

Participant Engagement and Motivation SAQ

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| --- | --- |
| Event Category: | Time-Based |
| Event: | 48M |
| Administration: | N/A |
| Instrument Target: | Primary Caregiver |
| Instrument Respondent: | Primary Caregiver |
| Domain: | Questionnaire |
| Document Category: | Questionnaire |
| Method: | Self-Administered |
| Mode (for this instrument\*): | In-Person, PAPI |
| OMB Approved Modes: | In-Person, PAPI; Phone, PAPI; Web-Based, CAI |
| Estimated Administration Time: | 6 minutes |
| Multiple Child/Sibling Consideration: | Per Event |
| Special Considerations: | N/A |
| Version: | 1.0 |
| MDES Release: | 4.0 |

\*This instrument is OMB-approved for multi-mode administration but this version of the instrument is designed for administration in this/these mode(s) only.

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Participant Engagement and Motivation SAQ

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Participant Engagement and Motivation SAQ

GENERAL PROGRAMMER INSTRUCTIONS:

WHEN PROGRAMMING INSTRUMENTS, VALIDATE FIELD LENGTHS AND TYPES AGAINST THE MDES TO ENSURE DATA COLLECTION RESPONSES DO NOT EXCEED THOSE OF THE MDES. SOME GENERAL ITEM LIMITS USED ARE AS FOLLOWS:

|  |  |  |  |
| --- | --- | --- | --- |
| **DATA ELEMENT FIELDS** | **MAXIMUM CHARACTERS PERMITTED** | **DATA TYPE** | **PROGRAMMER INSTRUCTIONS** |
| ADDRESS AND EMAIL FIELDS | 100 | CHARACTER |  |
| UNIT AND PHONE FIELDS | 10 | CHARACTER |  |
| \_OTH AND COMMENT FIELDS | 255 | CHARACTER | * Limit text to 255 characters |
| FIRST NAME AND LAST NAME | 30 | CHARACTER | * Limit text to 30 characters |
| ALL ID FIELDS | 36 | CHARACTER |  |
| ZIP CODE | 5 | NUMERIC |  |
| ZIP CODE LAST FOUR | 4 | NUMERIC |  |
| CITY | 50 | CHARACTER |  |
| DOB AND ALL OTHER DATE FIELDS (E.G., DT, DATE, ETC.) | 10 | NUMERIC  CHARACTER | * DISPLAY AS MM/DD/YYYY * STORE AS YYYY-MM-DD * HARD EDITS:   MM MUST EQUAL 01 TO 12  DD MUST EQUAL 01 TO 31  YYYY MUST BE BETWEEN 1900 AND CURRENT YEAR. |
| TIME VARIABLES | TWO-DIGIT HOUR AND TWO-DIGIT MINUTE, AM/PM DESIGNATION | NUMERIC | * HARD EDITS:   HOURS MUST BE BETWEEN 00 AND 12;  MINUTES MUST BE BETWEEN 00 AND 59 |

**Instrument Guidelines for Participant and Respondent IDs:**

PRENATALLY, THE **P\_ID** IN THE MDES HEADER IS THAT OF THE PARTICIPANT (E.G. THE NON-PREGNANT WOMAN, PREGNANT WOMAN, OR THE FATHER).

POSTNATALLY, A RESPONDENT ID WILL BE USED IN ADDITION TO THE PARTICIPANT ID BECAUSE SOMEBODY OTHER THAN THE PARTICIPANT MAY BE COMPLETING THE INTERVIEW. FOR EXAMPLE, THE PARTICIPANT MAY BE THE CHILD AND THE RESPONDENT MAY BE THE MOTHER, FATHER, OR ANOTHER CAREGIVER. THEREFORE, MDES VERSION 2.2 AND ALL FUTURE VERSIONS CONTAIN A **R\_P\_ID** (RESPONDENT PARTICIPANT ID) HEADER FIELD FOR EACH POST-BIRTH INSTRUMENT. THIS WILL ALLOW ROCs TO INDICATE WHETHER THE RESPONDENT IS SOMEBODY OTHER THAN THE PARTICIPANT ABOUT WHOM THE QUESTIONS ARE BEING ASKED.

**A REMINDER:**

ALL RESPONDENTS MUST BE CONSENTED AND HAVE RECORDS IN THE PERSON, PARTICIPANT, PARTICIPANT\_CONSENT AND LINK\_PERSON\_PARTICIPANT TABLES, WHICH CAN BE PRELOADED INTO EACH INSTRUMENT. ADDITIONALLY, IN POST-BIRTH QUESTIONNAIRES WHERE THERE IS THE ABILITY TO LOOP THROUGH A SET OF QUESTIONS FOR MULTIPLE CHILDREN, IT IS IMPORTANT TO CAPTURE AND STORE THE CORRECT CHILD **P\_ID** ALONG WITH THE LOOP INFORMATION. IN THE MDES VARIABLE LABEL/DEFINITION COLUMN, THIS IS INDICATED AS FOLLOWS: **EXTERNAL IDENTIFIER: PARTICIPANT ID FOR CHILD DETAIL.**

STUDY HISTORY

**SH00100.** Thank you again for your participation in the National Children's Study.  This questionnaire asks for your opinions about what it is like for you to participate in the study.  It will take about 6 minutes to complete.  Your responses will be used to help us understand more about what it is like to be a research participant and to try to improve your experience in the NCS.

Your answers are important to us.  There are no right or wrong answers.  You can always refuse to answer any question or group of questions, and your answers will be kept confidential.

**SH01000.** Please enter today's DATE:

**(PEMS\_DATE\_MM)** Month:

|\_\_\_\_\_|\_\_\_\_\_|

     M       M

**(PEMS\_DATE\_DD)** Day:

|\_\_\_\_\_|\_\_\_\_\_|

     D       D

**(PEMS\_DATE\_YYYY)** Year:

|\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|

    Y      Y       Y       Y

**SH02000.** How old was your child at the time of your last NCS Study visit?  The visit may have taken place at your home, at some other location, or over the telephone.  A study visit includes a survey and possibly a sample collection.

Please record age by using two digits and then check one box below the age to indicate whether the age is in months or years.  If less than one month, please enter 00.  *(Example:  a child who was 9 months old would be recorded as "09" and the "Months" box would be checked.)*

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| SOURCE |
| New |

**(LAST\_CHILD\_AGE)** Child's age at last visit

|\_\_\_\_\_|\_\_\_\_\_|

**(LAST\_CHILD\_AGE\_UNIT)**

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Months | 1 |  |
| Years | 2 |  |

**SH03000.** How old is your child now?

|  |
| --- |
| SOURCE |
| New |

**(CHILD\_AGE)** Child's age now

|\_\_\_\_\_|\_\_\_\_\_|

**(CHILD\_AGE\_UNIT)**

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Months | 1 |  |
| Years | 2 |  |

**SH04000/(NUM\_INPERSON\_VISIT).** How many times has NCS staff conducted face-to-face visits, either for interviews or for collecting samples, at your home, a clinic, or another location?

|\_\_\_\_|\_\_\_\_|

Number of face-to-face visits

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| SOURCE |
| New |

**SH05000/(NUM\_PHONE\_VISIT).** How many telephone interviews with the NCS have you participated in?

|\_\_\_\_|\_\_\_\_|

Number of telephone visits​

|  |
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| SOURCE |
| New |

PARTICIPANT ENGAGEMENT AND MOTIVATION

**PEM00100.** ​​On a scale of 1 to 10, with 1 being not at all important, and 10 being very important, how important are the following reasons for **why you now participate** in the National Children's Study?  Please circle one response for each question.

|  |
| --- |
| SOURCE |
| Gatny, H. H., and Axinn, W. G. (2011). Willingness to participate in research during pregnancy: Race, experience and motivation. *Field Methods*, 24(2), 135-154. (modified) |

**PEM01000/(PART\_SCIENCE).** I am contributing to science.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

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| --- |
| SOURCE |
| Gatny, HH, and Axinn, WG (2011).  Willingness to participate in research during pregnancy:  Race, experience and motivation.  *Field Methods*, 24(2), 135-154. (modified) |

**PEM02000/(PART\_CHILD\_HEALTH).** I am curious about children's health.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

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| --- |
| SOURCE |
| Gatny, HH, and Axinn, WG (2011).  Willingness to participate in research during pregnancy:  Race, experience and motivation.  *Field Methods*, 24(2), 135-154. (modified) |

**PEM03000/(PART\_FUN).** Participating is fun.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

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| SOURCE |
| Guay, F, Vallerand, RJ, and Blanchard, C (2001).  On the assessment of situational intrinsic and extrinsic motivation.  The Situational Motivation Scale (SIMS).  *Motivation and Emotion*, 24(3). (modified) |

**PEM04000/(PART\_HEALTH).** To get information about my health and my child's health from Study testing.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

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| --- |
| SOURCE |
| Gatny, HH, and Axinn, WG (2011).  Willingness to participate in research during pregnancy:  Race, experience and motivation.  *Field Methods*, 24(2), 135-154. ​(modified) |

**PEM05000/(PART\_INCENTIVE).** Receiving incentives (money, gift cards, etc.)

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

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| --- |
| SOURCE |
| Gatny, HH, and Axinn, WG (2011).  Willingness to participate in research during pregnancy:  Race, experience and motivation.  *Field Methods*, 24(2), 135-154. ​(modified) |

**PEM06000/(PART\_HAVETO).** I feel I have to participate.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

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| SOURCE |
| Guay, F, Vallerand, RJ, and Blanchard, C (2001).  On the assessment of situational intrinsic and extrinsic motivation.  The Situational Motivation Scale (SIMS).  *Motivation and Emotion*, 24(3). ​(modified) |

**PEM07000/(PART\_NEXT\_GENERATION).** Wanting to help out the next generation of children.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

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| --- |
| SOURCE |
| Gatny, HH, and Axinn, WG (2011).  Willingness to participate in research during pregnancy:  Race, experience and motivation. *Field Methods*, 24(2), 135-154. ​(modified) |

**PEM08000/(PART\_INTERESTING).** The Study visits are interesting.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

|  |
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| SOURCE |
| Guay, F, Vallerand, RJ, and Blanchard, C (2001).  On the assessment of situational intrinsic and extrinsic motivation.  The Situational Motivation Scale (SIMS).  *Motivation and Emotion*, 24(3). (modified) |

**PEM09000/(PART\_ACCESS\_HEALTHCARE).** To improve my child's access to healthcare.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

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| SOURCE |
| New |

**PEM10000/(PART\_IMPROVE\_HEALTH).** I think my participation may improve my child's health.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

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| --- |
| SOURCE |
| Guay, F, Vallerand, RJ, and Blanchard, C (2001).  On the assessment of situational intrinsic and extrinsic motivation.  The Situational Motivation Scale (SIMS).  *Motivation and Emotion*, 24(3). ​(modified) |

**PEM11000.** Other:

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| SOURCE |
| New |

**(PART\_IMPROVE\_HEALTH\_OTH)** Specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**(PART\_IMPROVE\_HEALTH\_OTH\_UNIT)**

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| 1 Not at All Important | 1 |  |
| 2 | 2 |  |
| 3 | 3 |  |
| 4 | 4 |  |
| 5 | 5 |  |
| 6 | 6 |  |
| 7 | 7 |  |
| 8 | 8 |  |
| 9 | 9 |  |
| 10 Very Important | 10 |  |

**PEM12000/(GREATEST\_RISKS\_NCS).** Please indicate what you believe are the greatest risks to you and your family from participating in the National Children's Study. From the list below, please rank the three greatest risks using:

1 = greatest risk to me and my family,

2 = second greatest risk to me and my family,

3 = third greatest risk to me and my family.

\_\_\_\_\_  Pain associated with giving blood or other specimens

\_\_\_\_\_  Having a data collector come to my home

\_\_\_\_\_  The loss of my time

\_\_\_\_\_  The stress involved in participating

\_\_\_\_\_  Having my privacy invaded

\_\_\_\_\_  Learning something about my child’s health that I would rather not know

\_\_\_\_\_  Learning something about our home environment that I would rather not know

\_\_\_\_\_  Someone who is not authorized seeing my data

\_\_\_\_\_  Other

|  |
| --- |
| SOURCE |
| New  Choice options of loss of time and learning about child's health: Kibler, JL, and Brisco, K (2006).  Evaluation of a brief questionnaire for assessing barriers to research participation.  *Ethnicity & Disease*, 16, 547-550. (modified) |

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| PROGRAMMER INSTRUCTIONS |
| * LOOP THROUGH **GREATEST\_RISKS\_NCS** THREE TIMES TO SELECT MOST IMPORTANT = 1, SECOND MOST IMPORTANT = 2, AND THIRD MOST IMPORTANT = 3 RESPONSES. * IF PARTICIPANT SELECTS "OTHER", GO TO **GREATEST\_RISKS\_NCS\_OTH.** * OTHERWISE, IF "OTHER" IS NOT SELECTED, GO TO **PEM13100.** |

**PEM13000/(GREATEST\_RISKS\_NCS\_OTH).** Other:  Specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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| SOURCE |
| New |

**PEM13100.** The following questions ask about **your participation in the Study**.  After reading each item, please tell us if you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree with each of the following statements.  Please choose one response per statement.

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| SOURCE |
| New |

**PEM14000/(CAN\_SKIP\_QUESTION).** I can skip any survey question I do not want to answer.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM15000/(CAN\_REFUSE\_SAMPLE).** I can refuse to give a blood sample for me or my child and still be in the study.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM16000/(CAN\_REFUSE\_VISIT).** I can refuse a visit from the data collector and still be in the study.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM17000/(CAN\_LEAVE\_REJOIN).** I can leave the study for a while and then rejoin later.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM17100.** ​The following questions ask about your experiences with the National Children's Study.  For each item, please tell us if you strongly disagree, disagree, are neutral, agree, or strongly agree. Please choose one response per statement.

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| SOURCE |
| ​National Children’s Study, Legacy Phase |

**PEM18000/(NCS\_EXPERIENCE\_POSITIVE).** Overall, my experience in the NCS has been positive.

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| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM19000/(NCS\_MET\_EXPECTATIONS).** NCS Study visits have met my expectations.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Bowling, A, Rowe, G, Lambert, N, Waddington, M, Mahtani, KR, Kenten, C, Howe, A & Francis, SA (2012).  The measurement of patients' expectation for health care:  a feview and psychometric testing of a measure of patients' expectations.  Health Technology Assessment, 16(30). (modified) |

**PEM20000/(LEARNING\_CHILD\_HEALTH).** I am learning about childhood health through my participation.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Gatny, HH, and Axinn, WG (2011).  Willingness to participate in research during pregnancy:  Race, experience and motivation.  *Field Methods*, 24(2), 135-154. ​(modified) |

**PEM21000/(STAFF\_ACCOMMODATE\_SCHEDULE).** NCS Study staff accommodate my schedule

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Goldfarb, N, & Huck, W (2006).  Measuring Site Performance with Subject Feedback.  *Journal of Clinical Research Best Practices,* Vol. 2, No. 5. (modified) |

**PEM22000/(RUN\_BY\_NIH).** I am comfortable participating in the NCS because it is run by the National Institutes of Health.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM23000/(HELP\_COMMUNITY).** I help my community by participating in the Study.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM23100/(FUTURE\_GENERATIONS).** The NCS may improve the health of children in future generations.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM23200/(QUESTIONS\_PERSONAL).** I find the questions too personal.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  *Accountability in Research*, 8, 27-47. (modified) |

**PEM24000/(PROUD\_NCS).** I feel proud to be in a Study that collects information about me to help other people.

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| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM25000/(NCS\_INCONVENIENT).** Participating in the NCS is not convenient for me.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  *Accountability in Research*, 8, 27-47. ​(modified) |

**PEM26000/(NCS\_EMOTIONAL).** NCS Study visits raise emotional issues for me that I had not expected.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  *Accountability in Research*, 8, 27-47. ​(modified) |

**PEM27000/(INSIGHT\_EXPERIENCES).** I gain insight about my experiences by being in the NCS.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  *Accountability in Research*, 8, 27-47. |

**PEM28000/(EXCITED\_VISIT).** I am looking forward to my next NCS Study visit.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| New |

**PEM29000/(NCS\_DISAPPOINTING).** Participating in the study has been disappointing.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Bowling, A, Rowe, G, Lambert, N, Waddington, M, Mahtani, KR, Kenten, C, Howe, A & Francis, SA (2012).  The measurement of patients' expectation for health care:  a feview and psychometric testing of a measure of patients' expectations.  Health Technology Assessment, 16(30). (modified) |

**PEM30000/(RESPONSES\_PRIVATE).** I trust that my replies will be kept private.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  *Accountability in Research*, 8, 27-47. |

**PEM31000/(INCENTIVES\_SUSPICIOUS).** Receiving incentives (gift cards, cash, etc.) makes me suspicious of the project.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Kibler, JL, and Brisco, K (2006).  Evaluation of a brief questionnaire for assessing barriers to research participation.  *Ethnicity & Disease*, 16, 547-550. (modified) |

**PEM32000/(NO\_THINK\_ABOUT).** The NCS makes me think about things I don't want to think about.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  Accountability in Research, 8, 27-47. ​(modified) |

**PEM33000/(CONTRIBUTING\_SCIENCE).** I like the idea that I am contributing to science.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  Accountability in Research, 8, 27-47. ​(modified) |

**PEM34000/(STOP\_PARTICIPATING).** I feel I can stop participating at any time.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  Accountability in Research, 8, 27-47. ​(modified) |

**PEM35000/(NCS\_BORING).** I find participating boring.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  Accountability in Research, 8, 27-47. ​(modified) |

**PEM36000/(KNOWN\_BEFORE\_NOPART).** Had I known in advance what participating would be like I still would have agreed to participate.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  Accountability in Research, 8, 27-47. |

**PEM37000/(SATISFIED\_INCENTIVES).** I am satisfied with the incentives I am given.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM38000/(VISITS\_LONG).** The Study visits take too long.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  Accountability in Research, 8, 27-47. ​(modified) |

**PEM39000/(NEGATIVE\_HEALTH\_INFO).** The NCS could provide information about my health or the health of my child that I would rather not know about.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Kibler, JL, and Brisco, K (2006).  Evaluation of a brief questionnaire for assessing barriers to research participation.  Ethnicity & Disease, 16, 547-550. (modified) |

**PEM40000/(NO\_TIME\_PARTICIPATE).** It is difficult to find time to participate in this Study.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Kibler, JL, and Brisco, K (2006).  Evaluation of a brief questionnaire for assessing barriers to research participation.  Ethnicity & Disease, 16, 547-550. (modified) |

**PEM41000/(PARTICIPATION\_CHOICE).** Participation is a choice I freely make.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Newman, E, Willard, T, Sinclair, R & Kaloupek, D (2001).  The costs and benefits of research from the participant's view:  The path to empirically informed research practice.  Accountability in Research, 8, 27-47. ​(modified) |

**PEM42000/(NOTHING\_TO\_GAIN).** There is not anything for me to gain by participating in the Study.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| Kibler, JL, and Brisco, K (2006).  Evaluation of a brief questionnaire for assessing barriers to research participation.  Ethnicity & Disease, 16, 547-550. (modified) |

**PEM43000/(FRIENDS\_FAMILY\_NCS).** Most of my friends and family know that I am participating in the NCS.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM44000/(NCS\_STAFF\_EXPLAINED).** When I joined the study, a staff person explained the study to me in a way I understood what was involved

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| New |

**PEM45000/(MORE\_INFO\_JOINING).** I would have liked more information about the Study before joining.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM46000/(CONTACT\_MORE).** The data collector should contact me more often between visits (phone calls, cards, newsletters, etc.)

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

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| SOURCE |
| New |

**PEM47000/(INCLUDE\_FATHER\_MORE).** I would like the data collector to include the father of my child more in the Study.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |

|  |
| --- |
| SOURCE |
| New |

**PEM47100.** The following questions ask about **how others currently feel** about your participation in the National Children's Study.  For each item, please circile one number that best describes your response.

**PEM48000/(BIO\_FATHER\_SUPPORTIVE).** My child's biological father is supportive of my being in the NCS.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |
| Does Not Apply | -7 |  |
| Don't Know | -2 |  |

|  |
| --- |
| SOURCE |
| New |

**PEM49000/(PARTNER\_SUPPORTIVE).** My husband/boyfriend/partner is supportive of my being in the NCS.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |
| Does Not Apply | -7 |  |
| Don't Know | -2 |  |

|  |
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| SOURCE |
| New |

**PEM50000/(PEOPLE\_APPROVE\_INVOLV).** Most people important to me think my involvement in research is good.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |
| Does Not Apply | -7 |  |
| Don't Know | -2 |  |

|  |
| --- |
| SOURCE |
| Frew, PM; Hou, S; Davis, M; Chan, K; Horton, T; Shuster, J; Hixson, B; delRio, C (2010). The likelihood of participation in clinical trials can be measured:  The clinical research involvement scales (CRIS).  *Journal of Clinical Epidemiology*, 63(10), 1110-1117. |

**PEM51000/(PEOPLE\_SUPPORT\_INTEREST).** Most people important to me usually support my interests.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |
| Does Not Apply | -7 |  |
| Don't Know | -2 |  |

|  |
| --- |
| SOURCE |
| ​Frew, PM; Hou, S; Davis, M; Chan, K; Horton, T; Shuster, J; Hixson, B; delRio, C (2010). The likelihood of participation in clinical trials can be measured:  The clinical research involvement scales (CRIS).  *Journal of Clinical Epidemiology*, 63(10), 1110-1117. |

**PEM52000/(PASTOR\_SUPPORT\_RESEARCH).** When my pastor/clergy supports research I am more inclined to be involved.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |
| Does Not Apply | -7 |  |
| Don't Know | -2 |  |

|  |
| --- |
| SOURCE |
| ​Frew, PM; Hou, S; Davis, M; Chan, K; Horton, T; Shuster, J; Hixson, B; delRio, C (2010). The likelihood of participation in clinical trials can be measured:  The clinical research involvement scales (CRIS).  *Journal of Clinical Epidemiology*, 63(10), 1110-1117. (modified) |

**PEM53000/(DR\_APPROVES\_NCS).** My doctor approves of my involvement in the NCS.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |
| Does Not Apply | -7 |  |
| Don't Know | -2 |  |

|  |
| --- |
| SOURCE |
| ​Frew, PM; Hou, S; Davis, M; Chan, K; Horton, T; Shuster, J; Hixson, B; delRio, C (2010). The likelihood of participation in clinical trials can be measured:  The clinical research involvement scales (CRIS).  Journal of Clinical Epidemiology, 63(10), 1110-1117. (modified) |

**PEM54000/(COWORKERS\_APPROVE\_NCS).** I think my co-workers would approve of me being in the NCS.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree | 1 |  |
| Disagree | 2 |  |
| Neither Agree nor Disagree | 3 |  |
| Agree | 4 |  |
| Strongly Agree | 5 |  |
| Does Not Apply | -7 |  |
| Don't Know | -2 |  |

|  |
| --- |
| SOURCE |
| ​Frew, PM; Hou, S; Davis, M; Chan, K; Horton, T; Shuster, J; Hixson, B; delRio, C (2010). The likelihood of participation in clinical trials can be measured:  The clinical research involvement scales (CRIS).  Journal of Clinical Epidemiology, 63(10), 1110-1117. (modified) |

**PEM54100.** These next statements are about **what you hope to gain** from your participation in the National Children's Study.  For each statement, please select one number that best describes your expectations.

**PEM54200.** I expect my participation in teh NCS to result in....

|  |
| --- |
| SOURCE |
| Bowling, A., Rowe, G., Lambert, N., Waddington, M., Mahtani, KR., Kenten, C., Howe, A., & Francis, SA. (2012). The measurement of patients’ expectations for health care: a review and psychometric testing of a measure of patients’ expectations. Health Technology Assessment, 16(30). (modified) |

**PEM55000/(IMPROVE\_HEALTH).** An improvement in my health.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree (No) | 1 |  |
| Disagree | 2 |  |
| Neutral (Maybe) | 3 |  |
| Agree | 4 |  |
| Strongly Agree (Yes) | 5 |  |

|  |
| --- |
| SOURCE |
| Bowling, A, Rowe, G, Lambert, N, Waddington, M, Mahtani, KR, Kenten, C, Howe, A & Francis, SA (2012).  The measurement of patients' expectation for health care:  a feview and psychometric testing of a measure of patients' expectations.  Health Technology Assessment, 16(30). (modified) |

**PEM56000/(IMPROVE\_CHILD\_HEALTH).** An improvement in my child's health.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree (No) | 1 |  |
| Disagree | 2 |  |
| Neutral (Maybe) | 3 |  |
| Agree | 4 |  |
| Strongly Agree (Yes) | 5 |  |

|  |
| --- |
| SOURCE |
| Bowling, A, Rowe, G, Lambert, N, Waddington, M, Mahtani, KR, Kenten, C, Howe, A & Francis, SA (2012).  The measurement of patients' expectation for health care:  a feview and psychometric testing of a measure of patients' expectations.  Health Technology Assessment, 16(30). (modified) |

**PEM57000/(IMPROVE\_LIVING\_ENV).** An improvement in my family's living environment.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree (No) | 1 |  |
| Disagree | 2 |  |
| Neutral (Maybe) | 3 |  |
| Agree | 4 |  |
| Strongly Agree (Yes) | 5 |  |

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| SOURCE |
| New |

**PEM58000/(IMPROVE\_FUTURE\_GENERATIONS).** An improvement in the health of children in future generations.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree (No) | 1 |  |
| Disagree | 2 |  |
| Neutral (Maybe) | 3 |  |
| Agree | 4 |  |
| Strongly Agree (Yes) | 5 |  |

|  |
| --- |
| SOURCE |
| New |

**PEM59000/(IMPROVE\_COMMUNITY\_HEALTH).** An improvement to the health of my community overall.

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Strongly Disagree (No) | 1 |  |
| Disagree | 2 |  |
| Neutral (Maybe) | 3 |  |
| Agree | 4 |  |
| Strongly Agree (Yes) | 5 |  |

|  |
| --- |
| SOURCE |
| New |

**PEM60000/(PREFERRED\_VISIT\_LOCATION).** I prefer Study visits be conducted . . .

|  |
| --- |
| PARTICIPANT INSTRUCTIONS |
| Please check **one** response you most prefer. |

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| At my home | 1 |  |
| At a clinic | 2 |  |
| At a community location (i.e. library, school, etc.) | 3 |  |
| Over the telephone | 4 |  |
| Web-based (internet) | 5 |  |
| Self-administered and returned by mail | 6 |  |

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| SOURCE |
| New |

**PEM61000/(CONTINUE\_PARTICIPATE).** How likely are you to continue to participate in the study?  Would you say very likely, somewhat likely, somewhat unlikely, or very unlikely?

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Very likely | 1 |  |
| Somewhat likely | 2 |  |
| Somewhat unlikely | 3 |  |
| Very unlikely | 4 |  |

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| SOURCE |
| New |

**PEM62000/(SHARE\_EXPERIENCES\_NCS).** Is there anything about your experiences in the National Children's Study you would like to share?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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| SOURCE |
| New |

**PEM63000.** ​Thank you for participating in the National Children's Study and for taking the time to complete this survey.

FOR OFFICE USE

**FOU01000/(P\_ID).** Participant ID:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**FOU02000/(R\_P\_ID).** Respondent ID:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_