

**Project: ICICE**

**Document: Adolescent Patient Survey – Version 1** (*patients age 12-17*)

**Revised: 2/27/01**

**Revised by: SRG and RITA MANGIONE-SMITH**

# **ICICE Patient Interview For Adolescent Asthma Patients Ages 12-17**



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05/21/2001

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INTRODUCTION OF STUDY TO RESPONDENT  
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Hello, my name is [FIRST AND LAST NAME]. Is this [CHILD'S NAME] I'm speaking with?

I work for a survey research center at a place called RAND in California. We're doing a study of young people from all over the United States who have asthma. We'd like to learn more about how your asthma is affecting you and how your doctor might be able to care for your asthma even better than he or she already does.

I just finished asking your (mom/dad/other guardian) some questions about your asthma. If you wouldn't mind, I'd like to spend a few minutes talking with you about your asthma. I'd like to ask you some questions about how you care for your asthma and how it affects you day-to-day. It would add a lot to what we can learn about teens with asthma and the care they get for it if we can combine what you tell us with the information your (mom/dad/other guardian) already gave us.

Of course the decision to take part or not is completely up to you. We can stop talking whenever you want or you can refuse to answer a question at any time. Talking to me about your asthma will not change the way your doctor treats you at all. We will keep your answers secret from your doctor. When we tell doctors and other people what we find out from doing this study, we will only tell them about the results for all young people as a group. We would never report anything about just you. If you decide to take part, we would like to send you a \$10 gift certificate to thank you for helping us with this study. Would it be OK with you if I ask you some questions about your asthma now?

**For all respondents, who say they don't have sampled condition:**

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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]

**B. Adherence**

B0. Do you have a peak flow meter at home?

DEFINITION: This is where you blow air as hard as you can into a tube that measures how bad your asthma is by giving you a number, like 150 or 200.

- 1 Yes
- 5 No → Skip to B3

B1. Do you check your peak flows at home?

DEFINITION: This is where you blow air as hard as you can into a tube that measures how bad your asthma is by giving you a number, like 150 or 200.

- 1 Yes
- 5 No → Skip to B3

- B2. During the last 4 weeks, how often did you check your peak flows at home? Was it:
- 1 Never
  - 2 Less than once a week
  - 3 A few times per week
  - 4 Once a day, or
  - 5 Twice a day or more?
- B3. Some people with asthma take daily, inhaled medications to help keep their asthma under control. For example, they use a long-acting inhaler like Vanceril or Beclovent. Is this something your doctor has prescribed for you?

DEFINITION: A long-acting inhaler contains longer-lasting asthma medicine that you “puff” or inhale. This type of medicine helps to keep you from having breathing problems or asthma attacks before they start and is often used on a daily basis.

INTERVIEWER: IF R MENTIONS CORTISONE INHALER, SAY: “Think of your cortisone inhaler as you answer these next few questions.”

- 1 Yes
  - 5 No → **Skip to C1**
  - 3 Not Sure
- B4. I need to know which kind of long-acting inhaler your doctor prescribed. Can you tell me what color it is? (I can wait while you go get it.)
- 1 Name or colors match long-acting inhalers on sheet
  - 2 Name or colors match fast-acting inhalers on sheet
  - 3 Name or colors do not match any inhaler on sheet

(Enter Name/Colors: \_\_\_\_\_ )

**LONG-ACTING INHALERS TO BE COUNTED IN B4:**

COLOR	MEDICATION NAME
GRAY WITH A PURPLE CAP	AEROBID (ARROW-BID)
LIGHT GREEN WITH A DARK GREEN CAP	AEROBID (ARROW-BID)
WHITE WITH WHITE CAP	AZMACORT (ASTHMA-COURT)
TAN WITH A BROWN CAP	BECLOVENT (BECK-LOW-VENT)
DARK ORANGE WITH A LIGHT ORANGE CAP.	FLOVENT (FLOW-VENT)
WHITE AND BROWN TUBE	PULMICORT (PUHL-MIH-COURT)
PINK WITH A PURPLE CAP	VANCERILL (VAN-SIR-ILL)

COLOR	MEDICATION NAME
WHITE WITH WHITE CAP	ALBUTEROL (AL-BEW-TER-ALL)
LIGHT BLUE WITH DARK BLUE CAP	ALBUTEROL (AL-BEW-TER-ALL) OR VENTOLIN (VEN-TOE-LIN)
CLEAR WITH BLUE CAP	ALUPENT (AL-YOU-PENT)
WHITE WITH BLUE CAP	ALUPENT (AL-YOU-PENT) OR INTAL (IN-TALL)
CLEAR WITH GREEN CAP	ATROVENT (AT-ROW-VENT)
WHITE WITH GREEN CAP	ATROVENT (AT-ROW-VENT)
YELLOW WITH AN ORANGE CAP	PROVENTILL (PRO-VENT-ILL)
WHITE WITH GREEN LETTERS ON TUBE AND CAP	TILADE (TIE-LADE)

B5. Over the last 4 weeks, how often were you able to use your inhalers the way your doctor or nurse told you to? Was it:

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

### C. Self-Efficacy and Perceived Control

**REF: Adapted from: Katz PP, Yelin EH, Smith S, Blanc PD. Perceived Control of Asthma: Development and Validation of a Questionnaire. *American Journal of Respiratory Critical Care Medicine* Feb. 1997; 155(2):577-82.**

I'm going to read you some statements about you and your asthma. For each one, tell me how much you disagree or agree with the statement.

C1. If I do all the right things, I can control my asthma. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

**REF: C2 through C9: Adapted from: Bursch, B., Schwankovsky, L., Gilbert, J., Zeiger, R. Construction and Validation of Four Childhood Asthma Self-Management Scales: Parent Barriers, Child and Parent Self-Efficacy, and Parent Belief in Treatment Efficacy. *Journal of Asthma* 1999; 36(1):115-128.**

C2. I know the right way to take my asthma medications. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

C3. I know how to stop myself from having a serious breathing problem. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

C4. It is hard to avoid things I am allergic to. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

C5. It is hard to ask someone who is smoking near me to stop. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

C6. I know when my breathing problems are serious enough to go to the emergency room. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

C7. Once I start wheezing and coughing it is hard for me to keep my symptoms from getting worse. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

C8. It's hard for me to stay calm when I'm having a serious breathing problem. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

C9. I know which inhalers to use when I'm having a serious breathing problem. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

C10. Sometimes I don't take my asthma medicine because I worry about side effects. Do you:  
DEFINITION OF SIDE EFFECTS: Medicines that help your asthma can sometimes cause things like stomach aches, headaches, or make you sleepy.

- 1 Disagree
- 2 Agree
- 3 Are you not sure

#### D. 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.**

I'd like to find out about how much you know about asthma and treatment of asthma.

D1. Long-acting inhalers (like Vanceril or Flovent) are for quick relief of coughing or problems breathing. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

D2. Asthma attacks are not really harmful or dangerous. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

D3. Asthma attacks usually occur suddenly without warning. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

D4. Many different things can bring on an asthma attack. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

D5. Asthma cannot be cured, but it can be controlled. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

D6. People with asthma cannot monitor how well their lungs are working. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

D7. Smoking or being around someone who is smoking can make asthma worse. Do you:

- 1 Disagree
- 2 Agree
- 3 Are you not sure

- D8. People with asthma should not exercise. Do you:
- 1 Disagree
  - 2 Agree
  - 3 Are you not sure
- D9. Avoiding things like animal air or dust is helpful in preventing asthma attacks. Do you:
- 1 Disagree
  - 2 Agree
  - 3 Are you not sure
- D10. Staying calm will help keep a serious breathing problem from getting worse. Do you:
- 1 Disagree
  - 2 Agree
  - 3 Are you not sure

### E. Health Related Quality of Life

**REF: E1-E15: PedsQL (Pediatric Quality of Life Inventory), Teen Report (ages 13-18), Version 4 Short Form (SF15); Copyright © 1998 JW Varni, PhD. Address correspondence to: James W. Varni, PhD, Professor and Senior Scientist, Center for Child Health Outcomes, Children's Hospital and Health Center, 3020 Children's Way, San Diego, CA 92123.**

The next questions are about things that might be a problem for you during the past month. Keep in mind there are no right or wrong answers.

- E1. During the past month, has it been hard for you to walk more than one block:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E2. During the past month, has it been hard for you to run:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E3. During the past month, has it been hard for you to do sports activity or exercise:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E4. During the past month, has it been hard for you to lift something heavy:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E5. During the past month, has it been hard for you to do chores around the house:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

- E6. During the past month, have you felt afraid or scared:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E7. During the past month, have you felt sad or blue:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E8. During the past month, have you felt angry:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E9. During the past month, have you worried about what will happen to you:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E10. During the past month, have you had trouble getting along with people your age:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E11. During the past month, have people your age not wanted to be your friend:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E12. During the past month, have you been teased by people your age?
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E13. During the past month, has it been hard for you to pay attention in class:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E14. During the past month, have you forgotten things (in school):
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E15. During the past month, have you had trouble keeping up with your schoolwork:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

These next questions are about asthma symptoms you may have had in the past month.

**REF: E16-E38: PedsQL (Pediatric Quality of Life Inventory), Asthma Module, Teen Report (ages 13-18), Version 3 Short Form (SF22); Copyright © 1998 JW Varni, PhD. Address correspondence to: James W. Varni, PhD, Professor and Senior Scientist, Center for Child Health Outcomes, Children's Hospital and Health Center, 3020 Children's Way, San Diego, CA 92123.**

- E16. During the past month, has your chest hurt or felt tight:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E17. During the past month, have you felt wheezy:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E18. During the past month, have you had asthma attacks:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E19. During the past month, have you gotten scared when you have asthma attacks:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E20. During the past month, have you gotten out of breath:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E21. During the past month, have you coughed:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E22. During the past month, has it been hard for you to take a deep breath:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E23. During the past month, have you had a stuffy or runny nose:
- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |
- E24. During the past month, have you woken up during the night with trouble breathing or coughing:
- |                              |                 |
|------------------------------|-----------------|
| 1 Never → <b>Skip to E26</b> | 4 Often         |
| 2 Almost never               | 5 Almost always |
| 3 Sometimes                  |                 |

E25. About how many nights (in the past month) did that happen?

ENTER # NIGHTS: \_\_\_\_\_ (0-31) → **Skip to E26**

d Don't Know

r Refuse → **Skip to E26**

E25A. Was it:

- |                      |                       |
|----------------------|-----------------------|
| 1 Less than 3 nights | 3 5 to 10 nights      |
| 2 3 to 4 nights      | 4 More than 10 nights |

E26. During the past month, has it been hard for you to play with pets:

- |                |   |
|----------------|---|
| 1 Never        | 4 Often   |
| 2 Almost never | 5 Almost always   |
| 3 Sometimes    | n R volunteers: I don't play with any pets. → <b>Skip to E26b</b> |

**[If E26 = 1 → Skip to E26a]**

E26a. Do you ever play with pets?

- |       |                      |
|-------|----------------------|
| 1 Yes | → <b>Skip to E27</b> |
| 2 No  |                      |

E26b. Is that because of your asthma?

- |       |
|-------|
| 1 Yes |
| 2 No  |

E27. During the past month, has it been hard for you to play outside:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E28. During the past month, have your medicines made you feel sick:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E29. During the past month, have you had trouble sleeping because of your medicines:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E30. During the past month, have you had trouble using your inhaler:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E31. During the past month, have you not liked to carry your inhaler:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E32. During the past month, has it been hard for you to be responsible for your medicines:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E33. During the past month, has it been hard for you to control your asthma:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E34. During the past month, have you decided not to take your medicines:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E35. During the past month, have you forgotten to take your medicines:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E36. During the past month, have you gotten scared when you have to have medical treatments:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E37. During the past month, have you gotten scared when you have to go to the doctor:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

E38. During the past month, have you gotten scared when you have to go to the hospital:

- |                |                 |
|----------------|-----------------|
| 1 Never        | 4 Often         |
| 2 Almost never | 5 Almost always |
| 3 Sometimes    |                 |

## F. Asthma Related Symptoms, Disease Control, and Severity

**REF: F4-F7 - New items created using severity criteria outlined in the NHLBI 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. Bethesda, MD: NIH Publication No. 97-4053; p. 10, Figure 3, and p. 13, Figure 6, October 1997.**

These next questions ask about how your asthma symptoms have been in the past 4 weeks.

F1. During the past 4 weeks, have you had more asthma symptoms at home or at school?

- 1 Home
- 2 School
- 3 Equal at both

F2. During the past 4 weeks, about how many days of school did you miss because of your asthma?

# Days (0-20): \_\_\_\_\_ → **Skip to F4**  
d Don't Know

F3. Would you say:

- 0 No days
- 1 Less than 3 days
- 2 3 to 6 days
- 3 Every day

F4. During the past week, on how many days did you have asthma symptoms during the daytime? Was it:

- 4 No days
- 5 Less than 3 days
- 6 3 to 6 days
- 7 Every day

F5. During the past week, did you use a fast acting or quick relief medication (like Albuterol, Ventolin, Proventil) from an inhaler (or a nebulizer)?

DEFINITION: Fast acting inhalers contain medication that you "puff" or inhale to get quick relief from coughing or breathing problems.

- 1 Yes
- 2 No → **Skip to F8**
- 3 Not Sure → **Skip to F8**

F6. In the past week, about how many times each day did you use fast acting or quick relief medication?

- 0 Not at all
- 1 1 to 2 times
- 2 3 times
- 3 4 to 6 times
- 4 More than 6 times

F7. I need to know which kind of fast acting or quick relief inhaler you used. Can you tell me what color it is? (I can wait while you go get it.)

- 1 Name or colors match fast-acting inhalers listed on sheet.
- 2 Name or colors match long-acting inhalers listed on sheet.
- 3 Name or colors do not match any inhaler listed on sheet.

(Enter Name/Colors: \_\_\_\_\_)

**FAST ACTING/QUICK RELIEF INHALERS TO BE COUNTED IN F7**

<b>COLOR</b>	<b>MEDICATION NAME</b>
WHITE WITH WHITE CAP	ALBUTEROL (AL-BEW-TER-ALL)
LIGHT BLUE WITH DARK BLUE CAP	ALBUTEROL (AL-BEW-TER-ALL)  OR  VENTOLIN (VEN-TOE-LIN)
CLEAR WITH BLUE CAP	ALUPENT (AL-YOU-PENT)
WHITE WITH BLUE CAP	ALUPENT (AL-YOU-PENT) OR  INTAL (IN-TALL)
CLEAR WITH GREEN CAP	ATROVENT (AT-ROW-VENT)
WHITE WITH GREEN CAP	ATROVENT (AT-ROW-VENT)
YELLOW WITH AN ORANGE CAP	PROVENTILL (PRO-VENT-ILL)
WHITE WITH GREEN LETTERS ON TUBE AND CAP	TILADE (TIE-LADE)

*QXQ ISSUE: CAN'T DISTINGUISH FROM AZMACORT, SO GIVE CREDIT IN F11*

**LONG-ACTING INHALERS SHOULD NOT BE COUNTED IN F7:**

<b>COLOR</b>	<b>MEDICATION NAME</b>
GRAY WITH A PURPLE CAP	AEROBID (ARROW-BID)
LIGHT GREEN WITH A DARK GREEN CAP	AEROBID (ARROW-BID)
WHITE WITH WHITE CAP	AZMACORT (ASTHMA-COURT)
TAN WITH A BROWN CAP	BECLOVENT (BECK-LOW-VENT)
DARK ORANGE WITH A LIGHT ORANGE CAP.	FLOVENT (FLOW-VENT)
WHITE AND BROWN TUBE	PULMICORT (PUHL-MIH-COURT)
PINK WITH A PURPLE CAP	VANCERILL (VAN-SIR-ILL)





H7. (In the past 6 months) did you get information about asthma from the internet or an asthma web site?

1 Yes

5 No

H8. Certain things like tobacco smoke, dust, pets or animal hair, cockroaches, and mold can make asthma worse. In the past 6 months did a doctor, nurse or other health provider talk with you about ways to avoid these kinds of things?

1 Yes

5 No

## I. Demographics

These last questions are about you and your family and will help us to describe all the young people in our study.

I1. Do you live with someone who smokes?

1 Yes

5 No

I2. When was the last time you smoked? Was it:

1 Today

2 Last week

3 Last month

4 More than a month ago

n R volunteers: I never smoked/just tried it once or twice.

I3. Did your doctor or any other health provider ever tell you smoking is especially bad if you have asthma?

1 Yes

5 No

>kidmr<

The letter we sent your parent(s) said that we would like to put your answers from this interview together with your health care records from [FILL SITE]. Your health care records are made up of your medical charts, information [FILL SITE] may have about the cost of your care, prescription medicines you have taken, test or health procedures you had at [FILL SITE], and general information about your health insurance.

A member of our study team would look at your health care records from [FILL SITE] to learn more about your care from [FILL SITE].

We won't look at your health care records at [FILL SITE] without your permission and permission from your parent(s). You can tell me if you don't want anyone from our study team to look at your health care records at [FILL SITE]. No matter what you decide you will still receive your \$10 gift certificate. We don't tell your doctors at [FILL SITE] if you say yes or no, so whatever you decide will not matter to them.

Do you give your permission for a member of the RAND study team to look at your health care records?

1 Yes, Give permission

2 No, Do not give permission

3 Not sure at this time

>check<

Thank you for taking the time to answer these questions. We will send you a \$10 gift certificate for completing this interview.