
- 3  Mail
- 4  Self-Administered
- 5  Other, \_\_\_\_\_

Survey (check one):

- 1  Baseline
- 2  6 month follow-up
- 3  12 month follow-up
- 4  Other, \_\_\_\_\_

#### PLEASE CHECK INTERVENTIONS IN WHICH CHILD/FAMILY HAS PARTICIPATED

#### **Chicago**

- 1  School Screening with Yes We Can
- 2  Mobile Pediatric Van
- 3  Open Airways
- 4  Home Visitation
- 5  BPAS+ Asthma Screening
- 6  Freedom From Smoking (parents)

#### **Los Angeles**

- 1  Breathmobile
- 2  Received Materials/Instructions from Nurse Case Manager
- 3  Health Insurance Outreach, Enrollment, and Retention
- 4  Open Airways
- 5  Starbright Asthma Kit used in school curriculum
- 6  Tobacco Use Prevention Education Program
- 7  Home Visitation by Nurse Case Manager using CASA Teaching Manual
- 8  Received Home Mitigation Materials

#### **New York**

- 1  NCICAS or Modified NCICAS Intervention (modified has no home visit)
- 2  Enroll children in health insurance plan
- 3  Modified NCICAS asthma prevalence screening survey (in schools)
- 4  Wee Wheezers
- 5  Asthma Basics for Children
- 6  Open Airways
- 7  Received modified NCICAS asthma information materials through schools
- 8   NCICAS Integrated Pest Management Home Environmental Assessment & Trigger Reduction Activities

## A.2 Spanish Version

### ***Philadelphia***

- 1  School BPAS Screening
- 2  Asthma Awareness Days
- 3  Open Airways
- 4  Door to Door Screening
- 5  Home Visits using Modified NCICAS
- 6  Link Line
- 7  ACT Asthma Education
- 8  You Can Control Asthma Community Class

### ***Puerto Rico***

- 1  Yes We Can home treatment protocol
- 2  Yes We Can clinical recruitment protocol
- 3  Clinical Risk Assessment
- 4  Open Airways
- 5  ICAS home educational module

## A.2 Spanish Version

NOS GUSTARÍA HACERLE ALGUNAS PREGUNTAS SOBRE LOS MEDICAMENTOS QUE [CHILD'S NAME] PUEDA ESTAR TOMANDO PARA SU ASMA. ESTOS PUEDEN SER MEDICAMENTOS QUE SE PUEDEN COMPRAR SIN NECESIDAD DE UNA RECETA MÉDICA O MEDICAMENTOS QUE UN DOCTOR HAYA RECETADO O LE HAYA DADO A USTED PARA EL ASMA DE [CHILD'S NAME].

1. ¿Toma [CHILD'S NAME] algún medicamento para el asma actualmente? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

- 1  Sí [IR A LA PREG. 2]  
2  No [PASAR A LA PREG. 4]  
994  No sabe [PASAR A LA PREG. 4]  
997  Se rehusó [PASAR A LA PREG. 4]

2. Por favor, díganos los nombres de esos medicamentos y si los toma todos los días o cuando es necesario: [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT; ADD MORE LINES IF CHILD TAKES MORE THAN SIX (6) MEDICATIONS FOR ASTHMA]

[NOTA: ESTOS PUEDEN SER MEDICAMENTOS QUE SE PUEDEN COMPRAR SIN NECESIDAD DE UNA RECETA MÉDICA O MEDICAMENTOS RECETADOS POR UN DOCTOR]  
[NOTA: SI EL PARTICIPANTE RESPONDE QUE SE USA UN INHALADOR, PREGÚNTELE SI SABE EL NOMBRE DEL INHALADOR]

- |                          |  |  |
|--------------------------|--|--|
| 2.1M Medicamento 1 _____ | 2.1T 1 <input type="checkbox"/> Todos los días | 2 <input type="checkbox"/> Cuando es necesario |
|                          | 994 <input type="checkbox"/> No sabe           | 997 <input type="checkbox"/> Se rehusó         |
| 2.2M Medicamento 2 _____ | 2.2T 1 <input type="checkbox"/> Todos los días | 2 <input type="checkbox"/> Cuando es necesario |
|                          | 994 <input type="checkbox"/> No sabe           | 997 <input type="checkbox"/> Se rehusó         |
| 2.3M Medicamento 3 _____ | 2.3T 1 <input type="checkbox"/> Todos los días | 2 <input type="checkbox"/> Cuando es necesario |
|                          | 994 <input type="checkbox"/> No sabe           | 997 <input type="checkbox"/> Se rehusó         |
| 2.4M Medicamento 4 _____ | 2.4T 1 <input type="checkbox"/> Todos los días | 2 <input type="checkbox"/> Cuando es necesario |
|                          | 994 <input type="checkbox"/> No sabe           | 997 <input type="checkbox"/> Se rehusó         |
| 2.5M Medicamento 5 _____ | 2.5T 1 <input type="checkbox"/> Todos los días | 2 <input type="checkbox"/> Cuando es necesario |
|                          | 994 <input type="checkbox"/> No sabe           | 997 <input type="checkbox"/> Se rehusó         |
| 2.6M Medicamento 6 _____ | 2.6T 1 <input type="checkbox"/> Todos los días | 2 <input type="checkbox"/> Cuando es necesario |
|                          | 994 <input type="checkbox"/> No sabe           | 997 <input type="checkbox"/> Se rehusó         |

- 994  No sabe  
997  Se rehusó

[NOTA: PREGÚNTELE AL PARTICIPANTE SI SE LE VIENE A LA MENTE ALGÚN MEDICAMENTO ADICIONAL ANTES DE CONTINUAR CON LA SIGUIENTE PREGUNTA]

## A.2 Spanish Version

3. Durante los últimos 14 días, ¿cuántos días usó [CHILD's NAME] su medicamento para alivio rápido o de rescate para el asma, por tener silbido (pito) al respirar o por sentir presión en el pecho, o tos? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[NOTA: AL DECIR UN DÍA, PIENSE EN UN PERÍODO DE 24 HORAS. SI EL/LA NIÑO(A) TUVO EPISODIOS MÚLTIPLES DE ASMA YA SEA DURANTE EL DÍA O LA NOCHE EN UN PERÍODO DE 24 HORAS, POR FAVOR, CUÉNTVELO COMO UN (1) DÍA]

\_\_\_\_\_ Días [RANGO DEL 0 AL 14]

992  No aplica [EL/LA NIÑO(A) NO TOMA MEDICAMENTOS DE RESCATE]

994  No sabe

997  Se rehusó

4. Un plan de acción o de control de asma es un formulario impreso que indica cuándo aumentar la cantidad del medicamento, cuándo tomar otro medicamento, cuándo llamar al doctor para una consulta y cuándo ir a la sala de emergencias. ¿Alguna vez un doctor u otro profesional de la salud le ha dado a [CHILD's NAME] o al padre/madre/guardián/tutor de [CHILD's NAME] un plan de control para el asma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

1  Sí

2  No

994  No sabe

997  Se rehusó

## A.2 Spanish Version

AHORA QUEREMOS HABLAR CON USTED ACERCA DE CÓMO EL ASMA LE AFECTA A USTED Y A [CHILD'S NAME] CADA DÍA.

LAS SIGUIENTES PREGUNTAS SON ACERCA DE LA SALUD DE [CHILD'S NAME] EN LAS ÚLTIMAS DOS SEMANAS, ES DECIR, LOS ÚLTIMOS 14 DÍAS, DESDE [GIVE RESPONDENT THE DATE 14 DAYS PRIOR TO TODAY]. ALGUNAS PREGUNTAS SON ACERCA DEL ASMA DE SU NIÑO(A) DURANTE EL DÍA Y ALGUNAS PREGUNTAS SON ACERCA DEL ASMA DE SU NIÑO(A) DURANTE LA NOCHE.

5. En los últimos 14 días, ¿cuántos días tuvo [CHILD'S NAME] silbido (pito) al respirar o presión en el pecho, o tos? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[NOTA: SI EL/LA NIÑO(A) TUVO EPISODIOS MÚLTIPLES DE ASMA DURANTE EL DÍA, POR FAVOR, CUÉNTELO COMO UN (1) DÍA]

\_\_\_\_\_ Días [RANGO DEL 0 AL 14]

994  No sabe

997  Se rehusó

6. En las últimas 14 noches, ¿cuántas noches se despertó [CHILD'S NAME] debido al asma, silbido (pito) al respirar o presión en el pecho, o tos? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[NOTA: SI EL/LA NIÑO(A) TUVO EPISODIOS MÚLTIPLES DE ASMA DURANTE LA NOCHE, POR FAVOR, CUÉNTELO COMO UNA (1) NOCHE]

\_\_\_\_\_ Noches [RANGO DEL 0 AL 14]

994  No sabe

997  Se rehusó

7. En los últimos 14 días, ¿cuántos días ha tenido [CHILD'S NAME] que disminuir o parar de jugar o hacer sus actividades debido al asma, silbido (pito) al respirar o presión en el pecho, o tos? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[NOTA: SI EL/LA NIÑO(A) TUVO QUE JUGAR MÁS DESPACIO O TUVO QUE PARAR DE JUGAR VARIAS VECES EN UN DÍA, POR FAVOR, CUÉNTELO COMO UN (1) DÍA]

\_\_\_\_\_ Días [RANGO DEL 0 AL 14]

994  No sabe

997  Se rehusó

## A.2 Spanish Version

LAS SIGUIENTES PREGUNTAS SE REFIEREN A LOS ÚLTIMOS 12 MESES. ES DECIR, DESDE [GIVE RESPONDENT THE DATE ONE YEAR PRIOR TO TODAY'S DATE]

8. Durante los últimos doce (12) meses, ¿cuántos días ha faltado [CHILD'S NAME] a la escuela por cualquier razón? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[NOTA: POR FAVOR, INCLUYA SOLAMENTE LOS DÍAS CUANDO LA ESCUELA (O LA GUARDERÍA/CENTRO PRE-ESCOLAR, DEPENDIENDO DE LA EDAD DEL/DE LA NIÑO(A)) TENÍA CLASES REGULARES O ATENCIÓN REGULAR]

\_\_\_\_\_ Días [RANGO DEL 0 AL 365]

992  No aplica [EL/LA NIÑO(A) NO ASISTE A LA ESCUELA; PASAR A LA PREG. 10]

994  No sabe

997  Se rehusó

9. Durante los últimos doce (12) meses, ¿cuántos días ha faltado [CHILD'S NAME] a la escuela debido al asma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[NOTA: POR FAVOR, INCLUYA SOLAMENTE LOS DÍAS CUANDO LA ESCUELA (O LA GUARDERÍA/CENTRO PRE-ESCOLAR, DEPENDIENDO DE LA EDAD DEL/DE LA NIÑO(A)) TENÍA CLASES REGULARES O ATENCIÓN REGULAR]

\_\_\_\_\_ Días [RANGO DEL 0 AL 365; NO DEBE EXCEDER EL NÚMERO DE LA RESPUESTA A LA PREG. 8]

992  No aplica [EL/LA NIÑO(A) NO ASISTE A LA ESCUELA]

994  No sabe

997  Se rehusó

10. En los últimos doce (12) meses, ¿cuántas veces ha sido tratado(a) [CHILD'S NAME] en la sala de emergencias debido al asma (sin hospitalización)? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[NOTA: NO INCLUYA LAS VECES CUANDO SU NIÑO(A) FUE ADMITIDO(A) PARA QUEDARSE EN EL HOSPITAL POR UNA NOCHE INMEDIATAMENTE DESPUÉS DE HABER SIDO TRATADO(A) EN LA SALA DE EMERGENCIAS]

\_\_\_\_\_ Veces [RANGO DEL 0 AL 365]

994  No sabe

997  Se rehusó

11. En los últimos doce (12) meses, ¿cuántas veces ha tenido que pasar la noche [CHILD'S NAME] en un hospital debido al asma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[NOTA: ESTE NÚMERO DE VECES NO INCLUIRÍA LAS VISITAS A LA SALA DE EMERGENCIAS QUE NO RESULTARON EN QUE EL/NIÑO(A) SE QUEDARA EN EL HOSPITAL POR UNA NOCHE]

\_\_\_\_\_ Veces [RANGO DEL 0 AL 365]

994  No sabe

997  Se rehusó

## A.2 Spanish Version

AHORA ME GUSTARÍA PREGUNTARLE ACERCA DE LAS COSAS QUE HA HECHO PARA CONTROLAR EL ASMA DE [CHILD's NAME] EN EL HOGAR. ALGUNOS PADRES PIENSAN QUE ESTAS COSAS SON ÚTILES; OTROS PADRES PIENSAN QUE NO SON ÚTILES.

12. Los factores que provocan el asma son cosas que pudieran iniciar o producir un ataque de asma en su niño(a). El humo del cigarrillo, mascotas y polvo son factores que provocan ataques de asma en algunos niños. ¿Ha tomado usted algunas medidas para reducir los factores que provocan el asma para [CHILD's NAME] en su hogar? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[NOTA: LOS FACTORES QUE PROVOCAN EL ASMA TAMBIÉN PUEDEN HACER QUE EL ASMA DE SU NIÑO(A) EMPEORE]

- 1  Sí [IR A LA PREG. 13]  
2  No [PASAR A LA PREG. 14]  
994  No sabe [VEA LA NOTA A CONTINUACIÓN; SI LA RESPUESTA SIGUE SIENDO NO SABE, PASAR A LA PREG. 14]  
997  Se rehusó [PASAR A LA PREG. 14]

[NOTA: SI LA RESPUESTA ES NO SABE: LAS MEDIDAS QUE SE TOMAN PUEDEN SER COSAS COMO QUITAR EL POLVO CON MÁS FRECUENCIA O NO PERMITIR EL FUMAR EN SU HOGAR]

13. ¿Qué medidas ha tomado usted para reducir los factores que provocan el asma en su hogar? [ASK THIS QUESTION OPEN-ENDED AND SEPARATELY RECORD EACH STEP MENTIONED BY THE RESPONDENT]

- 1  \_\_\_\_\_  
2  \_\_\_\_\_  
3  \_\_\_\_\_  
4  \_\_\_\_\_  
5  \_\_\_\_\_  
6  \_\_\_\_\_  
7  \_\_\_\_\_  
8  \_\_\_\_\_  
9  \_\_\_\_\_  
10  \_\_\_\_\_  
994  No sabe  
997  Se rehusó

## A.2 Spanish Version

14. Para responder a la siguiente pregunta, le voy a leer una lista de opciones desde sumamente de acuerdo hasta sumamente en desacuerdo. ¿Qué tan de acuerdo está usted con la siguiente declaración?: Tengo control sobre el asma de [CHILD's NAME]. [READ OPTIONS TO RESPONDENT AND SELECT APPROPRIATE ANSWER]

- 1  Sumamente de acuerdo
- 2  De acuerdo
- 3  En desacuerdo
- 4  Sumamente en desacuerdo
- 994  No sabe [DO NOT READ]
- 997  Se rehusó [DO NOT READ]



## A.2 Spanish Version

### Datos demográficos

Suggested text to preface demographic questions – each site may use or not use this text as they want

*PUEDA QUE ALGUNAS DE LAS PREGUNTAS QUE LE VAMOS A HACER AHORA LES PAREZCAN PERSONALES A ALGUNAS PERSONAS. USTED NO TIENE QUE CONTESTAR NINGUNA PREGUNTA QUE LO(A) HAGA SENTIRSE INCÓMODO(A). SU NOMBRE NO SE RELACIONARÁ CON NINGUNA DE SUS RESPUESTAS.*

*SIN EMBARGO, SUS RESPUESTAS A ESTAS PREGUNTAS AYUDARÁN A [NAME OF SITE'S PROGRAM] A APRENDER MÁS SOBRE EL ASMA Y SOBRE LA SALUD Y EL BIENESTAR DE LOS NIÑOS QUE VIVEN EN NUESTRA COMUNIDAD.*

*SUS RESPUESTAS TAMBIÉN NOS AYUDARÁN A SERVIR MEJOR A LOS NIÑOS CON ASMA EN NUESTRA COMUNIDAD Y TAMBIÉN SERVIRÁN PARA AYUDAR A QUE OTRAS COMUNIDADES COMO LAS NUESTRAS MEJOREN SUS SERVICIOS PARA EL ASMA.*

1. ¿Cuál es la fecha de nacimiento de [CHILD'S NAME]? [RANGO DEL MES: DEL 0 AL 12; RANGO DEL DÍA: DEL 1 AL 31; EL AÑO SE REGISTRA CON 4 DÍGITOS]

\_\_\_\_/\_\_\_\_/\_\_\_\_ [POR EJEMPLO: 12/31/1999 (MES / DÍA / AÑO)]  
M M/ D D/ A A A A

- 994  No sabe  
997  Se rehusó

2. ¿Cuál es el sexo de [CHILD'S NAME]? [NO NEED TO ASK, JUST MARK APPROPRIATE RESPONSE]

- 1  Masculino  
2  Femenino

3. ¿Cuál es su relación con [CHILD'S NAME]? [MADRE, PADRE, ABUELA, ETC]

\_\_\_\_\_ Parentesco  
994  No sabe  
997  Se rehusó

## A.2 Spanish Version

4. ¿Cómo describiría la raza, nacionalidad u origen étnico de [CHILD'S NAME]? [ASK OPEN-ENDED AND USE CODES BELOW]

- 1  Hispano(a) [IF PERSON SAYS "HISPANO(A)," PROMPT BY READING THROUGH THE OPTIONS: "¿DIRÍA USTED PUERTORRIQUEÑO(A)? ¿DOMINICANO(A)? ¿MEXICANO(A)?" AND USE CODES BELOW]
- 11  Puertorriqueño(a)  
12  Dominicano(a)  
13  Mexicano(a)  
14  Sudamericano(a)  
15  Centroamericano(a)/Latinoamericano(a)  
16  Cubano(a)  
17  Otro origen hispano
- 2  Negro(a)/Afroamericano(a)  
3  Blanco(a)  
4  Asiático(a)  
5  De dos o más razas, [ESPECIFICAR] \_\_\_\_\_  
6  Indio(a) nativo(a) americano(a)  
7  Otro, [ESPECIFICAR] \_\_\_\_\_
- 994  No sabe  
997  Se rehusó

[NOTE ON CODING: HISPANIC IS CODED AS 1 IF NO MORE DETAIL IS PROVIDED. PUERTO RICAN IS CODED 11, ETC.]

5. ¿Cuántas personas viven en su hogar, incluyéndose usted?

[NOTA: CUENTE A [CHILD'S NAME] Y CUÉNTENSE USTED MISMO(A)]

- \_\_\_\_\_ Personas
- 994  No sabe  
997  Se rehusó

6. ¿Cuántos niños viven en su hogar?

[NOTA: ESTAMOS PREGUNTANDO ACERCA DE LOS NIÑOS MENORES DE 18 AÑOS DE EDAD. CUENTE A [CHILD'S NAME]]

- \_\_\_\_\_ Niños [NO DEBE EXCEDER EL NÚMERO DE LA RESPUESTA A LA PREG. 5]
- 994  No sabe  
997  Se rehusó

7. ¿Habla la persona principal del cuidado de [CHILD'S NAME] otro idioma aparte del inglés en el hogar?

- 1  Sí [IR A LA PREG. 8]  
2  No [PASAR A LA PREG. 9]  
994  No sabe [PASAR A LA PREG. 9]  
997  Se rehusó [PASAR A LA PREG. 9]

## A.2 Spanish Version

8. Si la respuesta fue sí, ¿qué idioma habla?

Idioma \_\_\_\_\_

- 994  No sabe  
997  Se rehusó

9. ¿Cuál es el grado o nivel de educación más avanzado que ha COMPLETADO la persona principal del cuidado de [CHILD's NAME]?

*[IF THE QUESTION IS ASKED OVER THE PHONE OR IF IT IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE. IF QUESTION IS ASKED IN-PERSON BY AN INTERVIEWER, CONSIDER USING A SHOWCARD WITH THE OPTIONS LISTED AND ASK THE RESPONDENTS TO POINT TO THEIR CATEGORY]*

- 1  No asistió a la escuela/ sólo asistió a kindergarten  
2  1° grado  
3  2° grado  
4  3° grado  
5  4° grado  
6  5° grado  
7  6° grado  
8  7° grado  
9  8° grado  
10  9° grado  
11  10° grado  
12  11° grado  
13  12° grado, SIN DIPLOMA  
14  Diploma de Equivalencia General o GED o su equivalente  
15  GRADUADO(A) DE LA SECUNDARIA/PREPARATORIA O “HIGH SCHOOL” – DIPLOMA de secundaria/preparatoria o “high school”  
16  Algo de universidad, pero no recibió un título  
17  Título de universidad de 2 años o Asociado: programa ocupacional, técnico o vocacional  
18  Título de universidad de 2 años o Asociado: programa académico  
19  Título de universidad de 4 años  
20  Maestría  
21  Título profesional (por ejemplo: doctor en medicina)  
22  Doctorado  
994  No sabe  
997  Se rehusó

## A.2 Spanish Version

*Note: Sites choosing not to ask about income need to provide the Census tract for each respondent*

*[IF THE INCOME QUESTION IS ASKED OVER THE PHONE OR IF IT IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE.]*

10. Refiriéndonos al mes pasado, ¿cuál fue su ingreso familiar total de todas las fuentes? Incluya los ingresos de todos los miembros de su hogar. Por favor, dénos la cantidad sin contar los impuestos y otras deducciones. Si se desconoce el ingreso mensual, haga un cálculo de su ingreso anual.

- 1  Menos de \$833 dólares al mes (menos de \$10,000 dólares al año)  
 2  De \$834 a \$1,666 dólares al mes (de \$10,000 a \$19,999 dólares al año)  
 3  De \$1,667 a \$2,500 dólares al mes (de \$20,000 a \$29,999 dólares al año)  
 4  De \$2,501 a \$3,333 dólares al mes (de \$30,000 a \$39,999 dólares al año)  
 5  De \$3,334 a \$3,750 dólares al mes (de \$40,000 a \$49,999 dólares al año)  
 6  Más de \$4,166 dólares al mes (más de \$50,000 dólares al año)  
 994  No sabe  
 997  Se rehusó

*[IF THE INCOME QUESTION IS ASKED IN PERSON BY AN INTERVIEWER, USE THIS QUESTION AND CONSIDER SHOWING THE TABLE AND ASKING RESPONDENTS TO POINT TO THEIR CATEGORY, THEN ENTER THE INCOME CODE, RATHER THAN THE DOLLAR AMOUNT]*

10. Refiriéndonos al mes pasado, ¿cuál fue el ingreso familiar total de todas las fuentes de ingresos? Incluya los ingresos de todos los miembros de su hogar. Por favor, señale la respuesta que sea más cercana al total de su ingreso familiar.

Código del ingreso \_\_\_\_\_

- 994  No sabe  
 997  Se rehusó

<u>Mensual</u>	<u>Código del ingreso</u>	<u>Anual</u>
Menos de \$833 dólares al mes	<b>1</b>	menos de \$10,000 dólares al año
De \$834 a \$1,666 dólares al mes	<b>2</b>	de \$10,000 a \$19,999 dólares al año
De \$1,667 a \$2,500 dólares al mes	<b>3</b>	de \$20,000 a \$29,999 dólares al año
De \$2,501 a \$3,333 dólares al mes	<b>4</b>	de \$30,000 a \$39,999 dólares al año
De \$3,334 a \$3,750 dólares al mes	<b>5</b>	de \$40,000 a \$49,999 dólares al año
Más de \$4,166 dólares al mes	<b>6</b>	más de \$50,000 dólares al año
- Incluya todas las fuentes de ingresos - Si se desconoce el ingreso mensual, haga un cálculo del ingreso anual - Por favor, dénos la cantidad sin contar los impuestos y otras deducciones.		

11. ¿Tiene seguro médico el/la niño(a)?

- 1  Sí  
 2  No  
 994  No sabe  
 997  Se rehusó

## A.2 Spanish Version

12. ¿Cuántos años ha vivido usted en su vivienda actual?

- 1  Menos de un año
- 2  De 1 a 2 años
- 3  De 3 a 5 años
- 4  Más de 5 años
- 994  No sabe
- 997  Se rehusó

## **Appendix B. Response Coding Example**

## Appendix B. Response Coding Example

The survey instrument below is an example that has been marked as if it were from an interview. Following the survey instrument is a table displaying the coded responses from the instrument.

### SITE-SPECIFIC INTRODUCTION AND INSTRUCTIONS

#### **Interview information**

Patient ID 12345

Date 05 / 22 / 2008 [E.G., 12/31/1999]  
MM / DD / YYYY

Survey Administration Method

- 1  Telephone  
2  In-person by Interviewer  
3  Mail  
4  Self-Administered  
5  Other, Respondent Completed on Computer

Survey (check one):

- 1  Baseline  
2  6 month follow-up  
3  12 month follow-up  
4  Other, 3 month follow up

### PLEASE CHECK INTERVENTIONS IN WHICH CHILD/FAMILY HAS PARTICIPATED

#### **Chicago**

- 1  School Screening with Yes We Can  
2  Mobile Pediatric Van  
3  Open Airways  
4  Home Visitation  
5  BPAS+ Asthma Screening  
6  Freedom From Smoking (parents)

WE WOULD LIKE TO ASK YOU A FEW QUESTIONS ABOUT MEDICATIONS [CHILD'S NAME] MAY TAKE FOR [HIS/HER] ASTHMA. THESE COULD BE OVER-THE-COUNTER MEDICATIONS OR A DOCTOR MAY HAVE PRESCRIBED OR GIVEN THEM TO YOU FOR [CHILD'S NAME] ASTHMA.

1. Does [CHILD'S NAME] currently take medication for asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

- 1  Yes [GO TO QUESTION 2]  
2  No [SKIP TO QUESTION 4]  
994  Don't Know [SKIP TO QUESTION 4]  
997  Refused [SKIP TO QUESTION 4]

2. Please tell us the names of those medications and whether it is taken every day or as needed: *[ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT; ADD MORE LINES IF CHILD TAKES MORE THAN SIX (6) MEDICATIONS FOR ASTHMA]*

*[PROMPT: THESE COULD BE OVER-THE-COUNTER OR DOCTOR PRESCRIBED MEDICATIONS]*

*[PROMPT: IF RESPONDENT ANSWERS INHALER, ASK IF THEY KNOW THE NAME OF THE INHALER]*

2.1M Medication 1	<u>Singulair</u>	2.1T	1	<input type="checkbox"/> Every day	2	<input checked="" type="checkbox"/> As needed
		994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.2M Medication 2	<u>Aerolate</u>	2.2T	1	<input checked="" type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
		994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.3M Medication 3	_____	2.3T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
		994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.4M Medication 4	_____	2.4T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
		994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.5M Medication 5	_____	2.5T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
		994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused
2.6M Medication 6	_____	2.6T	1	<input type="checkbox"/> Every day	2	<input type="checkbox"/> As needed
		994		<input type="checkbox"/> Don't Know	997	<input type="checkbox"/> Refused

994  Don't Know

997  Refused

*[PROMPT: ASK RESPONDENT IF THERE ARE ANY ADDITIONAL MEDICATIONS THEY CAN THINK OF BEFORE MOVING ON TO THE NEXT QUESTION]*

3. During the past 14 days, how many days did *[CHILD'S NAME]* use *[HIS/HER]* quick-relief or rescue medication for asthma, wheezing or tightness in the chest, or cough? *[ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]*

*[PROMPT: THINK OF A DAY AS BEING A 24-HOUR PERIOD. IF THE CHILD HAD MULTIPLE EPISODES DURING EITHER THE DAY OR NIGHT OF A 24-HOUR PERIOD, PLEASE COUNT THAT AS ONE (1) DAY]*

5 Days *[RANGE 0-14]*

992  Does not apply *[CHILD DOES NOT TAKE RESCUE MEDICATIONS]*

994  Don't Know

997  Refused



4. An asthma action or management plan is a printed form that tells when to increase medicine, when to take other medicine, when to call the doctor for advice, and when to go to the emergency room. Has a doctor or other health professional ever given [CHILD's NAME] or [CHILD's NAME]'s parent/caregiver/guardian an asthma management plan? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

- 1  Yes  
2  No  
994  Don't Know  
997  Refused

NOW WE WANT TO TALK WITH YOU ABOUT HOW ASTHMA AFFECTS YOU AND [CHILD's NAME] EACH DAY.

THE NEXT FEW QUESTIONS ARE ABOUT [CHILD's NAME] HEALTH IN THE LAST TWO WEEKS, THAT IS, THE PAST 14 DAYS, SINCE [GIVE RESPONDENT THE DATE 14 DAYS PRIOR TO TODAY]. SOME QUESTIONS ARE ABOUT YOUR CHILD'S ASTHMA DURING THE DAY AND SOME QUESTIONS ARE ABOUT YOUR CHILD'S ASTHMA DURING THE NIGHT.

5. In the last 14 days, how many days did [CHILD's NAME] have wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD MULTIPLE EPISODES DURING THE DAY, PLEASE COUNT THAT AS ONE (1) DAY]

2 Days [RANGE 0-14]

- 994  Don't Know  
997  Refused

6. In the last 14 nights, how many nights did [CHILD's NAME] wake up because of asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD MULTIPLE EPISODES DURING THE NIGHT, PLEASE COUNT THAT AS ONE (1) NIGHT]

1 Nights [RANGE 0-14]

- 994  Don't Know  
997  Refused

7. In the last 14 days, how many days did [CHILD's NAME] have to slow down or stop [HIS/HER] play or activities because of asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD TO SLOW DOWN OR STOP HIS PLAY MULTIPLE TIMES IN ONE DAY, PLEASE COUNT THAT AS ONE (1) DAY]

1 Days [RANGE 0-14]

- 994  Don't Know  
997  Refused

THE NEXT FEW QUESTIONS ARE ABOUT THE PAST YEAR, THAT IS, SINCE [GIVE RESPONDENT THE DATE ONE YEAR PRIOR TO TODAY'S DATE]

8. During the past twelve (12) months, how many days did [CHILD'S NAME] miss school for any reason? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: PLEASE INCLUDE ONLY DAYS WHEN SCHOOL (OR DAYCARE/PRE-SCHOOL, DEPENDING ON AGE OF THE CHILD) WAS IN SESSION]

8 Days [RANGE 0-365]

992  Does not apply [CHILD NOT IN SCHOOL; SKIP TO QUESTION 10]

994  Don't Know

997  Refused

9. During the past twelve (12) months, how many days did [CHILD'S NAME] miss school due to asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: PLEASE INCLUDE ONLY DAYS WHEN SCHOOL (OR DAYCARE/PRE-SCHOOL, DEPENDING ON AGE OF THE CHILD) WAS IN SESSION]

5 Days [RANGE 0-365; NUMBER SHOULD NOT EXCEED THE ANSWER IN QUESTION 8]

992  Does not apply [CHILD NOT IN SCHOOL]

994  Don't Know

997  Refused

10. In the past twelve (12) months, how many times has [CHILD'S NAME] been treated in the Emergency Room or ER for asthma (without hospitalization)? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: DO NOT INCLUDE TIMES WHEN YOUR CHILD WAS ADMITTED TO THE HOSPITAL FOR AN OVERNIGHT STAY RIGHT AFTER BEING TREATED AT THE EMERGENCY ROOM OR ER]

6 Times [RANGE 0-365]

994  Don't Know

997  Refused

11. In the past twelve (12) months, how many times has [CHILD'S NAME] had to stay overnight in a hospital for asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: THIS NUMBER WOULD NOT INCLUDE VISITS TO THE ER THAT DID NOT RESULT IN AN OVERNIGHT HOSPITAL STAY]

1 Times [RANGE 0-365]

994  Don't Know

997  Refused

NOW I'D LIKE TO ASK YOU ABOUT THINGS YOU MAY HAVE DONE TO MANAGE [CHILD'S NAME] AT HOME. SOME PARENTS FIND THESE THINGS HELPFUL; OTHERS FIND THEY ARE NOT HELPFUL.

12. Asthma triggers are things that may start or set off an asthma attack in your child. Cigarette smoke, pets and dust are triggers that set off asthma attacks in some children. Have you taken any steps to reduce asthma triggers for [CHILD'S NAME] in your home? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: TRIGGERS MAY ALSO MAKE YOUR CHILD'S ASTHMA WORSE]

- 1  Yes [GO TO QUESTION 13]
- 2  No [SKIP TO QUESTION 14]
- 994  Don't Know [SEE PROMPT BELOW; IF STILL DON'T KNOW, SKIP TO QUESTION 14]
- 997  Refused [SKIP TO QUESTION 14]

[PROMPT IF ANSWER IS DON'T KNOW: STEPS CAN BE THINGS LIKE DUSTING MORE OFTEN OR NOT ALLOWING SMOKING IN YOUR HOME]

13. What steps have you taken to reduce asthma triggers in your home? [ASK THIS QUESTION OPEN-ENDED AND SEPARATELY RECORD EACH STEP MENTIONED BY THE RESPONDENT]

- 1  Don't allow smoking in home
- 2  Got rid of carpets and rugs
- 3  Insect treatment
- 4  \_\_\_\_\_
- 5  \_\_\_\_\_
- 6  \_\_\_\_\_
- 7  \_\_\_\_\_
- 8  \_\_\_\_\_
- 9  \_\_\_\_\_
- 10  \_\_\_\_\_
- 994  Don't Know
- 997  Refused

14. I am going to read you a list of options from strongly agree to strongly disagree to answer this next question. How would you rate your agreement with the following statement; I have control over [CHILD's NAME] asthma. [READ OPTIONS TO RESPONDENT AND SELECT APPROPRIATE ANSWER]

- 1  Strongly agree
- 2  Agree
- 3  Disagree
- 4  Strongly disagree
- 994  Don't Know [DO NOT READ]
- 997  Refused [DO NOT READ]

## Demographics

Suggested text to preface demographic questions – each site may use or not use this text as they want

SOME OF THE QUESTIONS WE ARE NOW GOING TO ASK YOU MAY SEEM PERSONAL TO SOME PEOPLE. YOU DO NOT HAVE TO ANSWER ANY QUESTIONS THAT YOU FEEL UNCOMFORTABLE ANSWERING. YOUR NAME WILL NOT BE LINKED WITH ANY OF YOUR ANSWERS.

HOWEVER, YOUR ANSWERS TO THESE QUESTIONS WILL HELP [NAME OF SITE'S PROGRAM] TO LEARN MORE ABOUT ASTHMA AND ABOUT THE HEALTH AND WELL-BEING OF CHILDREN LIVING IN OUR COMMUNITY.

YOUR ANSWERS WILL ALSO HELP US BETTER SERVE CHILDREN WITH ASTHMA IN OUR COMMUNITY AND CAN HELP OTHER COMMUNITIES LIKE OURS IMPROVE THEIR ASTHMA SERVICES.

1. [CHILD'S NAME] date of birth? [MONTH RANGE 0-12; DAY RANGE 1-31; YEAR RECORDED AS 4 DIGITS]

05 / 01 / 1999 [E.G., 12/31/1999]  
MM/DD / YYYY

994  Don't Know

997  Refused

2. What is [CHILD'S NAME] gender? [NO NEED TO ASK, JUST MARK APPROPRIATE RESPONSE]

1  Male

2  Female

3. What is your relationship to [CHILD'S NAME]? [MOTHER, FATHER, GRANDMOTHER, ETC]

Mother Relationship

994  Don't Know

997  Refused

4. How would you describe [CHILD's NAME]'s race, nationality, or ethnic background? [ASK OPEN-ENDED AND USE CODES BELOW]

- 1  Hispanic [IF PERSON SAYS HISPANIC, PROMPT BY READING THROUGH THE OPTIONS: WOULD YOU SAY, PUERTO RICAN? DOMINICAN? MEXICAN? AND USE CODES BELOW]
  - 11  Puerto Rican
  - 12  Dominican
  - 13  Mexican
  - 14  South American
  - 15  Central/Latin American
  - 16  Cuban
  - 17  Other Hispanic
- 2  Black/African American
- 3  White
- 4  Asian
- 5  Mixed, [SPECIFY] Hispanic and Caucasian
- 6  Native American
- 7  Other, [SPECIFY] \_\_\_\_\_
- 994  Don't Know
- 997  Refused

[NOTE ON CODING: HISPANIC IS CODED AS 1 IF NO MORE DETAIL IS PROVIDED. PUERTO RICAN IS CODED 11, ETC.]

5. How many people live in your household, including yourself?

[PROMPT: INCLUDE [CHILD's NAME] AND YOURSELF IN THE COUNT]

- 8 People
- 994  Don't Know
  - 997  Refused

6. How many children live in your household?

[PROMPT: WE ARE ASKING ABOUT CHILDREN LESS THAN 18 YEARS OLD. INCLUDE [CHILD's NAME] IN THE COUNT]

- 6 Children [NOT TO EXCEED ANSWER GIVEN IN QUESTION 5]
- 994  Don't Know
  - 997  Refused

7. Does [CHILD's NAME] primary caregiver speak a language other than English at home?

- 1  Yes [GO TO QUESTION 8]
- 2  No [SKIP TO QUESTION 9]
- 994  Don't Know [SKIP TO QUESTION 9]
- 997  Refused [SKIP TO QUESTION 9]

8. If yes, what language do they speak?

Spanish Language

- 994  Don't Know
- 997  Refused

9. What is the highest degree or level of school [CHILD's NAME]'s primary caregiver has COMPLETED?

*[IF THE QUESTION IS ASKED OVER THE PHONE OR IF IT IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE. IF QUESTION IS ASKED IN-PERSON BY AN INTERVIEWER, CONSIDER USING A SHOWCARD WITH THE OPTIONS LISTED AND ASK THE RESPONDENTS TO POINT TO THEIR CATEGORY]*

- 1  Never attended/ kindergarten only
- 2  1<sup>st</sup> grade
- 3  2<sup>nd</sup> grade
- 4  3<sup>rd</sup> grade
- 5  4<sup>th</sup> grade
- 6  5<sup>th</sup> grade
- 7  6<sup>th</sup> grade
- 8  7<sup>th</sup> grade
- 9  8<sup>th</sup> grade
- 10  9<sup>th</sup> grade
- 11  10<sup>th</sup> grade
- 12  11<sup>th</sup> grade
- 13  12<sup>th</sup> grade, NO DIPLOMA
- 14  GED or equivalent
- 15  HIGH SCHOOL GRADUATE – high school DIPLOMA
- 16  Some college credit, but no degree
- 17  Associate degree: occupational, technical, or vocational program
- 18  Associate degree: academic program
- 19  Bachelor's degree (for example: BA, AB, BS)
- 20  Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
- 21  Professional degree (for example: MD, DDS, DVM, LLB, JD)
- 22  Doctorate degree (for example: PhD, EdD)
- 994  Don't Know
- 997  Refused

*Note: Sites choosing not to ask about income need to provide the Census tract for each respondent*

*[IF THE INCOME QUESTION IS ASKED OVER THE PHONE OR IF IT IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE.]*

**10.** For the last month, what was your total household income from all sources? Include income from everyone in your home. Give amount before taxes and other deductions. If monthly income is unknown, estimate your income per year.

- 1  Less than \$833 per month (less than \$10,000 per year)
- 2  \$834 to \$1,666 per month (\$10,000 to \$19,999 per year)
- 3  \$1,667 to \$2,500 per month (\$20,000 to \$29,999 per year)
- 4  \$2,501 to \$3,333 per month (\$30,000 to \$39,999 per year)
- 5  \$3,334 to \$3,750 per month (\$40,000 to \$49,999 per year)
- 6  More than \$4,166 per month (more than \$50,000 per year)
- 994  Don't Know
- 997  Refused

*[IF THE INCOME QUESTION IS ASKED IN PERSON BY AN INTERVIEWER, USE THIS QUESTION AND CONSIDER SHOWING THE TABLE AND ASKING RESPONDENTS TO POINT TO THEIR CATEGORY, THEN ENTER THE INCOME CODE, RATHER THAN THE DOLLAR AMOUNT]*

**10.** For the last month, what was the total household income from all sources? Include income from everyone in your home. Please point to the answer closest to your total household income.

Income code \_\_\_\_\_  
 994  Don't Know  
 997  Refused

<b>Monthly</b>	<b>Income Code</b>	<b>Yearly</b>
Less than \$833 per month	<b>1</b>	less than \$10,000 per year
\$834 - \$1,666 per month	<b>2</b>	\$10,000 - \$19,999 per year
\$1,667 - \$2,500 per month	<b>3</b>	\$20,000 - \$29,999 per year
\$2,501 - \$3,333 per month	<b>4</b>	\$30,000 - \$39,999 per year
\$3,334 - \$3,750 per month	<b>5</b>	\$40,000 - \$49,999 per year
More than \$4,166 per month	<b>6</b>	more than \$50,000 per year
- Include all sources of income - If monthly income is unknown, estimate income per year - Give amount before taxes and other deductions.		

**11.** Does child have health or medical insurance?

- 1  Yes
- 2  No
- 994  Don't Know
- 997  Refused



**12.** How many years have you lived at your current residence?

- 1  Less than 1 year
- 2  1 to 2 years
- 3  3 to 5 years
- 4  More than 5 years
- 994  Don't Know
- 997  Refused

**Table B.1 Coded Responses from Example: Common Data Elements**

<b>Variable Name</b>	<b>Coded Response: Common Data Elements</b>
patientid	12345
date	05/22/2008
method	5
method_t	Respondent Completed on Computer
survey	4
survey_t	3 Month Follow Up
intervention1	0
intervention2	1
intervention3	0
intervention4	0
intervention5	1
intervention6	0
intervention7	.
intervention8	.
Q1	1
Q2	.
Q2_1M	Singular
Q2_1T	2
Q2_2M	Aerolate
Q2_2T	1
Q2_3M	.
Q2_3T	.
Q2_3M	.
Q2_3T	.
Q2_4M	.
Q2_4T	.
Q2_5M	.
Q2_5T	.
Q2_6M	.
Q2_6T	.
Q3	5
Q4	2
Q5	2
Q6	1
Q7	1
Q8	8

<b>Variable Name</b>	<b>Coded Response: Common Data Elements</b>
Q9	5
Q10	6
Q11	1
Q12	1
Q13	
Q13_1	Don't allow smoking in home
Q13_2	Got rid of carpets and rugs
Q13_3	Insect treatment
Q13_4	.
Q13_5	.
Q13_6	.
Q13_7	.
Q13_8	.
Q13_9	.
Q13_10	.
Q14	1

**Table B.2 Coded Responses from Example: Demographics**

<b>Variable Name</b>	<b>Coded Response: Demographics</b>
patientid	12345
date	05/22/2008
method	5
method_t	Respondent Completed on Computer
survey	4
survey_t	3 Month Follow Up
D1	05/01/1999
D2	2
D3	Mother
D4	5
D4_t	Hispanic and Caucasian
D5	8
D6	6
D7	1
D8	Spanish
D9	13

<b>Variable Name</b>	<b>Coded Response: Demographics</b>
D10	2
D11	1
D12	2