Manual of Operations for the Follow-up Parent/Caregiver Survey, MCAN Care Coordination Initiative

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Contents

Introduction

The Parent/Caregiver survey instrument was created to collect standardized outcome information from patients enrolled in the four MCAN Care Coordination Initiative sites. This Manual of Operations provides instructions for administering the surveys, data entry formatting and coding, and delivery of the data to CMCD. The following appendices are critical components of this manual:

Appendix A Instrument administration instructions

Appendix B Codebook

Appendix C Example of coded data

1. Expectations for Administration

1.1 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 instructions in Appendix A. Computerized instruments should be programmed with appropriate prompts and instructions.

Sites will train all interviewers on how to administer the survey instruments to obtain as much uniformity in data collection as possible. See Appendix A for detailed instrument administration instructions.

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

1.1.1 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 household is expected to be no more than 30 calls, except for unusual circumstances.

➢ After initial contact with a household, the table below specifies which procedure to follow depending on the type of initial contact.

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.

1.2   Sample Size

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.

In the October 2010 cross site evaluation meeting, each site specified its expected final sample size:

- Philadelphia: 200
- Chicago: 225
- Los Angeles: 200
- Puerto Rico: 200

2.   Data Entry and Coding

2.1   Coding Data

The table in Appendix B displays the codebook with variable names, definitions, and coding information. The variable names listed in the "Variable Name" column of the codebook in Appendix B should be used. Data should be coded as specified in the "Valid Codes" and "Data Type" columns in the codebook in Appendix B. In the survey instruments, the numeric codes for each response category are listed to the left of the response categories for each question. For the variables where

the data type is numeric, only the values listed in the "Valid Codes" columns in the codebook in Appendix B are allowed. If a value is missing (for any reason), please code as a period ("."").

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 cannot be entered.**

We provide an example of coding in Appendix C. 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.

2.2   Data Entry, Security and Cleaning

2.2.1   Double-entry of Data

CMCD strongly 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 at least 10% of the data should be double entered and checked for errors.

2.2.2   Data Security

Sites are expected to adhere to their IRB requirements regarding data security.   All data will be stored on a password-protected network with stringent security measures designed to protect personally identifiable data, but CMCD will only work with de-identified data from caregivers of the cross-site evaluation.

2.2.3   Data Cleaning

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

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

- Sections filled out by the interviewer should be complete and coded correctly.
- Patient's unique ID should be verified.
- Correct variable names are used according to the codebook (Appendix B), "Variable Name" column
- Correct labels are used according to the codebook, "Label" column
- Verify numeric data are valid according to the "Valid Codes" column in the codebook
- Verify data are properly formatted as text or numeric as indicated in the "Data Type" column in the codebook
- Resolve any issues with the data internally *before* sending to CMCD.

CMCD recommends running summary statistics as one method of data cleaning. Running frequencies can be used to verify all values are within the valid range and to spot outliers which may be in fact due to an entry error. Text codes can be sorted and examined to ensure consistency in spelling, capitalization, etc.

The table below contains an example of data with error descriptions. All errors need to be corrected.

Sample Data with Errors

uniqueID	B1.1	Error Description
546321	flovent	Not capitalized
546322	Flovent	No error
546323	Flovint	misspelled
546324	Flovent	Space before characters
546325	Flovent	No error

If the data files contain numerous errors or inconsistent information, CMCD will work with the sites to identify the problem.

3.   Delivering Data to CMCD

3.1   Quarterly Progress Updates

At the end of each quarter starting in June 2011, the sites will provide CMCD with a progress update on data collection. The quarterly updates are needed to track sample size, identify data problems, and plan for data analysis. **Sites do not need to send any data as part of the progress update.**

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

- The target and actual number of 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.

3.2   Data Files and Supplemental Information

Data provided to CMCD 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.

Data files need to follow the order and structure detailed in the codebook (Appendix B) and be cleaned according to the instructions in Section 2.2.3. The data file should contain all the cumulative Parent/Caregiver follow-up data collected to date (not just new records). Also include a description of changes to data previously delivered or problems encountered during interviews or data entry/cleaning (anomaly report).

Sites should tell CMCD what type of file they will use when they deliver their data. The following file types are preferred for data delivered to CMCD:

- SPSS (file type .sav)

- SAS (file type .sas7bdat)

3.3   Data Delivery Schedule

Each site will deliver to CMCD its first 10 follow-up data records so that any problems can be identified and resolved early on. Thereafter, data should be delivered to CMCD after every additional 50 records are entered and cleaned.

3.4   What if the Sites or CMCD Make Changes to a Data File After It is Delivered?

In cases where the sites discover problems with data files that have already been delivered, the sites should contact CMCD to discuss as soon as possible. Together, CMCD 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, CMCD will contact sites with questions about data files and together CMCD and the sites will resolve any problems.

Each time a data file is delivered it should contain all the follow-up data collected to date and an explanation of any changes to the records and/or the data structure (anomaly report) since the last delivery. This provides CMCD with the most recent data from the sites.

Appendix A: Instrument Administration Instructions

This appendix presents the instructions for administering the Parent/Caregiver survey instrument. The survey instrument is available in both English and Spanish. Below are general rules that apply to the survey as a whole:

- The questions should be read exactly as written (unless otherwise noted)

- The interviewer should insert the child's name in the text for [*child's name*] wherever it appears

- Likewise, the interviewer should select the appropriate pronoun when the question contains [*his/her*] or [s/he]

- If the respondent asks what is meant by a question, the interviewer should reply, "Whatever it means to you." In some cases noted in the instructions that follow, the interviewer may provide example response options to help the respondent understand the question better

- It is important that education, for example about asthma triggers in the home, should not take place during survey administration.

- Response options should not be read to the respondent unless otherwise indicated

- In the cases where the response options should be read, which is always indicated on the survey itself as well as in the instructions that follow, the interviewer should never read "don't know" or "refused"

- When the interviewer is instructed to read the response options, there may be times when the respondent does not answer with one of the given options. In such cases, the interviewer should prompt the respondent by repeating the answer choices. If the respondent's answer clearly eliminates some of the options, the interviewer may reduce the answer choices to those that apply. For example:
  Respondent: "sometimes"
  Interviewer: "which of these two choices best describes your answer: "a little of the time" or "most of the time"?

First Page: Interview Information

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

The Interview Information section at the beginning of the MCAN Parent/Caregiver must be completed at the beginning or end of the interview by the interviewer.

Each site may use its own protocol for assigning unique ID numbers. These numbers are to be assigned in a logical manner and not repeated across respondents. Each respondent must have a unique ID number that must be identical at baseline and 12-month follow-up. This unique ID should be used again if the same patient enters a program multiple times. CMCD 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 dates required in the *Interview Information* section includes the date(s) the interview was started and completed. If the survey takes place over multiple interview sessions, provide the dates of the first and the final sessions for the administration of the interview. If the survey is completed in one session, only the first date field should be completed.

Ideally the administration method will be consistent across the survey periods but the sites' budget constraints may make that difficult. CMCD 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 the survey must pay close attention to the instructions. If the survey is administered in a method not listed in the Interview Information section, sites should specify how the interview is administered.

MCAN expects sites to administer surveys at baseline and 12 months. The sites may have trouble reaching an individual between interviews, resulting in a gap larger than 12 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 12-month window.

A   Diagnosis, Exposure To Program Components, & Referrals

Question A1 asks about asthma diagnosis. If asthma diagnosis was confirmed through medical records, the interviewer may check "Yes" box instead of asking this question.

A1. Has a doctor or other medical professional diagnosed [*child's name*] with asthma?
  1 ☐ Yes
  2 ☐ No
 88 ☐ Don't know
 99 ☐ Refused

Questions A2-A12 ask the parent or caregiver about components of the project that they or their child may have been exposed to in the last year. Each site may modify the introductory language below to ensure that respondents are answering about components of the program; please send CMCD a copy of your final survey so that CMCD may track the the language your site decides to use. If a respondent is unclear on what is considered part of the program, the interviewer may clarify for them.

Since enrolling in this program one year ago [*or say month and year*], we want to know what kinds of help for your child's asthma you or your child received as a part of this program. Did you or your child receive:

If your project did not offer a particular component described in Questions A2 to A7, you need not include that item in your survey. Similarly, if your project did not include a Breathmobile, "Breathmobile" can be removed from questions A2 and A3.

Since enrolling in this program one year ago [*or say month and year*], we want to know what kinds of help for your child's asthma you or your child received as a part of this program. Did you or your child receive:

A2. Care for asthma from a doctor or nurse in a clinic, doctor's office, or Breathmobile?	1 ☐ Yes 2 ☐No 88 ☐Don't know 99 ☐ Refused
A3. Education about asthma while in the clinic/Breathmobile?	1 ☐ Yes 2 ☐No 88 ☐Don't know 99 ☐ Refused
A4. Education about asthma in school or the classroom?	1 ☐ Yes 2 ☐No 88 ☐Don't know 99 ☐ Refused
A5. Did you receive asthma devices such as a spacer or peak flow meter?	1 ☐ Yes 2 ☐No 88 ☐Don't know 99 ☐ Refused
A6. Did you receive materials for you to use to reduce asthma triggers in your home?	1 ☐ Yes 2 ☐No 88 ☐Don't know 99 ☐ Refused

A7. What did you receive?

A7_1	☐ Did not receive anything for triggers
A7_2	☐ Pillow cover
A7_3	☐ Mattress cover
A7_4	☐ Caulk
A7_5	☐ No smoking sign
A7_6	☐ Other, please specify
A7_6t	_____
A7_88	☐ Don't know
A7_99	☐ Refused

The interviewer should not read the response options to Question A7.

For questions A8, A10, and A11, "health educator" may be replaced with another word or phrase to describe the person who makes home visits in your project; again, please send CMCD a final copy of your survey so the exact language you use can be tracked. For example, Los Angeles will use "asthma nurse" instead of "health educator."

A8. Did you receive home visits by a health educator?	1 ☐ Yes 2 ☐No 88 ☐Don't know 99 ☐ Refused

A9. How many times did she visit your home?	*Enter only one number [range 0-76]:* _____ 88 ☐Don't know 99 ☐ Refused 77 ☐ Did not receive home visit
A10. During a home visit, did the health educator ever talk with you about changes in your home to reduce triggers such as dust, pests, mold, or smoke?	1 ☐ Yes 2 ☐No 88 ☐Don't know 99 ☐ Refused 77 ☐ Did not receive home visit
A11. During a home visit, did the health educator ever help you make changes in your home to reduce triggers?	1 ☐ Yes 2 ☐No 88 ☐Don't know 99 ☐ Refused 77 ☐ Did not receive home visit

Question A12 asks if any *other* health care providers have visited the home to talk about asthma.

A12. In the past 12 months, has any <u>other</u> health care provider visited your home to talk with you about [child's name]'s asthma?

1 ☐ Yes

2 ☐ No

88 ☐ Don't know

99 ☐ Refused

> "HEALTH CARE PROVIDER" CAN BE A DOCTOR, NURSE, HEALTH EDUCATOR, COMMUNITY HEALTH WORKER, RESPIRATORY THERAPIST, MEDICAL TECHNICIAN, PHYSICIAN ASSISTANT, RECEPTIONIST AT CLINIC, ETC.

IF YES→A12a. Who was that person?

_____

_____

The intention of Question A13 is to ascertain if the parent or child has been exposed to any other asthma programs in the last year--in addition to what they've been exposed to as part of your program. Again, each site may modify the language used to describe the program so that parents understand. The parent may name components that are a part of your program, but the interviewer should record whatever the parent names. If the parent asks for clarification, the interviewer may say that the this question is asked to determine if the parent or child has been a part of other asthma programs beyond your program, and the interviewer may help the parent decide which component were part of your program.

A13. Of course, we know you've been part of the program for about the last year. Have you or your child participated in any *other* asthma programs in the last year?

     1 ☐ Yes
     2 ☐ No
    88 ☐ Don't know
    99 ☐ Refused

IF YES➔ A13a. Can you name or describe the program or programs?

_____

_____

Question A14 is designed to capture information, from the perpspective of the parent, on referrals given by the program's health educator. Again, each site may modify the language used to describe the program and the health educator. The interviewer should <u>not</u> remind the parent of referrals that the interviewer is aware of.

A14. **Since enrolling in this program one year ago [or say month and year], did the health educator recommend or refer you to any services? A few examples are services to help with housing needs or concerns, financial assistance, or to help someone stop smoking.**

     1 ☐ Yes
     2 ☐ No
    88 ☐ Don't know
    99 ☐ Refused

    ➔*IF YES:* WRITE IN THE SERVICE AND ASK THE FOLLOW-UP QUESTION IN COLUMN 2 FOR EACH SERVICE LISTED. ASK IF THEY RECEIVED ANY OTHER REFERRALS AND REPEAT UNTIL ALL REFERRALS ARE NOTED.

Service referred to:	Did you receive that service/assistance?
A14_1 Service 1	A14_1a 1 ☐ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 3 ☐ Other, specify: [A14_1a_oth] _____
A14_2 Service 2	A14_2a 1 ☐ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 3 ☐ Other, specify: [A14_2a_oth] _____
A14_3 Service 3	A14_3a 1 ☐ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 3 ☐ Other, specify: [A14_3a_oth] _____
A14_4 Service 4	A14_4a 1 ☐ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 3 ☐ Other, specify: [A14_4a_oth] _____
A14_5 Service 5	A14_5a 1 ☐ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 3 ☐ Other, specify: [A14_5a_oth] _____

B   Medicines

Section B contains several questions about asthma medicines and their use. Both here and throughout the survey instrument, the interviewer may choose to read the transition sentences if needed and appropriate.

Question B1 specifically asks about <u>prescription</u> medicines the child takes for asthma. Do not read options to the respondent; add more lines if the child takes more than six prescription medicines for asthma. If the caregiver says that the child does not take any prescription medicines for asthma, doesn't know, or refuses, then the interviewer marks the appropriate response and moves to Question B2.

If the respondent answers "inhaler," ask for the name of the inhaler. Additionally, the interviewer should probe for a specific drug name if a general name is given. The interviewer should not make judgment calls on what does or does not qualify as an asthma medication. If a respondent lists, for example, "Provigil" as a medication, the interviewer should record the response and the frequency of use. Likewise, the interviewer should not make judgment calls on what does or does not qualify as a prescription.

If the interview is taking place in the respondent's home, it is strongly recommended that the interviewers ask to see the medicines so that they can read and record the names. If the interview is over the phone, the interviewer should ask the respondent to get the medications so they can be sure to get the names right. If this is not possible and the caregiver does not know the names of the medicines, the interviewer should try to collect as much information as possible: interviewers can ask how many prescription medicines the child takes for asthma, and for each, ask the caregiver the mode of delivery (pill, syrup, pump, breathing machine, etc) and how frequently the child is supposed to take the medicine. The interviewer should record what information is collected; for example, if the caregiver does not know the name of the medicine and does not have it with her but says it is a white pill taken every day, the interviewer would write "white pill" in the B1.1 box, check "no" for B1.1a, and check "every day" for B1.1b.

The interviewer should make sure to indicate if they visually confirmed the name of the medicine. If the interviewer learns through visual inspection that the respondent misnamed the medicine, the interviewer should record the correct name. It is important to collect frequency information for each medication; for each medication, whether it is taken every day or as needed. This may require additional prompting on the part of the interviewer. If the caregiver indicates that the medicine is supposed to be taken more than once a day on a regular schedule, then the interviewer should record "every day." After recording the name, frequency, and whether the medicine was confirmed visually, the interviewer should ask, "are there any others?"

[INTERVIEWER READS TRANSITION SENTENCES IF NEEDED AND APPROPRIATE] **We would like to ask you a few questions about <u>prescription medicines</u> [*child's name*] may take for [*his/her*] asthma. These are medicines a doctor has prescribed or given for [*child's name*]'s asthma.**

B1. Please tell me the names of prescription medicines your child takes for asthma and whether each is supposed to be taken every day or as needed:

1 ☐ None [GO TO B2]
88 ☐ Don't know [GO TO B2]
99 ☐ Refused [GO TO B2]

Name of Medicine	Visually confirmed by interviewer?	**Is [*name of med*] supposed to be taken every day, or as needed?**
B1.1 Medicine 1	B1.1a 1 ☐ Yes 2 ☐ No	B1.1b 1 ☐ Every day 2 ☐ As needed 88 ☐ Don't know 99 ☐ Refused
B1.2 Medicine 2	B1.2a 1 ☐ Yes 2 ☐ No	B1.2b 1 ☐ Every day 2 ☐ As needed 88 ☐ Don't know 99 ☐ Refused

Question B2 asks about other, nonprescription medicines or home rememdies that the child takes for asthma. If the caregiver says that the child does not take any other medicines or remedies for asthma, then the interviewer should check the "no" box and move to Question B3.

If the caregiver says the child does take other medicines or remedies for asthma, then the interviewer should check "yes" and move to Question B2.1. As with Question B1, the interviewer should write the name of the medicine/remedy, whether s/he visually confirmed the medicine's or remedy's name, and frequency of use. The survey instrument allows for data collection on two nonprescription medicines or remedies, so if the respondent names more than two, the interviewer should only record the first two.

> ➔ **If yes: What is the name of the medicine?**
> **B2_1** Medicine 1_____
> **B2_1a** Visually confirmed by interviewer? Y   N
> **B2_1b** Is [*name of med*] supposed to be taken every day, or as needed?
>
> 1 ☐ Every day
> 2 ☐ As needed
> 88 ☐ Don't know
> 99 ☐ Refused
>
> **B2_2.** Medicine 2_____
> **B2_2a** Visually confirmed by interviewer? Y   N
> **B2_2b** Is [*name of med*] supposed to be taken every day, or as needed?
>
> 1 ☐ Every day
> 2 ☐ As needed
> 88 ☐ Don't know
> 99 ☐ Refused

Question B3 should be asked of the respondents who indicated that the child takes a prescription asthma medication that should be taken daily. If the respondent indicated that the child does not have a prescription medicine meant to be taken daily, then the interviewer should not read Question 3B. Instead, the interviewer should mark "does not apply" and then move on to Question B4. The interviewer should not read the information in brackets or the answer choices aloud. The answer to this question should be a number between 0 and 14, inclusive.

If the respondent indicates that the child missed their daily asthma medicine on one or more days, the interviewer should read Question B3a to determine the reason the medicine was not taken. The interviewer should not read the list of response options, but if the respondent has trouble understanding the question or describing the main reason, the interviewer may choose to provide a prompt by reading the first three response options as examples of common reasons why medicines might be missed. If the respondent gives several reasons why the medicine was missed, the interviewer should ask which reason they consider to be the *main* reason; only one response option should be checked. If the respondent indicates that the child did not miss their daily asthma medicine in the last two weeks (0 days), then the interviewer should select "Not applicable" as a response to Question B3a.

B3. For a lot of reasons, many people don't always take medicines the way their doctor tells them to. In the past 14 days, how many days has [*child's name*] not taken [*his/her*] daily asthma medicine?

_____ Days [range 0-14]

77 ☐ Does not apply [child does not take daily asthma medicines]

88 ☐ Don't know

99 ☐ Refused

    B3a. What was the main reason it was not taken? [DO NOT READ RESPONSE OPTIONS; CHECK ONLY ONE RESPONSE]

    1 ☐ Forgot

    2 ☐ Couldn't afford to buy medicine

    3 ☐ Worried about side effects

    4 ☐ Prescription ran out and didn't seek new one from health care provider

    5 ☐ Couldn't get medicine (i.e., no transportation to store, lost prescription)

    6 ☐ Does not think medicine is effective

    7 ☐ Child refused to take

    9 ☐ Not applicable

    8 ☐ Other, {B3a_t}_____

    88 ☐ Don't know

    99 ☐ Refused

Question B4 should be asked of all respondents, including those who did not indicate that the child takes a quick-relief or rescue medication for asthma. If the participant has trouble understanding the question, the interviewer can read the definition for quick-relief medicines provided on the survey. If the participant has trouble answering, 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." If the respondent says "0" or "none" or something similar and the interview is not sure if this is due to the fact that the child does not take rescue medication, then the interviewer should ask for clarification in order to determine whether to enter "0" or check "NA."

B4. During the past 14 days, how many days did [*child's name*] use [*his/her*] quick-relief or rescue medicine (by pump or machine) to help stop asthma symptoms like wheezing, shortness of breath, tightness in the chest, or cough?

> IF PARENT DOESN'T UNDERSTAND, GIVE THIS DEFINITION: "Quick-relief medicines, also called rescue medicines, relieve or stop asthma symptoms once they have started. A common quick-relief medicine is called Albuterol."
>
> A DAY IS A 24-HOUR PERIOD. MULTIPLE EPISODES IN 24 HOURS EQUALS ONE DAY.

_____ days [range 0-14]
77 ☐ Does not apply [child does not take rescue medicines]
88 ☐ Don't know
99 ☐ Refused

C   Symptoms and Functioning

Interviewers are strongly encouraged to read the transition statement at the start of Section C. It is important to orient respondents to the time period for the next three questions, and therefore the interviewer should state "the last four weeks" as well as the actual date one month prior to the current date.

For Questions C1, C2, and C3, the interviewer should not read 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 31, inclusive.

C1. During the last four weeks, how many days did [*child's name*] have any daytime asthma symptoms (like wheezing, shortness of breath, tightness in the chest, or cough)?

_____ days [range 0-31]
88 ☐ Don't know
99 ☐ Refused

> IF THE CHILD HAD MULTIPLE EPISODES DURING THE DAY, PLEASE COUNT THAT AS ONE (1) DAY.

C2. During the last four weeks, how many nights did [*child's name*] wake up during the night because of asthma?

_____ nights [range 0-31]
88 ☐ Don't know
99 ☐ Refused

> IF THE CHILD AWAKENED MORE THAN ONCE DURING THE SAME NIGHT, COUNT AS ONE (1) NIGHT.

C3. In the last four weeks, on how many days did [*child's name*] have to slow down or stop [*his/her*] play or activities because of asthma symptoms: shortness of breath, wheezing, tightness in the chest, or cough?

_____ days [range 0-31]
88 ☐ Don't know
99 ☐ Refused

> IF THE CHILD HAD TO SLOW DOWN OR STOP MULTIPLE TIMES IN THE SAME DAY, COUNT AS ONE (1) DAY.

Question C4 deals with school absences due to asthma. The question asks about a much longer time frame than the previous questions: the last 12 months. The interviewer may wish to point this out before asking the question by saying something like, "Now I'm going to be asking about a longer time period." Question C4 should be asked of all respondents, regardless of the age of the child. The interviewer should not read the answer choices aloud. Numerical answers to Question C4 should be between 0 and 365, inclusive. School not being in session is not a reason for missing school (e.g., Saturdays and Sundays should not be counted as absences). Realistically, answers should not be as high as 365, but interviewers should record the response given by the respondent. 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. If the respondent says the child is not in school/preschool/daycare, the interviewer should Select NA and proceed to Question C5.

C4. There are many reasons children sometimes stay home from school, preschool, or daycare. During the past twelve (12) months, how many days did [*child's name*] miss school, preschool or daycare due to <u>asthma</u>?

_____ days [range 0-365]
777 ☐ NA (child not in school, preschool, or daycare)
888 ☐ Don't know
999 ☐ Refused

Question C5 deals with caregivers' missed work. Question C5 should be asked of all respondents. The interviewer should not read the answer choices aloud. Numerical answers to Question C4 should be between 0 and 365, inclusive. If the respondent says that the parent or caregiver doe not work outside the home, the interviewer should select "NA."

C5. In the past 12 months, on how many days did you [or other caregivers] have to miss work to care for [*child's name*]'s asthma?

_____ days [range 0-365]
777 ☐ NA (parent or caregiver does not work outside the home)
888 ☐ Don't know
999 ☐ Refused

D   Health Care Utilization

Question D1 should be asked of all respondents. Interviewers should not read possible answer choices. Numerical answers to Questions D1, D2, and D3 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.

For Question D3, these times should be when the child has been admitted to the hospital, not kept overnight in the ER for observation. If the child was admitted once but stayed in the hospital for multiple consecutive nights, this should be counted as 1 time and reported as "1." If the child was admitted to the hospital one or more times in the last year, then the interviewer should ask Question D3a for each hospitalization. A partial day would be counted as one day; for example, if the child was admitted at 4 pm Tuesday and discharged 10 am Wednesday, the interviewer would record as two days.

D1. In the past twelve (12) months, how many times has [*child's name*] made unscheduled visits to the <u>doctor's office</u> or clinic for urgent asthma care?

_____ times [range 0-365]
888 ☐ Don't know
999 ☐ Refused

D2. In the past twelve (12) months, how many times has [*child's name*] been treated in the Emergency Department or ER for asthma?

_____ times [range 0-365]
888 ☐ Don't know
999 ☐ Refused

D3. In the past twelve (12) months, how many times has [*child's name*] been admitted to a hospital for asthma and had to stay overnight for one or more nights?
_____ times [range 0-365]
888 ☐ Don't know
999 ☐ Refused

    D3a. How many days was [*child's name*] in the hospital, for each time [*he/she*] was hospitalized?
        D3a_1 Hospitalization 1 _____days
          888 ☐ Don't know
          999 ☐ Refused
        D3a_2 Hospitalization 2 _____days
          888 ☐ Don't know
          999 ☐ Refused
        D3a_3 Hospitalization 3 _____days
          888 ☐ Don't know
          999 ☐ Refused
        D3a_4 Hospitalization 4 _____days
          888 ☐ Don't know
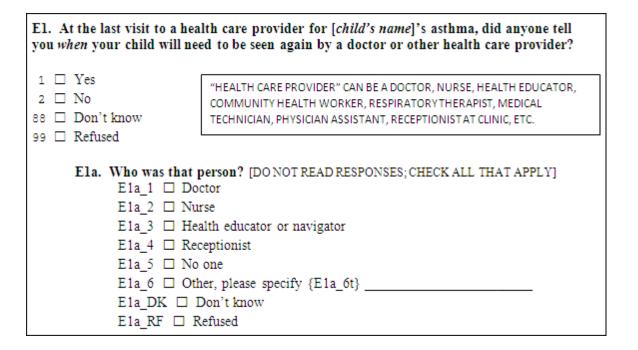   999 ☐ Refused

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E Care Coordination

The interviewer may choose to read the transition statement for section E.

For Question E1, the interviewer should read the question but not the answer choices. If the respondent seems unsure about the definition of "health care provider," the interviewer should read the definition given in the box.

The interviewer should ask Question E1a if the respondent answers "yes" to Question E1. The interviewer should not read the responses and should check all answers stated by the respondent. It is important that the respondent understands that "that person" refers to the person who told them when they needed to be seen again; the interviewer may add language to this effect if he or she suspects it may be unclear to the respondent.

If the respondent answered "no" to Question E1, the interviewer should not read Question E1a and should just mark "no one" and move on to the next question. If the respondent answered "don't know" to Question E1, the interviewer should not read Question E1a and should just mark "don't know" and move on to the next question. If the respondent refused to answer Question E1, the interviewer should not read Question E1a and should just mark "refused" and move on to the next question. If respondents are unsure who "that person" refers to in E1a, the interviewer may modify E1a to "who told you that?" or something similar. Questions E2 and E2a should be handled in the same manner as Questions E1 and E1a.

E1. At the last visit to a health care provider for [*child's name*]'s asthma, did anyone tell you *when* your child will need to be seen again by a doctor or other health care provider?

1 ☐ Yes
2 ☐ No
88 ☐ Don't know
99 ☐ Refused

> "HEALTH CARE PROVIDER" CAN BE A DOCTOR, NURSE, HEALTH EDUCATOR, COMMUNITY HEALTH WORKER, RESPIRATORY THERAPIST, MEDICAL TECHNICIAN, PHYSICIAN ASSISTANT, RECEPTIONIST AT CLINIC, ETC.

    E1a. Who was that person? [DO NOT READ RESPONSES; CHECK ALL THAT APPLY]
        E1a_1 ☐ Doctor
        E1a_2 ☐ Nurse
        E1a_3 ☐ Health educator or navigator
        E1a_4 ☐ Receptionist
        E1a_5 ☐ No one
        E1a_6 ☐ Other, please specify {E1a_6t} _____
        E1a_DK ☐ Don't know
        E1a_RF ☐ Refused

Question E3 should be asked of all participants, and answer choices should not be read aloud.

E3. Do [*child's name*]'s doctors or other health care providers communicate with [*his/her*] school, early intervention program, or child care providers?

1 ☐ Yes

2 ☐ No

77 ☐ Not applicable because child not in school / program / child care

88 ☐ Don't know

99 ☐ Refused

Question E3a should be handled in a manner consistent with Question E1a, as described above.

Questions E4, E4a, and E5 were removed in this follow-up version of the survey because these topics are covered in Section A.

Question E6 should be asked of all participants, and the examples in parenthesis should always be read. This is the first question in the survey that requires the interviewer to read aloud the first four answer choices [NONE OF THE TIME, A LITTLE OF THE TIME, MOST OF THE TIME, ALWAYS] before the respondent gives an answer. The interviewer should NOT read "don't know" and "refused." The interviewer may need to reread the statement if the respondent has trouble answering the question.

E6. During the past 12 months, did you get as much help as you wanted from a health care provider with coordinating [*child's name*]'s asthma care (e.g., scheduling visits, getting referrals, getting information, getting prescriptions, etc): [READ THE RESPONSES: NONE OF THE TIME, A LITTLE OF THE TIME, MOST OF THE TIME, ALWAYS]

1 ☐ None of the time   2 ☐ A little of the time   3 ☐ Most of the time   4 ☐ Always

88 ☐ Don't Know   99 ☐ Refused

Question E6a should be asked after the respondent answers Question E6. Question E6a should be asked of all respondents <u>except</u> those who answered "always" to Question E6. Interviewers should record the respondent's answer exactly as spoken (verbatim) unless it is very lengthy, in which case the interviewer should summarize the main points made by the respondent. If the respondent does not know how to answer, the interviewer should prompt the respondent by providing some examples. For example:

> *Respondent: I don't understand.*
> *Interviewer: Sometimes people want or need more help with things like scheduling visits or getting more information, referrals, or prescriptions. Do you want or need help in any areas like these?*

If the respondent says they do not know, the interviewer should record "DK" in the space provided. If the respondent refuses to answer, the interviewer should record "refused" in the space provided.

E6a. If not, what other help do you need?

Question E7 should be asked of all participants. The interviewer should read aloud the first four answer choices [NOT AT ALL, SOME, A LOT, COMPLETELY] before the respondent gives an answer. The interviewer should NOT read "don't know" and "refused." If the respondent says they don't understand the question or that they don't have goals, the interviewer should mark "don't know."

E7. How well have your goals for managing [*child's name*]'s asthma been met? [READ THE RESPONSES: NOT AT ALL, SOME, A LOT, COMPLETELY]
1 ☐ Not at all
2 ☐ Some
3 ☐ A lot
4 ☐ Completely
88 ☐ Don't know [DO NOT READ]
99 ☐ Refused [DO NOT READ]

The interviewer should read the instructions prior to Question E8. Questions E8 to E15 refer to experiences in the last 12 months, and all eight questions should be asked of all respondents. After reading each item, the interviewer should read aloud the first four answer choices [STRONGLY DISAGREE, DISAGREE, AGREE, STRONGLY AGREE] before the respondent gives an answer. The interviewer should NOT read "don't know" and "refused." If the respondent replies to Questions E9 or E11 stating that they never had to call or didn't receive asthma care in the last year, then the interviewer should record "don't know."

E8. If my child had difficulties because of asthma he/she could see a health care provider without any problem.

1 ☐ Strongly Disagree   2 ☐ Disagree   3 ☐ Agree   4 ☐ Strongly Agree
88 ☐ Don't Know   99 ☐ Refused

E9. It was easy to get my child's asthma care provider for asthma on the phone.

1 ☐ Strongly Disagree   2 ☐ Disagree   3 ☐ Agree   4 ☐ Strongly Agree
88 ☐ Don't Know   99 ☐ Refused

E10. My child's asthma problems were carefully explained to me by a health care provider.

1 ☐ Strongly Disagree   2 ☐ Disagree   3 ☐ Agree   4 ☐ Strongly Agree
88 ☐ Don't Know   99 ☐ Refused

E11. I trust the doctors, nurses and community health workers who gave my child care for asthma.

1 ☐ Strongly Disagree   2 ☐ Disagree   3 ☐ Agree   4 ☐ Strongly Agree
88 ☐ Don't Know   99 ☐ Refused

F   Asthma Action Plan

Questions F1 through F6 relate to a written asthma action plan. All six of these questions should be asked of <u>all</u> respondents, regardless of their answers to Question F1.

For Question F1, the interviewer may read the definition of an asthma action plan that appears on the survey. The interviewer may also add a reference such as "the form with the red, green, and yellow sections." 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.

F1. Do you have a written asthma action plan for [*child's name*]?

1 ☐ Yes
2 ☐ No
88 ☐ Don't know
99 ☐ Refused

> IF A DEFINITION OF AAP IS NEEDED: "An asthma action plan is a printed form that tells you when to increase medicine, when to take other medicine, when to call the doctor for advice, and when to go to the emergency room."

It is encouraged that Questions F2- F4 be asked of all respondents, including those who answer "no" to F1. However, if respondent answers "no" to F1 and the interviewer senses that asking Questions F2-F4 could damage the interviewer-respondent rapport, the interviewer may opt to not ask these questions and instead record the following answers: "no one" for F2; "No" for F3; and "Other, 'NA'" for F4. If the questions are asked, answer choices should not be read to the respondent. The interviewer should record all answers.

F2. Who gave the written asthma action plan to you? [CHECK ALL THAT APPLY]

F2_7 ☐ No one
F2_1 ☐ Doctor
F2_2 ☐ Nurse at clinic or doctor's office
F2_3 ☐ School nurse
F2_4 ☐ Community health worker or educator / navigator
F2_6 ☐ Other, specify {F2_6t}_____
F2_DK ☐ Don't know
F2_RF ☐ Refused

F3. Do you have a copy of the asthma action plan at home?

1 ☐ Yes
2 ☐ No
88 ☐ Don't know
99 ☐ Refused

For F4, the interviewer should check all that apply. If the respondent answers that no one has a copy of the action plan, the interviewer should record "other" and write in "no one."

F4. Who else has a copy of the action plan? [CHECK ALL THAT APPLY]

F4_7 ☐ No one
F4_1 ☐ Doctor
F4_2 ☐ Child's school or daycare
F4_3 ☐ Other family caretakers
F4_4 ☐ Other, please specify {F4_4t}_____
F4_DK ☐ Don't know
F4_RF ☐ Refused

Questions F5 and F6 should be asked of all respondents, including those who answer "no" to F1. Interviewers may opt to change "the written action plan" to "a written action plan." Both questions are about the last 12 months, and the interviewer should read aloud the answer choices (NONE OF THE TIME, A LITTLE OF THE TIME, MOST OF THE TIME, ALWAYS) after reading each question and before the respondent answers.

F5. In the past 12 months, when you saw a health care professional for [child's name]'s asthma care, how often did he or she discuss the written action plan with you? [READ THE RESPONSES: NONE OF THE TIME, A LITTLE OF THE TIME, MOST OF THE TIME, ALWAYS]

1 ☐ None of the time   2 ☐ A little of the time 3 ☐ Most of the time   4 ☐ Always
88 ☐ Don't Know   99 ☐ Refused

F6. In the past 12 months, how often did you use the written asthma action plan to decide what to do when there were changes in [*child's name*]'s asthma symptoms? [READ THE RESPONSES: NONE OF THE TIME, A LITTLE OF THE TIME, MOST OF THE TIME, ALWAYS]

1 ☐ None of the time   2 ☐ A little of the time 3 ☐ Most of the time   4 ☐ Always
88 ☐ Don't Know   99 ☐ Refused

Questions F7 through F12 are prefaced by instructions that the interviewer should read to the respondent. For each question, the interviewer should read aloud the answer choices (STRONGLY DISAGREE, DISAGREE, AGREE, STRONGLY AGREE) after reading each questions and before the respondent answers.

F7. I know the correct way for [*child's name*] to take [*his/her*] asthma medicines. Do you:

1 ☐ Strongly Disagree   2 ☐ Disagree   3 ☐ Agree   4 ☐ Strongly Agree
88 ☐ Don't Know   99 ☐ Refused

Note: Section G, demographic, was intentionally omitted in the follow-up survey.

H   Environmental Triggers

Section H is the final section of the survey. Typically, demographic questions are asked last, but environmental triggers were moved to the end so that sites that wanted to take advantage of the opportunity to provide education on environmental triggers could do so immediately after completing the survey when the questions are fresh in the respondents' minds. It is important to note, however, that education should not take place until <u>after</u> the survey is complete.

Question H1, about smoking, should be read to all respondents; the answer choices should not be read aloud.

Question H2 should be asked of all respondents regardless of their response to Question H1. The answer choices should <u>not</u> be read aloud. The interviewer should check <u>all that apply</u>. The answer choices are listed so that interviewers need not repeatedly write out the most common answers. Because there are so many options, it is strongly recommended that the interviewers become very familiar with the options prior to the interview. If the interviewer is unsure how to categorize an answer, the interviewer can select "other" and write the answer under "other." If the respondent is confused by the question, the interviewer may provide a few examples.

H1. Does anyone who lives in the same home as [*child's name*] smoke cigarettes, cigars, or pipes anywhere inside the home or in the car when [*child's name*] is there?

- 1 ☐ Yes
- 2 ☐ No
- 88 ☐ Don't know
- 99 ☐ Refused

H2. Sometimes families try to keep their child with asthma away from smoke. What have you done to reduce the amount of smoke your child is around? [DO NOT READ RESPONSES; CHECK ALL THAT APPLY]

- H2_1 ☐ Don't let anyone smoke around my child
- H2_2 ☐ Don't let anyone smoke in the car when child is in it
- H2_3 ☐ Don't let anyone smoke in the house
- H2_4 ☐ Don't let anyone smoke in the house when child is home
- H2_5 ☐ Don't let anyone smoke in child's bedroom
- H2_6 ☐ Don't let anyone smoke in child's bedroom and keep door closed
- H2_7 ☐ Ask friends and family members to smoke outside
- H2_8 ☐ Ask family members to smoke in a room where child does not usually spend time
- H2_9 ☐ Try to increase ventilation in the house by opening windows and/or doors
- H2_10 ☐ Don't sit in smoking sections of public places
- H2_11 ☐ Talked to people in homes or places where my child spends a lot of time about smoking is bad for asthma
- H2_12 ☐ Person(s) who smoke have enrolled in a program to stop smoking
- H2_13 ☐ Other
- {H2_13t}_____
  _____
  _____
- H2_DK ☐ Don't know
- H2_RF ☐ Refused

Question H3 should be asked of all respondents. The first four answer choices [A SEVERE PROBLEM, A MODERATE PROBLEM, A SMALL PROBLEM, OR NO PROBLEM AT ALL] should be read aloud after reading the question and before the respondent answers. The interviewer should only record one response.

H3. Problems with roaches are common in most cities. How much of a problem are roaches in your home? [READ FIRST FOUR RESPONSE OPTIONS]

- 1 ☐ A severe problem
- 2 ☐ A moderate problem
- 3 ☐ A small problem
- 4 ☐ No problem at all
- 88 ☐ Don't know [DO NOT READ]
- 99 ☐ Refused [DO NOT READ]

Question H4 should be asked of all respondents. If the respondent replies "yes," then the interviewers should record "yes" and then ask what the test showed and check either box 1.1 or 1.2. If respondent knows child was tested but cannot recall the results, check the "yes" box but leave 1.1 and 1.2 blank. If the test showed that roaches do not affect the child, then the interviewer will check "NA" for Question H5 and move on to Question H6.

H4. Has a medical professional tested [*child's name*] to see if roaches affect [*his/her*] asthma?

- 1 ☐ Yes→ what did the test show?   1.1 ☐ Affects child   1.2 ☐ Does not affect child
- 2 ☐ No
- 88 ☐ Don't know
- 99 ☐ Refused

DO NOT ASK H5; CHECK "NA" in H5

Question H5 is asked of all respondents except those who said that a medical test showed that roaches do not affect the child. If a professional test showed that roaches do not affect the child, the interviewer should not read H5; instead, the interview should check "NA" in H5 and move on to H6. As with Question H2, the answer choices should <u>not</u> be read aloud. The interviewer should check <u>all that apply</u>. The answer choices are listed so that interviewers need not repeatedly write out the most common answers. Because there are several options, it is strongly recommended that the interviewers become very familiar with the options prior to the interview. If the interviewer is unsure how to categorize an answer, the interviewer can select "other" and write the answer under "other." If the respondent is confused by the question, the interviewer may provide a few examples.

H5. **If your child is sensitive (allergic) to roaches, what have you done to get rid of roaches or keep roaches out of your home?** [DO NOT READ OPTIONS TO RESPONDENT] [CHECK ALL THAT APPLY]

H5_1 ☐ NA (not applicable because child not sensitive)
H5_2 ☐ Clean dirty dishes soon after using them
H5_3 ☐ Clean spilled food or liquids right way
H5_4 ☐ Store food in closed containers
H5_5 ☐ Keep trash in a closed container
H5_6 ☐ Remove trash from home every day
H5_7 ☐ Poison baits, gels, powders, paste, boric acid, traps
H5_8 ☐ Sprays
H5_9 ☐ Sprays—keep child away until odor goes away
H5_10 ☐ Other
{H5_10t}_____
_____
_____

H5_11 ☐ Nothing
H5_DK ☐ Don't know
H5_RF ☐ Refused

Question H7 is administered in a similar manner to Question H4. It is important to note that if the respondent says that a medical test showed that pet dander does not affect the child, the interviewer will still ask the *next* question (Question H8) but not Question H9; the interviewer will mark "NA" for Question H9 and move on to Question 10.

H7. Has a medical professional tested [*child's name*] to see if dander from furry or feathered animals affects [*his/her*] asthma?

1 ☐ Yes→ what did the test show?   1.1 ☐ Affects child   1.2 ☐ Does not affect child
2 ☐ No
88 ☐ Don't know
99 ☐ Refused

DO NOT ASK H9; CHECK "NA" in H9]

H8. Do you think that being around furry or feathered pets affects your child's asthma?

1 ☐ Yes
2 ☐ No
88 ☐ Don't know
99 ☐ Refused

If the response to Question H8 is "no," the interviewer should still read Question H9; if no actions were taken, the interviewer should mark "nothing" for H9. The interviewer should ask H9 if the response to H8 is "yes," "don't know," or "refused." As with Questions H2 and H5, the answer choices to Question H9 should not be read aloud. The interviewer should check all that apply. The answer choices are listed so that interviewers need not repeatedly write out the most common answers. Because there are several options, it is strongly recommended that the interviewers become very familiar with the options prior to the interview. If the interviewer is unsure how to categorize an answer, the interviewer can select "other" and write the answer under "other" in no more than a few phrases or sentences. If the respondent is confused by the question, the interviewer may provide a few examples.

H9. If your child is sensitive (allergic) to pets, what have you done to limit any possible affects pets may have on our child's asthma symptoms? [DO NOT READ OPTIONS TO RESPONDENT] [CHECK ALL THAT APPLY]

H9_1 ☐ NA (not applicable because child not sensitive)
H9_2 ☐ Got rid of pet
H9_3 ☐ Keep pet outside or don't allow pets in the home
H9_4 ☐ Keep pet off furniture with fabric
H9_5 ☐ Keep pet out of rooms with carpet and/or furniture with fabric
H9_6 ☐ Keep pet out of child's sleeping area
H9_7 ☐ Don't allow child near pets
H9_8 ☐ Have child wash hands after touching pet
H9_9 ☐ Other
{H9_9t}_____
_____
_____

H9_10 ☐ Nothing
H9_DK ☐ Don't know
H9_RF ☐ Refused

Question H10 should be asked of all respondents. The first four answer choices [A SEVERE PROBLEM, A MODERATE PROBLEM, A SMALL PROBLEM, OR NO PROBLEM AT ALL] should be read aloud after reading the question and before the respondent answers. The interviewer should only record one response.

H10. Mold and mildew sometimes grow in areas of a home that are often moist or wet. How much of a problem is mold or mildew in your home? [READ FIRST FOUR RESPONSE OPTIONS]

1 ☐ A severe problem

2 ☐ A moderate problem

3 ☐ A small problem

4 ☐ No problem at all

88 ☐ Don't know [DO NOT READ]

99 ☐ Refused [DO NOT READ]

Note that there is not a question about a medical test for the child's sensitivity to mold or mildew. Instead, Question 11 asks for the respondent's opinion. If the respondent replies "no," the respondent should not ask Question H12, mark "NA" for Question H12, and move on to Question H13. These instructions differ from other questions in this section.

As with Questions H2, H5, and H9, the answer choices to Question H12 should <u>not</u> be read aloud. The interviewer should check <u>all that apply</u>. The answer choices are listed so that interviewers need not repeatedly write out the most common answers. Because there are several options, it is strongly recommended that the interviewers become very familiar with the options prior to the interview. If the interviewer is unsure how to categorize an answer, the interviewer can select "other" and write the answer under "other." If the respondent is confused by the question, the interviewer may provide a few examples.

H11. Do you think that being around mold or mildew affects [*child's name*]'s asthma?

1 ☐ Yes
2 ☐ No ──────▶ | DO NOT ASK H12; CHECK "NA" in H12 |
88 ☐ Don't know
99 ☐ Refused

H12. If your child is sensitive (allergic) to mold or mildew, what have you done to prevent, reduce, or get rid of mold and mildew in your home?
[DO NOT READ OPTIONS TO RESPONDENT; CHECK ALL THAT APPLY]

H12_1 ☐ NA (not applicable because caregiver believes child not sensitive)
H12_2 ☐ Make sure bathroom is well ventilated (fan, window)
H12_3 ☐ Run a dehumidifier
H12_4 ☐ Fix any leaky faucets, pipes, or other sources of water
H12_5 ☐ Clean up any standing water
H12_6 ☐ Clean things with mold or mildew
H12_7 ☐ Get rid of moldy things
H12_8 ☐ Other
{H12_8t}_____
_____
_____

H12_9 ☐ Nothing
H12_DK ☐ Don't know
H12_RF ☐ Refused

Question H13 should be asked of all respondents. As with other questions in this section, if the respondent answers "yes," then the interviewer should ask "What did the test show?" and then mark either 1.1 or 1.2. If respondent knows child was tested but cannot recall the results, check the "yes" box but leave 1.1 and 1.2 blank. If the respondent says the test showed that dust mites do not affect the child, then the interviewer should not ask Question H15. Instead, the interviewer should check "NA" under Question H15. Note that Question H14 should be asked of all respondents.

H13. For many people with asthma, dust in a house can make their symptoms worse because of dust mites. Even dust that can't be seen can cause problems such as dust in carpets, stuffed animals, pillows, and mattresses. Has a doctor checked to see if dust mites are a problem for [*child's name*]'s asthma?

1 ☐ Yes→ what did the test show?   1.1 ☐ Affects child   1.2 ☐ Does not affect child

2 ☐ No

88 ☐ Don't know

99 ☐ Refused

> DO NOT ASK H15; CHECK "NA" in H15

H14. Do you think that being around dust affects [*his/her*] asthma?

1 ☐ Yes

2 ☐ No

88 ☐ Don't know

99 ☐ Refused

If the response to Question H14 is "no," the interviewer should still read Question H15; if no actions were taken, the interviewer should mark "nothing" for H15. As with several previous questions in this section, the answer choices to Question H15 should not be read aloud (see QH15 on next page). The interviewer should check all that apply. The answer choices are listed so that interviewers need not repeatedly write out the most common answers, and the common answers are grouped by category to help the interviewer locate the responses quickly. Because there are several options, it is strongly recommended that the interviewers become very familiar with the options prior to the interview. If the interviewer is unsure how to categorize an answer, the interviewer can select and write the answer under the "other" option. If the respondent is confused by the question, the interviewer may provide a few examples.

Question H16 is the final question of the survey. It is an open ended question. Interviewers should record the respondent's answer exactly as spoken (verbatim) unless it is very lengthy, in which case the interviewer should summarize the main points made by the respondent. CMCD will later code these responses.

H16. What other things do you do around the house to control your child's asthma?

H15. If your child is sensitive (allergic) to dust mites, what have you done, or do you do anything regularly, to reduce the dust in your home?
[DO NOT READ OPTIONS TO RESPONDENT] [CHECK ALL THAT APPLY]

H15_1 ☐ NA (not applicable because child not sensitive)

Covers
H15_2 ☐ Use pillow covers made to keep out dust mites
H15_3 ☐ Use mattress cover made to keep out dust mites
H15_4 ☐ Use box spring cover made to keep out dust mites

Washing in hot water
H15_5 ☐ Wash pillow weekly in hot water (130 degrees F or higher)
H15_6 ☐ Wash sheets and blankets weekly in hot water (130 degrees F or higher)
H15_7 ☐ Regularly wash rugs in hot water (130 degrees F or higher)
H15_8 ☐ Regularly wash curtains in hot water (130 degrees F or higher)
H15_9 ☐ Wash stuffed animals weekly in hot water (130 degrees F or higher)

Flooring type and cleaning
H15_10 ☐ Make sure child sleeps in room with bare hard floors (includes removing carpeting)
H15_11 ☐ Reduce amount of carpets or rugs in home
H15_12 ☐ Regularly vacuum carpet
H15_13 ☐ Use a vacuum with a HEPA filter or a double-layered bag
H15_14 ☐ Regularly mop floors

Other
H15_15 ☐ Keep stuffed animals out of child's sleeping area
H15_16 ☐ Don't let child lie on furniture with fabric (except beds)
H15_17 ☐ Keep furniture with fabric (except beds) out of the bedroom
H15_18 ☐ Vacuum drapes regularly
H15_19 ☐ Dust regularly (wiping, not scattering)
H15_20 ☐ Frequently change the filter on the furnace or air conditioning
H15_21 ☐ Other
{H15_21t}_____
_____
_____

H15_22 ☐ Nothing
H15_DK ☐ Don't know
H15_RF ☐ Refused

Appendix B: Codebook of Follow-up Parent/Caregiver Survey

Variable Name	Label	Valid Codes	Data Type	Notes
uniqueID	Site-assigned patient ID number		text	Should be unique for each patient
date1	Date of survey start		date	Entered as "03/17/2008"
date2	Date of survey completion		date	Entered as "03/25/2008"
method	Method of survey administration	1-3	numeric	
method_t	Method of "Other" survey administration		text	Only used if method=3
IXname	Interviewer name		text	
notes	Notes by interviewer		text	
A1	Asthma diagnosis	1,2,88,99	numeric	
A2	Last year received care in clinical setting	1,2,88,99	numeric	
A3	Last year received education in clinical setting	1,2,88,99	numeric	
A4	Last year received classroom education	1,2,88,99	numeric	
A5	Last year received asthma devices	1,2,88,99	numeric	
A6	Last year received trigger materials	1,2,88,99	numeric	
A7_1	Trigger material received – nothing	0,1	numeric	
A7_2	Trigger material received – pillow cover	0,1	numeric	
A7_3	Trigger material received – mattress cover	0,1	numeric	
A7_4	Trigger material received – caulk	0,1	numeric	
A7_5	Trigger material received – no smoking sign	0,1	numeric	
A7_6	Trigger material received – other	0,1	numeric	
A7_6t	Trigger material received – other specified		text	
A7_88	Trigger material received – don't know	0,1	numeric	
A7_99	Trigger material received – refused	0,1	numeric	
A8	Received home visit by health educator last year	1,2,88,99	numeric	
A9	Number of home visits last year	0-76,77,88,99	numeric	
A10	Discussed changes in home last year	1,2,77,88,99	numeric	
A11	Helped make changes in home last year	1,2,77,88,99	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
A12	Other health care provider made home visit last year	1,2,88,99	Numeric	
A12a	Other health care provider who visited home		text	
A13	Patricipated in other asthma programs last year	1,2,88,99	numeric	
A13a	Description of other asthma programs		text	
A14	Referred to services last year	1,2,88,99	numeric	
A14_1	Service 1 referred to last year		text	
A14_1a	If received service 1 last year	1,2,3,88,99	numeric	
A14_1a_oth	If received service 1 last year-other specified		text	
A14_2	Service 2 referred to last year		text	
A14_2a	If received service 2 last year	1,2,3,88,99	numeric	
A14_2a_oth	If received service 2 last year-other specified		text	
A14_3	Service 3 referred to last year		text	
A14_3a	If received service 3 last year	1,2,3,88,99	numeric	
A14_3a_oth	If received service 3 last year-other specified		text	
A14_4	Service 4 referred to last year		text	
A14_4a	If received service 4 last year	1,2,3,88,99	numeric	
A14_4a_oth	If received service 4 last year-other specified		text	
A14_5	Service 5 received last year		text	
A14_5a	If received service 5 last year	1,2,3,88,99	numeric	
A14_5a_oth	If received service 5 last year-other specified		text	
B1	Asthma prescription medicines taken	1,88,99	numeric	
B1_1	Name of medicine - 1		text	replaced B1.1 in order to remove the "."
B1_1a	Visual confirmation by interviewer	1,2	numeric	replaced B1.1a
B1_1b	When medicine is supposed to be taken	1,2,88,99	numeric	replaced B1.1b
B1_2	Name of medicine - 2		text	replaced B1.2
B1_2a	Visual confirmation by interviewer	1,2	numeric	replaced B1.2a
B1_2b	When medicine is supposed to be taken	1,2,88,99	numeric	replaced B1.2b

Variable Name	Label	Valid Codes	Data Type	Notes
B1_3	Name of medicine - 3		text	replaced B1.3
B1_3a	Visual confirmation by interviewer	1,2	numeric	replaced B1.3a
B1_3b	When medicine is supposed to be taken	1,2,88,99	numeric	replaced B1.3b
B1_4	Name of medicine - 4		text	replaced B1.4
B1_4a	Visual confirmation by interviewer	1,2	numeric	replaced B1.4a
B1_4b	When medicine is supposed to be taken	1,2,88,99	numeric	replaced B1.4b
B1_5	Name of medicine - 5		text	replaced B1.5
B1_5a	Visual confirmation by interviewer	1,2	numeric	replaced B1.5a
B1_5b	When medicine is supposed to be taken	1,2,88,99	numeric	replaced B1.5b
B1_6	Name of medicine - 6		text	replaced B1.6
B1_6a	Visual confirmation by interviewer	1,2	numeric	replaced B1.6a
B1_6b	When medicine is supposed to be taken	1,2,88,99	numeric	replaced B1.6b
B2	Use of asthma medications not prescribed	1,2,88,99	numeric	
B2_1	Name of non-prescribed medicine		text	replaced B2.1
B2_1a	Visual confirmation by interviewer	1,2		replaced B2.1a
B2_1b	When medicine is supposed to be taken	1,2,88,99		replaced B2.1b
B2_2	Name of non-prescribed medicine		text	replaced B2.2
B2_2a	Visual confirmation by interviewer	1,2		replaced B2.2a
B2_2b	When medicine is supposed to be taken	1,2,88,99		replaced B2.2b
B3	How many days has the child not taken daily asthma medicine	0-14,77,88,99	numeric	
B3a	Reason asthma medicine is not taken	1-9,88,99	numeric	
B3a_t	Reason asthma medicine is not taken-specified		text	Only used if QB3a=8
B4	Days child used quick relief/rescue medicine in past 14 days	0-14, 77,88,99	numeric	
C1	Days with daytime asthma symptoms in past 4 weeks	0-31,88,99	numeric	
C2	Nights with nighttime asthma symptoms in past 4 weeks	0-31,88,99	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
C3	Days child had to slow or stop activities due to asthma symptoms	0-31,88,99	numeric	
C4	School days child missed due to asthma	0-365,777, 888,999	numeric	
C5	Number of days caregiver missed work to care for child's asthma	0-365,777, 888,999	numeric	
D1	unscheduled visits to doctor due to severe asthma symptoms in past 12 months	0-365,888,999	numeric	
D2	Times treated in ER or ED for asthma symptoms in past 12 months	0-365,888,999	numeric	
D3	Times child stayed one or more nights in hospital due to asthma symptoms	0-365,888,999	numeric	
D3a_1	Number of days child was hospitalized 1	0-365,888,999	numeric	Replaced D3a.1 in order to remove the "."
D3a_2	Number of days child was hospitalized 2	0-365,888,999	numeric	Replaced D3a.2
D3a_3	Number of days child was hospitalized 3	0-365,888,999	numeric	Replaced D3a.3
D3a_4	Number of days child was hospitalized 4	0-365,888,999	numeric	Replaced D3a.4
E1	During last visit to provider did doctor say when to see a provider again	1,2,88,99	numeric	
E1a_1	Who was that person-Doctor	0,1	numeric	
E1a_2	Who was that person-Nurse	0,1	numeric	
E1a_3	Who was that person-Health educator or navigator	0,1	numeric	
E1a_4	Who was that person-Receptionist	0,1	numeric	
E1a_5	Who was that person-No one	0,1	numeric	
E1a_6	Who was that person-Other	0,1	numeric	
E1a_DK	Who was that person-Don't Know	0,1	numeric	
E1a_RF	Who was that person-Refused	0,1	numeric	
E1a_6t	Who was that person-specified		text	Only used if QE1a_6=1
E2	Last time child saw provider for asthma did person say why child needed to be seen again	1,2,88,99	numeric	
E2a_1	Who was that person-Doctor	0,1	numeric	
E2a_2	Who was that person-Nurse	0,1	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
E2a_3	Who was that person-Health educator or navigator	0,1	numeric	
E2a_4	Who was that person-Receptionist	0,1	numeric	
E2a_5	Who was that person-No one	0,1	numeric	
E2a_6	Who was that person-Other	0,1	numeric	
E2a_DK	Who was that person-Don't Know	0,1	numeric	
E2a_RF	Who was that person-Refused	0,1	numeric	
E2a_6t	Who was that person-specified		text	Only used if QE2a_6=1
E3	Do doctors communicate with child's school, early intervention program, or care providers	1,2,77,88,99	numeric	
E3a_1	Who was that person-Doctor	0,1	numeric	
E3a_2	Who was that person-Nurse	0,1	numeric	
E3a_3	Who was that person-Health educator or navigator	0,1	numeric	
E3a_4	Who was that person-Receptionist	0,1	numeric	
E3a_5	Who was that person-No one	0,1	numeric	
E3a_6	Who was that person-Other	0,1	numeric	
E3a_DK	Who was that person-Don't Know	0,1	numeric	
E3a_RF	Who was that person-Refused	0,1	numeric	
E3a_6t	Who was that person-specified		text	Only used if QE3a_6=1
E6	Satisfaction with provider help coordinating child's asthma care	1-4,88,99	numeric	
E6a	what other help is needed coordinating care		text	Only used if QE6=1,2, or 3
E7	How well have your goals for managing child's asthma been met	1-4,88,99	numeric	
E8	If child had asthma difficulties he/she could see a provider without any problem	1-4,88,99	numeric	
E9	It was easy to get child's asthma care provider for asthma on the phone	1-4,88,99	numeric	
E10	Child's asthma problems were carefully explained by a health care provider.	1-4,88,99	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
E11	Trust of doctors, nurses and community health workers who gave child asthma care	1-4,88,99	numeric	
E12	Child could see a specialist for asthma when he/she needed one	1-4,88,99	numeric	
E13	Child's different providers worked together and communicated regarding child's asthma.	1-4,88,99	numeric	
E14	Caregiver felt like an important part of the team that cares for child's asthma.	1-4,88,99	numeric	
E15	Caregiver satisfaction with the asthma care child got from providers in last 12 months.	1-4,88,99	numeric	
F1	Does caregiver have a written asthma action plan for child	1,2,88,99	numeric	
F2_1	Who gave the written asthma action plan to caregiver-Doctor	0,1	numeric	
F2_2	Who gave the written asthma action plan to caregiver-Nurse at clinic	0,1	numeric	
F2_3	Who gave the written asthma action plan to caregiver-School Nurse	0,1	numeric	
F2_4	Who gave the written asthma action plan to caregiver-Community Health Worker	0,1	numeric	
F2_6	Who gave the written asthma action plan to caregiver-Other	0,1	numeric	
F2_7	Who gave the written asthma action plan to caregiver-no one	0,1	numeric	
F2_DK	Who gave the written asthma action plan to caregiver-Don't Know	0,1	numeric	
F2_RF	Who gave the written asthma action plan to caregiver-Refused	0,1	numeric	
F2_6t	Who gave the written asthma action plan to caregiver-specified		text	Only used if QF2_6=1
F3	Do caregiver have a copy of the asthma action plan at home	1,2,88,99	numeric	
F4_1	Who else has a copy of the action plan-Doctor	0,1	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
F4_2	Who else has a copy of the action plan-School or Daycare	0,1	numeric	
F4_3	Who else has a copy of the action plan-family caretakers	0,1	numeric	
F4_4	Who else has a copy of the action plan-Other	0,1	numeric	
F4_DK	Who else has a copy of the action plan-Don't Know	0,1	numeric	
F4_RF	Who else has a copy of the action plan-Refused	0,1	numeric	
F4_4t	Who else has a copy of the action plan-specified		text	Only used if QF4_4=1
F5	When caregiver saw a provider for asthma care how often did provider discuss the action plan in past 12 months	1-4,88,99	numeric	
F6	How often did caregiver use the action plan when there where changes in child's asthma symptoms in past 12 months	1-4,88,99	numeric	
F7	caregiver knows the correct way for child to take their asthma medicines	1-4,88,99	numeric	
F8	caregiver knows which medicines to give my child during a serious breathing problem	1-4,88,99	numeric	
F9	Once child starts wheezing or coughing, caregiver can keep symptoms from getting worse	1-4,88,99	numeric	
F10	Caregiver knows when child's breathing problems are serious enough to go to the emergency room	1-4,88,99	numeric	
F11	Caregiver knows what things in the home may trigger asthma symptoms in child and how to remove or reduce those triggers	1-4,88,99	numeric	
F12	Caregiver can successfully manage child's asthma	1-4,88,99	numeric	
H1	Home resident smoking while child is there	1,2,88,99	numeric	
H2_1	Actions taken to reduce smoke around child-	0,1	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
	don't let anyone smoke around child			
H2_2	Actions taken to reduce smoke around child-don't let anyone smoke in car when child is in it	0,1	numeric	
H2_3	Actions taken to reduce smoke around child-don't let anyone smoke in house	0,1	numeric	
H2_4	Actions taken to reduce smoke around child-don't let anyone smoke in house when child is home	0,1	numeric	
H2_5	Actions taken to reduce smoke around child-don't let anyone smoke in child's bedroom	0,1	numeric	
H2_6	Actions taken to reduce smoke around child-don't let anyone smoke in child's bedroom and keep door closed	0,1	numeric	
H2_7	Actions taken to reduce smoke around child-ask friends and family to smoke outside	0,1	numeric	
H2_8	Actions taken to reduce smoke around child-ask family to smoke in room where child does not usually spend time	0,1	numeric	
H2_9	Actions taken to reduce smoke around child-try to increase ventilation in house by opening doors/windows	0,1	numeric	
H2_10	Actions taken to reduce smoke around child-don't sit in smoking sections of public places	0,1	numeric	
H2_11	Actions taken to reduce smoke around child-talked to people in homes or places where child spends a lot of time about smoking being bad for asthma	0,1	numeric	
H2_12	Actions taken to reduce smoke around child-person(s) who smoke have enrolled in a program to stop smoking	0,1	numeric	
H2_13	Actions taken to reduce smoke around child-other	0,1	numeric	
H2_DK	Actions taken to reduce smoke around child-Don't Know	0,1	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
H2_RF	Actions taken to reduce smoke around child-Refused	0,1	numeric	
H2_13t	Actions taken to reduce smoke around child-specified		text	Only used if QH2_13=1
H3	Problem of roaches in home	1-4,88,99	numeric	
H4	Has child been tested to see if roaches affect their asthma	1,1.1,1.2,2,88,99	numeric	Only use "1" if child was tested but respondent does not know or remember the test result
H5_1	Actions to get rid of roaches or keep roaches out of home-NA-child is not sensitive	0,1	numeric	
H5_2	Actions to get rid of roaches or keep roaches out of home-clean dirty dishes soon after using them	0,1	numeric	
H5_3	Actions to get rid of roaches or keep roaches out of home-clean spilled food or liquids right away	0,1	numeric	
H5_4	Actions to get rid of roaches or keep roaches out of home-store food in closed containers	0,1	numeric	
H5_5	Actions to get rid of roaches or keep roaches out of home-keep trash in a closed container	0,1	numeric	
H5_6	Actions to get rid of roaches or keep roaches out of home-remove trash from home everyday	0,1	numeric	
H5_7	Actions to get rid of roaches or keep roaches out of home-poison baits, gels, powders, paste, boric acid, traps	0,1	numeric	
H5_8	Actions to get rid of roaches or keep roaches out of home-sprays	0,1	numeric	
H5_9	Actions to get rid of roaches or keep roaches out of home-sprays-keep child away until odor goes away	0,1	numeric	
H5_10	Actions to get rid of roaches or keep roaches out of home-other	0,1	numeric	
H5_11	Actions to get rid of roaches or keep roaches out of home-nothing	0,1	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
H5_DK	Actions to get rid of roaches or keep roaches out of home-don't know	0,1	numeric	
H5_RF	Actions to get rid of roaches or keep roaches out of home-refused	0,1	numeric	
H5_10t	Actions to get rid of roaches or keep roaches out of home-specified		text	Only used if QH5_10=1
H6	Does family have furry or feathered pets	1,2,88,99	numeric	
H7	Has child been tested to see if animal dander affects their asthma	1,1.1,1.2,2,88,99	numeric	Only use "1" if child was tested but respondent does not know or remember the test result
H8	Does caregiver think furry or feathered pets affect child's asthma	1,2,88,99	numeric	
H9_1	Actions taken to limit possible pets affects on child's asthma symptoms-NA-child is not sensitive	0,1	numeric	
H9_2	Actions taken to limit possible pets affects on child's asthma symptoms-Got rid of pet	0,1	numeric	
H9_3	Actions taken to limit possible pets affects on child's asthma symptoms-keep pet outside or don't allow pets in the home	0,1	numeric	
H9_4	Actions taken to limit possible pets affects on child's asthma symptoms-keep pet off furniture with fabric	0,1	numeric	
H9_5	Actions taken to limit possible pets affects on child's asthma symptoms-keep pet out of rooms with carpet and/or furniture with fabric	0,1	numeric	
H9_6	Actions taken to limit possible pets affects on child's asthma symptoms-keep pet out of child's sleeping area	0,1	numeric	
H9_7	Actions taken to limit possible pets affects on child's asthma symptoms-don't allow child near pets	0,1	numeric	
H9_8	Actions taken to limit possible pets affects on child's asthma symptoms-have child wash hands after touching pet	0,1	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
H9_9	Actions taken to limit possible pets affects on child's asthma symptoms-other	0,1	numeric	
H9_10	Actions taken to limit possible pets affects on child's asthma symptoms-nothing	0,1	numeric	
H9_DK	Actions taken to limit possible pets affects on child's asthma symptoms-don't know	0,1	numeric	
H9_RF	Actions taken to limit possible pets affects on child's asthma symptoms-refused	0,1	numeric	
H9_9t	Actions taken to limit possible pets affects on child's asthma symptoms-specified		text	Only used if QH9_9=1
H10	Problem of mold or mildew in home	1-4,88,99	numeric	
H11	Does caregiver think being around mold or mildew affects child's asthma	1,2,88,99	numeric	
H12_1	Actions taken to prevent, reduce, or get rid of mold or mildew in home-NA-child is not sensitive	0,1	numeric	
H12_2	Actions taken to prevent, reduce, or get rid of mold or mildew in home-make sure bathroom is well ventilated	0,1	numeric	
H12_3	Actions taken to prevent, reduce, or get rid of mold or mildew in home-run a dehumidifier	0,1	numeric	
H12_4	Actions taken to prevent, reduce, or get rid of mold or mildew in home-fix any leaky faucets, pipes, or other sources of water	0,1	numeric	
H12_5	Actions taken to prevent, reduce, or get rid of mold or mildew in home-clean up any standing water	0,1	numeric	
H12_6	Actions taken to prevent, reduce, or get rid of mold or mildew in home-clean things with mold or mildew	0,1	numeric	
H12_7	Actions taken to prevent, reduce, or get rid of mold or mildew in home-get rid of moldy things	0,1	numeric	
H12_8	Actions taken to prevent, reduce, or get rid of	0,1	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
	mold or mildew in home-other			
H12_9	Actions taken to prevent, reduce, or get rid of mold or mildew in home-nothing	0,1	numeric	
H12_DK	Actions taken to prevent, reduce, or get rid of mold or mildew in home-Don't Know	0,1	numeric	
H12_RF	Actions taken to prevent, reduce, or get rid of mold or mildew in home-Refused	0,1	numeric	
H12_8t	Actions taken to prevent, reduce, or get rid of mold or mildew in home-specified		text	Only used if QH12_8=1
H13	Has a provider checked if dust mites are a problem for child's asthma	1,1.1,1.2,2,88,99	numeric	Only use "1" if child was tested but respondent does not know or remember the test result
H14	Does caregiver think being around dust affects child's asthma	1,2,88,99	numeric	
H15_1	Actions taken to reduce dust in home-NA-child is not sensitive	0,1	numeric	
H15_2	Actions taken to reduce dust in home-use pillow covers to keep out dust mites	0,1	numeric	
H15_3	Actions taken to reduce dust in home-use mattress cover made to keep out dust mites	0,1	numeric	
H15_4	Actions taken to reduce dust in home-use box spring cover to keep out dust mites	0,1	numeric	
H15_5	Actions taken to reduce dust in home-wash pillow weekly in hot water	0,1	numeric	
H15_6	Actions taken to reduce dust in home-wash sheets and blankets weekly in hot water	0,1	numeric	
H15_7	Actions taken to reduce dust in home-regularly wash rugs in hot water	0,1	numeric	
H15_8	Actions taken to reduce dust in home-regularly was curtains in hot water	0,1	numeric	
H15_9	Actions taken to reduce dust in home-wash stuffed animals weekly in hot water	0,1	numeric	
H15_10	Actions taken to reduce dust in home-make sure child sleeps in room with bare hard floors	0,1	numeric	

Variable Name	Label	Valid Codes	Data Type	Notes
H15_11	Actions taken to reduce dust in home-reduce amount of carpets or rugs in home	0,1	numeric	
H15_12	Actions taken to reduce dust in home-regularly vacuum carpet	0,1	numeric	
H15_13	Actions taken to reduce dust in home-use a vacuum with a HEPA filter or a double – layered bag	0,1	numeric	
H15_14	Actions taken to reduce dust in home-regularly mop floors	0,1	numeric	
H15_15	Actions taken to reduce dust in home-keep stuffed animals out of child's sleeping area	0,1	numeric	
H15_16	Actions taken to reduce dust in home-don't let child lie on furniture with fabric	0,1	numeric	
H15_17	Actions taken to reduce dust in home-keep furniture with fabric (except beds) out bedroom	0,1	numeric	
H15_18	Actions taken to reduce dust in home-vacuum drapes regularly	0,1	numeric	
H15_19	Actions taken to reduce dust in home-dust regularly	0,1	numeric	
H15_20	Actions taken to reduce dust in home-frequently change filter on the furnace or air conditioning	0,1	numeric	
H15_21	Actions taken to reduce dust in home-other	0,1	numeric	
H15_22	Actions taken to reduce dust in home-nothing	0,1	numeric	
H15_DK	Actions taken to reduce dust in home-don't know	0,1	numeric	
H15_RF	Actions taken to reduce dust in home-refused	0,1	numeric	
H15_21t	Actions taken to reduce dust in home-specified		text	Only used if QH15_21=1
H16	Other things done around the home to control child's asthma		text	

Appendix C. 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. This example only includes Section A of the survey.

NOTE: RESPONSE OPTIONS <u>ARE NOT READ</u> TO THE RESPONDENT UNLESS INDICATED AFTER THE QUESTION.

Parent/Caregiver 12 Month Follow-up Survey
MCAN Phase Two Cross-Site Evaluation

Interview information

Patient ID {uniqueID} _____EK584_____

Date administered, {date1} <u>0 3</u> / <u>1 0</u> / <u>2 0 1 2</u>
                       MM / DD/ Y Y Y Y

Date completed, {date2} __ __/__ __/__ __ __ __
(ONLY IF APPLICABLE)   M M / D D/ Y Y Y Y

> **IMPORTANT NOTE: RESPONSE OPTIONS <u>ARE NOT READ</u> TO THE RESPONDENT UNLESS INDICATED AFTER THE QUESTION. INTERVIEWER MAY PROMPT WITH EXAMPLE RESPONSE OPTIONS IF NEEDED.**

Survey Administration Method {method}:
1 ☒ Telephone
2 ☐ In-person by interviewer
3 ☐ Other, specify {method_t}_____

Interviewer name {IXname} __Rachel_____

<u>Notes</u> {notes}

Changes from baseline survey are:
- Removed items indicating recruitment method
- Added questions A2-A14
- Removed questions E4, E4A, and E5
- Added response option to F2 ("no one")
- Removed all demographic questions (Section G)

DIAGNOSIS, EXPOSURE TO PROGRAM COMPONENTS, & REFERRALS

Interviewer asks parent:

A1. Has a doctor or other medical professional diagnosed [*child's name*] with asthma?

1 ☒ Yes

2 ☐ No

88 ☐ Don't know

99 ☐ Refused

> IF ASTHMA DIAGNOSIS WAS CONFIRMED THROUGH MEDICAL RECORDS, INTERVIEWER MAY CHECK "YES" BOX INSTEAD OF ASKING THIS QUESTION.

Since enrolling in this program one year ago [*or say month and year*], we want to know what kinds of help for your child's asthma you or your child received as a part of this program. Did you or your child receive:

A2. Care for asthma from a doctor or nurse in a clinic, doctor's office, or Breathmobile?	1 ☒ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused
A3. Education about asthma while in the clinic/Breathmobile?	1 ☐ Yes 2 ☐ No 88 ☒ Don't know 99 ☐ Refused
A4. Education about asthma in school or the classroom?	1 ☒ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused
A5. Did you receive asthma devices such as a spacer or peak flow meter?	1 ☐ Yes 2 ☒ No 88 ☐ Don't know 99 ☐ Refused
A6. Did you receive materials for you to use to reduce asthma triggers in your home?	1 ☒ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused

A7. What did you receive?

A7_1   ☐ Did not receive anything for triggers

A7_2   ☒ Pillow cover

A7_3   ☒ Mattress cover

A7_4   ☐ Caulk

A7_5   ☐ No smoking sign

A7_6   ☐ Other, please specify

A7_6t   _____

A7_88   ☐ Don't know

A7_99   ☐ Refused

A8. Did you receive home visits by a health educator?	1 ☒ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused

A9. How many times did she visit your home?	*Enter only one number [range 0-76]:* _____4_____ 88 ☐ Don't know 99 ☐ Refused 77 ☐ Did not receive home visit
A10. During a home visit, did the health educator ever talk with you about changes in your home to reduce triggers such as dust, pests, mold, or smoke?	1 ☒ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 77 ☐ Did not receive home visit
A11. During a home visit, did the health educator ever help you make changes in your home to reduce triggers?	1 ☒ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 77 ☐ Did not receive home visit

A12. In the past 12 months, has any <u>other</u> health care provider visited your home to talk with you about [child's name]'s asthma?

    1 ☒ Yes

    2 ☐ No

  88 ☐ Don't know

  99 ☐ Refused

> "HEALTH CARE PROVIDER" CAN BE A DOCTOR, NURSE, HEALTH EDUCATOR, COMMUNITY HEALTH WORKER, RESPIRATORY THERAPIST, MEDICAL TECHNICIAN, PHYSICIAN ASSISTANT, RECEPTIONIST AT CLINIC, ETC.

    IF YES→A12a. Who was that person?

       _____doctor_____

       _____

A13. Of course, we know you've been part of the program for about the last year. Have you or your child participated in any *other* asthma programs in the last year?

    1 ☐ Yes

    2 ☒ No

  88 ☐ Don't know

  99 ☐ Refused

    IF YES→ A13a. Can you name or describe the program or programs?

NOTE: RESPONSE OPTIONS <u>ARE NOT READ</u> TO THE RESPONDENT UNLESS INDICATED AFTER THE QUESTION.

C-4

_____

_____

A14. Since enrolling in this program one year ago [or say month and year], did the health educator recommend or refer you to any services? A few examples are services to help with housing needs or concerns, financial assistance, or to help someone stop smoking.

    1 ☒ Yes
    2 ☐ No
  88 ☐ Don't know
  99 ☐ Refused

→*IF YES:* WRITE IN THE SERVICE AND ASK THE FOLLOW-UP QUESTION IN COLUMN 2 FOR EACH SERVICE LISTED. ASK IF THEY RECEIVED ANY OTHER REFERRALS AND REPEAT UNTIL ALL REFERRALS ARE NOTED.

Service referred to:	Did you receive that service/assistance?
A14_1 Service 1 Stop smoking program at health department	A14_1a 1 ☐ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 3 ☒ Other, specify: [A14_1a_oth] _attended one of five classes_____
A14_2 Service 2 Roach exterminator	A14_2a 1 ☒ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 3 ☐ Other, specify: [A14_2a_oth] _____
A14_3 Service 3	A14_3a 1 ☐ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 3 ☐ Other, specify: [A14_3a_oth] _____
A14_4 Service 4	A14_4a 1 ☐ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused 3 ☐ Other, specify: [A14_4a_oth] _____
A14_5 Service 5	A14_5a 1 ☐ Yes 2 ☐ No 88 ☐ Don't know 99 ☐ Refused

	3 □ Other, specify: [A14_5a_oth] _____

Coded Responses from Example

Note: The tables below are meant to demonstrate the correct codes only. Data sent to CMCD need to be formatted such that each variable name heads a column and each record is contained in a row.

Variable Name	Coded Response
uniqueID	EK584
date1	03/10/2012
date2	
method	1
method_t	
IXname	Rachel
notes	
A1	1
A2	1
A3	88
A4	1
A5	2
A6	1
A7_1	0
A7_2	1
A7_3	1
A7_4	0
A7_5	0
A7_6	0
A7_6t	
A7_7	0
A7_88	0
A7_99	0
A8	1
A9	4
A10	1
A11	1
A12	1
A12a	doctor

Variable Name	Coded Response
A13	2
A13a	
A14	1
A14_1	Stop smoking program at health department
A14_1a	3
A14_1a_oth	Attended one of 5 classes
A14_2	Roach exterminator
A14_2a	1
A14_2a_oth	
A14_3	
A14_3a	
A14_3a_oth	
A14_4	
A14_4a	
A14_4a_oth	
A14_5	
A14_5a	
A14_5a_oth	