

Project: ICICE

Document: Parent of Adolescent Patient Survey – Version 1 (*child age 12-17*)

Revised: 12/1/00

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ICICE Patient Interview

Parent of Adolescent with Asthma (12-17)



INTRODUCTION OF STUDY TO RESPONDENT

>intr<

Hello, my name is [FIRST AND LAST NAME]. May I speak with [R's NAME]?

I'm calling to follow up on a letter we sent you about research [FILL SITE NAME] and RAND are conducting on children with asthma. The letter was mailed on [DATE] and mentioned that an interviewer from RAND would be calling to request a telephone interview and to answer any questions you have about this study.

Do you remember getting the letter?

If Yes, go to >study<

If No, go to >nolet<

For respondents who don't remember getting letter:

>nolet<

The letter was from [fill SITE CO-SIGNER] of [fill SITE NAME] and Dr. Emmett Keeler, a researcher at RAND. The letter invited you to take part in research to improve the care of children who receive care for asthma from [fill SITE NAME]. The letter mentioned two telephone interviews and your child's health care records.

We are calling now to ask you to take part in the first telephone interview.

Of course participation in the study is voluntary. You can stop the interview or refuse to answer a question at any time. Your decision to take part will not affect the care your family gets from [fill SITE NAME] in any way. RAND will not give your child's doctors a copy of the answers you give in the interview. Any and all study results will be reported only at the group level. No individual person's information will be published separately in any report of results. The information we give to [fill SITE NAME], to help them improve the care they give to children with asthma will be limited to group summaries and statistics.

As a token of our thanks we will send you \$10 for taking part in this interview. With your permission, your answers to the interview will be combined with information from your child's health care records from [fill SITE NAME]. We have found that the additional information we can collect from your child's health care records is very valuable as it helps us to complete the picture of your child's health and the care (he/she) gets.

This screen is used to confirm that the listed adult is the person who knows most about the child's asthma

>proxy<

Before we begin, I just want to make sure the information we got from [fill SITE NAME] is correct. Their records list you as the person in your family who knows the most about [fill CHILD NAME] and (his/her) asthma. Is this right?

- 1 Yes, [fill R's NAME] is the right person to interview
- 2 No, someone else in family knows most about child's asthma (go to respondent identification screens)
- 3 R requests remail of letter before deciding to take part (Set call back and complete remail request slip)
4. R says child doesn't have asthma
5. R says child no longer lives at this address (Go to tracking screens)
- x Schedule a call back

Intro for respondents who have set callbacks before deciding

Hello, my name is [FIRST AND LAST NAME]. May I speak with [R's NAME]?

I'm calling about the research study on children with asthma. We had spoken with you a few weeks ago about talking to your child with asthma. We have some questions for (him/her) about what it is like to have asthma, and (his/her) daily activities. The interview will take about 20 minutes. Do we have permission to interview [fill CHILD NAME]?

- 1 Yes
- 2 No
- 3 R Never got copy of child interview (Set callback and notify supervisor)
- 4 R has still not decided

All respondents get this screen:

>study<

Our records indicate that your child [fill CHILD NAME] has asthma. Doctors sometimes call this wheezy bronchitis or trouble breathing. Your child's doctors may have used one of these names or a different name to describe your child's asthma. In our study interview we use the word asthma as the name of this condition. Is this a good time to start the interview?

IF NEEDED: Your name and contact information was given to RAND by [fill SITE NAME], because your child has had care for asthma.

IF NEEDED: The goal of this study is to find out about the services and treatment your child and other children in this study receive for asthma. The interview has questions about your child's asthma and the care (he/she) got from [fill SITE NAME] as well as questions about your child's daily activities, how your child's asthma affects your family, and some general questions about you. It should take less than 20 minutes.

IF NEEDED: The length of the interview varies depending on your child's asthma and your experiences with (his/her) healthcare. It can take less than 20 minutes.

IF NEEDED: We don't have to do the whole interview right now, we can go for a few minutes and then I can call you back at another time to complete the interview.

USE ADVANCE LETTERS AND QUESTION AND ANSWER SHEET TO ANSWER ANY QUESTIONS.

- 1 Continue with interview
- 2 R refuses to take part in study
- 3 R requests remail of letter before deciding to take part (Set call back and complete remail request slip)
- 4. R says child doesn't have asthma.
- 5. R says child no longer lives at this address. (Go to tracking screens)
- x Schedule a call back

For all respondents, who say child doesn't have sampled condition:

>noint <

We'll check our records again. Another interviewer may call you back in the next week or so to follow-up.

[CASE GOES TO SUPERVISOR FOR REVIEW AND VERIFICATION]

For all respondents, before any interview is started:

>inta <

Before we begin, I need to tell you that for the purposes of quality control, my supervisor may monitor this call.

AA. Child's Age and Gender

Please answer all the questions in this interview about [CHILD NAME], even if (he/she) is not your only child with asthma. Before we begin the interview, we need to confirm some information.

AA1. Is [CHILD'S NAME] a boy or a girl?

- 1 Boy 2 Girl

AA2. How old is (he/she)?

Enter Age: _____

Race, Ethnicity

AA3. How would you describe your child's race or ethnicity? Is your child:

- 1 Latino or Hispanic
- 2 White
- 3 Black or African-American
- 4 Asian or Pacific Islander
- 5 Another race or multiracial

A. Type and Duration of Asthma

REF: A1-A2: Adapted from RAND's ICICE Baseline Interview for Diabetes Patients[®]

I have some general questions about your child's asthma.

A1. Has a doctor ever told you that your child has asthma?

PROBE: Your child's doctor may have called this reactive airway disease, or wheezy bronchitis.

- 1 Yes → **Skip to A2**
- 5 No
- 3 Don't Know

A1a. We'll check our records again. Another interviewer may call you back in the next week or so to follow-up. INTERVIEWER: CODE CASE AS "PROBLEM"

A2. How long has (he/she) had asthma?

Enter number of years: _____ → **Skip to B1**

or, if "Don't know/Don't remember" → **ask A2a**

A2a. Has (he/she) had asthma for

- 1 Less than a year,
- 2 1 to 5 years, or
- 3 More than 5 years?

B. Adherence

B1. Some parents whose children have asthma do special things at home to help keep their child's asthma under control. For example, they put plastic covers over their child's mattress and pillow or they vacuum carpets more often. Has your child's doctor told you to do things like this to help control (his/her) asthma?

- 1 Yes, 5 No → **Skip to C1** d Don't Know → **Skip to C1**

B2. How many of the doctors' suggestions or recommendations have you been able to do?
Would you say:

- | | |
|--------|--------|
| 1 All | 3 Some |
| 2 Most | 4 None |

C. Knowledge

REF: All items adapted or taken directly from: National Asthma Education Program, Office of Prevention, Education, and Control, National Heart, Lung, and Blood Institute. Bethesda, MD: National Institutes of Health, Publication No. 91-3042, August 1991.

We want to know what you remember about asthma and the treatment of asthma. Tell me whether you think the following statements are true or false.

C1. Daily inhalers (like Vanceril or Flovent) are for quick relief of coughing or problems breathing.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

C2. Asthma attacks are not really harmful or dangerous.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

C3. Asthma attacks usually occur suddenly without warning.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

C4. Many different things can bring on an asthma attack.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

C5. Asthma cannot be cured, but it can be controlled.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

C6. People with asthma have no way to monitor how well their lungs are working.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

C7. Being around tobacco smoke can make a child's asthma worse.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

C8. Children with asthma should not exercise.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

C9. Avoiding things that cause allergic reactions (like animal hair or dust) is helpful in preventing asthma attacks.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

C10. Keeping a child calm will help keep a serious breathing problem from getting worse.

- | | |
|---------|--------------|
| 1 True | d Don't Know |
| 5 False | |

D. Impact on Family Functioning

REF: All items in this section are adapted from: Stein, R.E.K., Riessman, C.K. The development of an impact-on-family scale: Preliminary findings. *Medical Care* 18(4): 465-472 (1980).

I am going to read some statements that people have made about living with child who has asthma. For each statement, please tell me whether you disagree or agree.

D1. People in the neighborhood treat us special because of my child's illness. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D2. We have little desire to go out because of my child's illness. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D3. We see family and friends less because of my child's illness. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D4. Our family gives up things because of my child's illness. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D5. I don't have much time left for other family members after caring for my child with asthma. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D6. Nobody understands the burden I carry. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D7. Traveling to see the doctor is a strain on me. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D8. Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D9. I live from day-to-day and don't plan for the future. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D10. Learning to manage my child's illness has made me feel better about myself. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

D11. Because of what we have shared we are a closer family. Do you:

- | | |
|---------------------|------------------|
| 1 Strongly disagree | 3 Agree |
| 2 Disagree | 4 Strongly Agree |

E. Patterns of Service Use

REF: E1-E3: Adapted from RAND's ICICE Baseline Interview for Diabetes Patients®

I'm going to read you a list of health providers your child might have seen.

E1. Has your child ever seen an asthma specialist like a pulmonologist, or an allergy specialist?

- | | | |
|-------|--------------|--------------|
| 1 Yes | d Don't Know | → Skip to E3 |
| 5 No | | |

E2. Was that visit in the last six months?

- | | |
|-------|--------------|
| 1 Yes | d Don't Know |
| 5 No | |

E3. Did your child see an asthma educator in the past 6 months?

DEFINITION: An asthma educator is a health provider who teaches you and your child how to take medications, avoid asthma triggers, and tells you what to do to keep your child's asthma under control. An asthma educator often follows up with you to make sure you remember how to do these things after being taught.

- | | |
|-------|--------------|
| 1 Yes | d Don't Know |
| 5 No | |

E4. Has your child's doctor ever explained any of the possible side effects of your child's asthma medications?

- | | | |
|-------|--------------|--------------|
| 1 Yes | d Don't Know | → Skip to F1 |
| 5 No | | |

E5. Did your child's doctor answer none, some, most, or all of your questions about side effects from your child's asthma medications?

- | | |
|--------|--------|
| 1 None | 3 Most |
| 2 Some | 4 All |

F. Education

REF: Adapted from RAND's ICICE Diabetes Questionnaire. Content based on information obtained from: Practical Guide for the Diagnosis and Management of Asthma; Based on the Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma. U.S. Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute. NIH Publication No. 97-4053; October 1997

These next questions are about materials or programs you may have received or taken part in during the past 6 months.

F1. (In the past 6 months) did you get any materials, like a newsletter, magazine, pamphlet, or videotape about asthma?

- | | |
|-------|------|
| 1 Yes | 5 No |
|-------|------|

- F2. In the past 6 months did you get any one-on-one educational or counseling sessions on caring for your child's asthma?
 1 Yes 5 No
- F3. In the past 6 months did you or your child attend any group classes to learn more about asthma?
 1 Yes 5 No
- F4. In the past 6 months did any of your child's asthma care providers go over with you and your child how to use a peak flow meter?
 1 Yes 5 No
- F5. In the past 6 months did your child's asthma care providers go over with you how to help your child properly use (his/her) asthma medications?
 1 Yes 5 No
- F6. (In the past 6 months) did you get any information about asthma from the internet or visit a web site about asthma?
 1 Yes 5 No

G. Chronic Conditions

REF: Adapted from RAND's ICICE Baseline Interview for Diabetes Patients®

Now I would like to ask you about other health conditions your child may have.

- G1. Does your child have diabetes?
 PROBE: Has a doctor ever told you that your child has diabetes?
 1 Yes 5 No → **Skip to G2**
- G1a. Does your child receive treatment for it?
 1 Yes 5 No
- G1b. Does it limit your child's activities?
 1 Yes 5 No
- G2. Does your child have chronic lung disease other than asthma?
 DEFINITION: Chronic lung diseases include lung disease your child has because he or she was born early, cystic fibrosis or any other lung disease a doctor has told you that your child has.
 1 Yes 5 No → **Skip to G3**
- G2a. Does your child receive treatment for it?
 1 Yes 5 No
- G2b. Does it limit your child's activities?
 1 Yes 5 No

H3. In the last 6 months, were you advised to quit smoking by your child's doctor?

- 1 Yes
- 5 No
- n I did not see my child's doctor in the past 6 months.

H4. Does anyone else who lives with (CHILD NAME) smoke or use tobacco?

- 1 Yes
- 5 No
- d Don't Know

Age and Gender

REF: H5 – END, except for H11, H25, H26, and H32, are adapted or taken directly from RAND's ICICE Baseline Interview for Diabetes Patients®

H11, H25, H26, and H32 are new items created for this survey.

H5. What is your age now? Stop me when I get to the right category.

- | | |
|------------|---------------|
| 1 18 to 24 | 5 55 to 64 |
| 2 25 to 34 | 6 65 to 74 |
| 3 35 to 44 | 7 75 or older |
| 4 45 to 54 | |

H6. INTERVIEWER, ASK ONLY IF NECESSARY: Just so I can be sure, are you male or female?

- | | |
|--------|----------|
| 1 Male | 2 Female |
|--------|----------|

Education

H7. What is the highest grade or level of school that you have completed?

PROBE: Did you graduate with a diploma or degree?

INTERVIEWER: Code Trade School or Technical School as "Some College or 2-Year Degree"

- 1 8th Grade or less
- 2 Some High School, but did not graduate
- 3 High School graduate or GED
- 4 Some College or 2-Year Degree
- 5 4-Year College graduate
- 6 More than 4-Year College Degree

Health Insurance

H8. Does (CHILD NAME) have any kind of health insurance, or is (CHILD NAME) enrolled in any kind of program that helps to pay for (his/her) health care?

- | | |
|-------|---------------------------|
| 1 Yes | 5 No → Skip to H12 |
|-------|---------------------------|

H9. Does (CHILD NAME) belong to a health maintenance organization or HMO?

- | | |
|-------|------|
| 1 Yes | 5 No |
|-------|------|

H10. Does (CHILD NAME)'s insurance plan or program allow (him/her) to go to any doctor you want or does it require you to choose from a group or list of doctors?

- 1 Any doctor
- 2 Select from group or list
- d Don't Know

H11. Does (CHILD NAME)'s insurance plan or program pay all, part or none of the cost for:

	<u>All</u>	<u>Part</u>	<u>None</u>	<u>Don't Know</u>
a. Prescription medicine?	1	2	3	d
b. Peak Flow Meters?	1	2	3	d
c. Aerochambers (Spacers)?	1	2	3	d

DEFINITION: This is a tube you attach to your inhaler. You spray the medicine into the tube and then breath into through the tube.)

d. Renting or buying a nebulizer?.....	1	2	3	d
--	---	---	---	---

DEFINITION: A nebulizer is a machine that uses a liquid form of medicine (Albuterol for example) and turns it into a mist to help you breathe in through a mask or a tube.

H12. On average, how much do you spend out of your own pocket each month on (CHILD NAME)'s prescription medicines? Is it:

- | | |
|------------------------|--------------------------|
| 0 Nothing | 3 \$51 to \$100 dollars |
| 1 Less than \$20 | 4 \$101 to \$150 dollars |
| 2 \$20 to \$50 dollars | 5 More than \$150 |

H13. In the last 6 months, has (CHILD NAME) ever had to go without health care or medicine that (he/she) needed because you needed the money for food, clothing, housing, etc.?

- 1 Yes
- 5 No

Utilization

H14. Is (FILL PILOT OR CONTROL CARE LOCATION) the place your child goes most often for care related to asthma?

- 1 Yes → **Skip to H16**
- 5 No

H15. What is the name of the place your child goes to most often for care related to asthma?

Enter Place Name (Allow 50): _____ **Skip to H17**

IF H20 ≥ 3 (All Others Skip to H24)

H22. Now the stay before that one – how many nights was it?

Enter Number: _____ (acceptable range is 0-50 nights)

IF H20 ≥ 4 (All Others Skip to G24)

H23. Now the stay before that one – how many nights was it?

Enter Number: _____ (acceptable range is 0-50 nights)

H24. Think about all the doctor's offices and clinics (CHILD NAME) visited for health care in the last 6 months. In total, about how many visits has (he/she) made? (Your best estimate is fine.) Was it:

PROBE: Include all of your child's health care in your answer, not just care related to asthma.

- | | |
|-----------------|----------------------|
| 0 None | 2 4 to 6 |
| 1 1 to 3 visits | 3 More than 6 visits |

H25. During the last month, how many days did your child's health keep (him/her) out of school or day care all or most of the day?

Enter Days _____ (0-31)

H26. During the last month, how many days did your child's health keep (him/her) from taking part in after-school sports or physical education in school?

Enter Days _____ (0-31)

Language

H27. What language do you usually speak at home?

- 1 English → **Skip to H29**
- 2 Spanish
- 3 Other (Specify) _____

H28. In the last 6 months, how often did you have a problem communicating with your child's doctor or nurse because of language differences? Was it:

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

Marital Status and Household Composition

H29. At this time, are you married or living with a partner?

- | | |
|-------|------|
| 1 Yes | 5 No |
|-------|------|

H30. What is your current living arrangement? Right now, are you living . . .

(Code all that apply)

- 0 Alone
- 1 With your spouse or partner
- 2 With your children or others who are related to you
- 3 With others who are not related to you

What is your correct address? ENTER CORRECTIONS OR NEW ADDRESS

STREET ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

The phone number I have for you is: _____

Is this correct?

1 No
5 Yes

What is your correct phone number? _____

We would like to interview you again by phone about 12 months from now in order to find out about changes in your child's health and to ask about the care he/she receives over the next 12 months. Even if you agree to a follow-up interview now, you can change your mind when we call you next year.

Do we have your permission to call you back about 12 months from now?

1 No
5 Yes

In case we have trouble reaching you next year when we do our follow-up interview we'd like you to give us information we can use to locate you.

Do you expect to move any time between now and [MONTH 12 MONTHS FROM NOW]?

1 No
5 Yes

Do you know the address you will be moving to?

INTERVIEWER: ENTER AS MUCH INFORMATION AS R CAN GIVE YOU NOW.

STREET ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

PHONE: _____

We'd like to have the name of a friend or relative who always knows how to reach you. We would only contact this person if we are unable to reach you by mail or phone next year for the follow-up interview. Is there a friend or relative that you always keep in close contact with (other than your husband/wife)?

- 1 No
- 5 Yes

What is his or her name and address?

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

PHONE: _____

What is your relationship to [fill from above]?

- 1 Friend
- 2 Daughter/Son
- 3 Sister/Brother
- 4 Grandchild
- 5 Other Relative
- 6 Other

We respect your decision. To help the researchers in this study, would you mind telling me the main reason you don't want to do the follow-up interview?

ENTER MAIN REASON VERBATIM @

You may remember that the letter from [FILL SITE CO-SIGNER] of [SITE] and Dr. Emmett Keeler of RAND said that we would like to combine your answers to the interview with a review of your child's health care records at [SITE]. Your child's health care records include his/her medical charts, and any information [SITE] may have about the cost of his/her care, pharmacy use, tests and procedures, as well as general administrative data.

I'm asking for your permission to have a member of our study team look at your health care records at [SITE] to collect information RAND researchers can use to get the full picture of your child's care for asthma. Your decision is voluntary and will not affect the care your child gets from [SITE]. Do you give your OK for our study staff to look at your child's [SITE] health care records?

IF NEEDED: Any and all information that can be used to identify your child will be kept confidential. Your interview answers and his/her health care record data will be used only for the

purposes of this study. RAND will not release your child's information to anyone without your prior consent, except as required by law.

IF NEEDED: RAND will give [SITE] name a report that combines your child's information with the information we get from other patients treated there. All information will be reported as group summaries and other group statistics. No individual patient information will be given to your doctors or anyone else at [SITE].

- 1 Yes, can look at health care record
- 2 No, refused health care record
- 3 Undecided at this time

If more than one child in the household use >check< to verify and ask:

We also would like to interview you about [Fill CHILD NAME]. The questions are similar and the interview will take less than 20 minutes.

- 1 Continue with interview
- 2 R refuses to take part in study
- 3 R requests remail of letter before deciding to take part (Set call back and complete remail request slip)
6. R says child doesn't have asthma.
7. R says child no longer lives at this address. (Go to tracking screens)
- x Schedule a call back.

If the child is age 12-17, the following screen is used to collect the parent's permission to interview the child. Current plan is to collect consent after the parent completes his/her interview.

We'd like to talk with [fill CHILD NAME] too. We have some questions for (him/her) about what it is like to have asthma, what doctors and other care providers have told (him/her) about asthma, and (his/her) daily activities. The interview will take about 20 minutes.

Do we have your permission to interview [fill CHILD NAME]?

- 1 Yes
- 2 No
- 3 R requests copy of child interview before deciding (Set call back and complete special mail request slip)
- 4 R wants to talk with child/family before deciding (Set call back)

>nopanel2<

We respect your decision. To help the researchers in this study, would you mind telling me the main reason you don't want to do the follow-up interview?

ENTER MAIN REASON VERBATIM

That's all of the questions I have for you today. You should receive your \$10 check in the next 4 weeks. We'll send you a letter to remind you about the follow-up interview. Thank you for your help.