



## Non-Interview Respondent SAQ

<b>Event Category:</b>	Trigger-Based
<b>Event:</b>	Non-Interview Respondent
<b>Administration:</b>	Pregnancy Screener Sibling Birth Cohort, Pre-Pregnancy Screener, PV1, PV2, Birth, 3M, 6M, 9M, 12M, 18M, 24M, 30M, 36M, 42M, 48M, 54M, 60M
<b>Instrument Target:</b>	Pre-Pregnant Woman (Pre-Pregnancy Screener, Pregnancy Screener Sibling Cohort); Pregnant Woman (PV1, PV2); Father/Father Figure (PV1, PV2, 9M, 18M); Biological Mother (Birth); Biological Father (42M); Primary Caregiver (3M, 6M, 9M, 12M, 18M, 24M, 30M, 36M, 42M, 48M, 54M, 60M)
<b>Instrument Respondent:</b>	Pre-Pregnant Woman (Pre-Pregnancy Screener, Pregnancy Screener Sibling Cohort); Pregnant Woman (PV1, PV2); Father/Father Figure (PV1, PV2, 9M, 18M); Biological Mother (Birth); Biological Father (42M); Primary Caregiver (3M, 6M, 9M, 12M, 18M, 24M, 30M, 36M, 42M, 48M, 54M, 60M)
<b>Domain:</b>	Questionnaire
<b>Document Category:</b>	Questionnaire
<b>Method:</b>	Self-Administered
<b>Mode (for this instrument*):</b>	In-Person, PAPI
<b>OMB Approved Modes:</b>	In-Person, PAPI; Phone, PAPI; Web-Based, CAI
<b>Estimated Administration Time:</b>	5 minutes
<b>Multiple Child/Sibling Consideration:</b>	Per Event
<b>Special Considerations:</b>	N/A
<b>Version:</b>	1.0
<b>MDES Release:</b>	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.

Public reporting burden for this collection of information is estimated to average 5 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0593\*). Do not return the completed form to this address.

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## Non-Interview Respondent 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	<ul style="list-style-type: none"> <li>• Limit text to 255 characters</li> </ul>
FIRST NAME AND LAST NAME	30	CHARACTER	<ul style="list-style-type: none"> <li>• Limit text to 30 characters</li> </ul>
ALL ID FIELDS	36	CHARACTER	
ZIP CODE	5	CHARACTER	
ZIP CODE LAST FOUR	4	CHARACTER	
CITY	50	CHARACTER	
DOB AND ALL OTHER DATE FIELDS (E.G., DT, DATE, ETC.)	10	NUMERIC CHARACTER	<ul style="list-style-type: none"> <li>• DISPLAY AS MM/DD/YYYY</li> <li>• STORE AS YYYY-MM-DD</li> <li>• HARD EDITS: MM MUST EQUAL 01 TO 12 DD MUST EQUAL 01 TO 31 YYYY MUST BE BETWEEN 1900 AND CURRENT YEAR.</li> </ul>
TIME VARIABLES	TWO-DIGIT HOUR AND TWO-DIGIT MINUTE, AM/PM DESIGNATION	NUMERIC	<ul style="list-style-type: none"> <li>• HARD EDITS: HOURS MUST BE BETWEEN 00 AND 12; MINUTES MUST BE BETWEEN 00 AND 59</li> </ul>
NUMBER OF HOURS PER DAY	TWO-DIGIT HOUR	NUMERIC	<ul style="list-style-type: none"> <li>• HARD EDITS: HOURS MUST BE BETWEEN 1 AND 24</li> </ul>
NUMBER OF DAYS PER WEEK	ONE-DIGIT	NUMERIC	<ul style="list-style-type: none"> <li>• HARD EDITS: DAYS PER WEEK MUST BE BETWEEN 1 AND 7</li> </ul>

### **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.**

## NON-INTERVIEW RESPONDENT SAQ

**NIR01000.** We are sorry to hear that you have decided not to join or to stop participating in the National Children’s Study. We would like you to answer a few questions about your decision. Your answers are very important to us. There are no right or wrong answers. You can skip over any question or leave the questionnaire at any time. We will use this information to improve the quality of the National Children’s Study for future participants.

**NIR02000/(NIR\_REFUSAL\_REASON).** What is the main reason you do not want to join or to continue participating in the National Children’s Study? If there is more than one reason, select the main reason.

<b>Label</b>	<b>Code</b>	<b>Go To</b>
<b>Too busy/no time</b>	<b>1</b>	<b>NIR_LOW_BURDEN</b>
<b>Confidentiality/privacy issues</b>	<b>2</b>	<b>NIR05000</b>
<b>Not interested (in topic or in general)</b>	<b>3</b>	<b>NIR05000</b>
<b>Lack of incentives/benefit (nothing in it for me)</b>	<b>4</b>	<b>NIR05000</b>
<b>Too intrusive</b>	<b>5</b>	<b>NIR05000</b>
<b>Do not believe in studies</b>	<b>6</b>	<b>NIR05000</b>
<b>Afraid to participate</b>	<b>7</b>	<b>NIR05000</b>
<b>Legitimacy issues/think study is a scam</b>	<b>8</b>	<b>NIR05000</b>
<b>Waste of time or money</b>	<b>9</b>	<b>NIR05000</b>
<b>Concerns about providing specimens</b>	<b>10</b>	<b>NIR05000</b>
<b>None of the government's business</b>	<b>11</b>	<b>NIR05000</b>
<b>Not sure of purpose</b>	<b>12</b>	<b>NIR05000</b>
<b>Family reasons</b>	<b>13</b>	<b>NIR05000</b>
<b>Safety concerns</b>	<b>14</b>	<b>NIR05000</b>
<b>Concerns about genetic information</b>	<b>15</b>	<b>NIR05000</b>
<b>Moving</b>	<b>16</b>	<b>NIR05000</b>
<b>Social/religious reasons</b>	<b>17</b>	<b>NIR05000</b>
<b>Goals of study not congruent with original understanding</b>	<b>18</b>	<b>NIR05000</b>
<b>Medical issues</b>	<b>19</b>	<b>NIR05000</b>
<b>Lost interest in participating</b>	<b>20</b>	<b>NIR05000</b>
<b>Spouse/partner not supportive of participation</b>	<b>21</b>	<b>NIR05000</b>
<b>External pressure to withdraw</b>	<b>22</b>	<b>NIR05000</b>
<b>Heard bad things about the</b>	<b>23</b>	<b>NIR05000</b>

Label	Code	Go To
study		
No reason	24	NIR05000
Other	-5	

<b>SOURCE</b>
National Children's Study Vanguard Phase (modified)

NIR03000/(NIR\_REFUSAL\_REASON\_OTH). Specify: \_\_\_\_\_

<b>SOURCE</b>
National Children's Study Vanguard Phase (modified)

NIR04000/(NIR\_LOW\_BURDEN). We understand that joining or continuing to participate in the National Children's Study requires you to give up valuable personal time. Would you change your mind if there was an option to participate that required less of your time?

Label	Code	Go To
Yes	1	
No	2	

<b>SOURCE</b>
National Children's Study Vanguard Phase (modified)

NIR05000. Read each of the statements below. Please indicate whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree with each statement. If the statement does not apply to your situation, select "Not applicable".

<b>SOURCE</b>
National Children's Study Vanguard Phase

NIR06000/(NIR\_BUSY\_SCHEDULE). My work/personal schedule is very busy and I do not have time to participate in the National Children's Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

<b>SOURCE</b>
National Children's Study Vanguard Phase (modified)

NIR07000/(NIR\_NO\_SUPPORT). My partner, husband, and/or family supports my participation in the National Children's Study.

Label	Code	Go To
Strongly agree	1	



Label	Code	Go To
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children's Study Vanguard Phase (modified)

**NIR08000/(NIR\_STAFF\_ANSWERED).** The Study staff answered my questions about the National Children's Study to my satisfaction.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children's Study Vanguard Phase (modified)

**NIR09000/(NIR\_NEGATIVE\_PRESS).** I heard or read something negative or uncomplimentary about the National Children's Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children's Study Vanguard Phase

**NIR10000/(NIR\_STAFF\_INHOME).** I was comfortable with Study staff coming to my home for Study appointments.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children's Study Vanguard Phase

**NIR11000/(NIR\_PROVIDE\_SAMPLES).** I was comfortable with the idea of providing biological samples, such as blood and urine.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children’s Study Vanguard Phase

**NIR12000/(NIR\_CONFIDENTIALITY).** I worried the information about me and my family might not be kept confidential.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children’s Study Vanguard Phase

**NIR13000/(NIR\_COMPENSATION1).** If the Study had offered more cash as compensation for my time and effort, I might have joined or stayed in the Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children’s Study Vanguard Phase (modified)

**NIR14000/(NIR\_COMPENSATION3).** If I had felt that I was learning more about children’s health, I might have joined or stayed in the Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children's Study Vanguard Phase

**NIR15000/(NIR\_COMPENSATION2).** If I had felt that I was learning more about my own child's health, I might have joined or stayed in the Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children's Study Vanguard Phase

**NIR16000/(NIR\_COMPENSATION4).** If I had felt more a part of the National Children's Study community, I might have joined or stayed in the Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children's Study Vanguard Phase (modified)

**NIR17000/(NIR\_TIME\_COMMITMENT).** Committing to participate in a study lasting 21 years seemed overwhelming to me.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children's Study Vanguard Phase

**NIR18000/(NIR\_FRIENDLY\_STAFF).** The National Children's Study staff were friendly.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	

Label	Code	Go To
Not applicable	-7	

<b>SOURCE</b>
National Children's Study Vanguard Phase

**NIR19000/(NIR\_STUDY\_UNCLEAR).** I was unclear about what I would be asked to do if I participated in the Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

<b>SOURCE</b>
National Children's Study Vanguard Phase (modified)

**NIR20000/(NIR\_CHILD\_PARTICIPATION).** I was uncomfortable with having my child participate in the Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

<b>SOURCE</b>
National Children's Study Vanguard Phase

**NIR21000/(NIR\_FEWER\_QUESTIONS).** If I was asked fewer questions, I might have joined or stayed in the Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

<b>SOURCE</b>
National Children's Study Vanguard Phase (modified)

**NIR22000/(NIR\_INTERNET\_SURVEY).** If I was able to complete a written or Internet-based survey, I might have joined or stayed in the Study.

Label	Code	Go To
Strongly agree	1	
Somewhat agree	2	
Somewhat disagree	3	
Strongly disagree	4	
Not applicable	-7	

**SOURCE**

National Children's Study Vanguard Phase (modified)

**NIR23000/(NIR\_ENOUGH\_INFO).** Do you feel that you were provided enough information about the National Children's Study before you were asked to join?

Label	Code	Go To
Yes	1	NIR_COMMUNICATION_FRE Q
No	2	

**SOURCE**

National Children's Study Vanguard Phase (modified)

**NIR24000/(NIR\_ENOUGH\_INFO\_OTH).** What type or types of information do you feel would have been helpful to you before you were asked to join the Study?

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**SOURCE**

National Children's Study Vanguard Phase (modified)

**NIR25000/(NIR\_COMMUNICATION\_FREQ).** Thinking about the number of letters, phone calls, and other correspondence you received from us to review your information, remind you of upcoming appointments, and provide other Study updates, would you say we communicated with you:

Label	Code	Go To
Much too often	1	
Too often	2	
Just the right amount	3	
Too little	4	
Much too little	5	

**SOURCE**

National Children's Study Vanguard Phase

**NIR26000/(NIR\_IMPORTANCE).** How important do you think the National Children's Study is?

Would you say that the National Children's Study is...

Label	Code	Go To
Very important	1	
Somewhat important	2	
Neither important nor unimportant	3	
Not very important	4	
Not important at all	5	

**SOURCE**

National Children's Study Vanguard Phase

**NIR27000/(NIR\_INFLUENCE).** Did any friends or family influence your decision not to join or to stop participating in the National Children's Study?

Label	Code	Go To
Yes	1	
No	2	NIR_FRIENDS_FAMILY

**SOURCE**

National Children's Study Vanguard Phase (modified)

**NIR28000/(NIR\_WHO\_INFLUENCE).** Who influenced your decision not to join or to stop participating in the National Children's Study? Select all that apply.

Label	Code	Go To
Mother/Father	1	
Brother/Sister	2	
Aunt/Uncle	3	
Grandparent	4	
Neighbor	5	
Friend	6	
Other	-5	

**SOURCE**

National Children's Study Vanguard Phase (modified)

**PARTICIPANT INSTRUCTIONS**

- If you selected "Other" and any other response(s), please go to **NIR29000**.
- If you did not select "Other," please go to **NIR30000**.

**PROGRAMMER INSTRUCTIONS**

- IF **NIR\_WHO\_INFLUENCE = -5 OR ANY COMBINATION OF 1 THROUGH 6 AND -5,** GO TO **NIR\_WHO\_INFLUENCE\_OTH**.
- OTHERWISE, GO TO **NIR\_FRIENDS\_FAMILY**.

**NIR29000/(NIR\_WHO\_INFLUENCE\_OTH).** Specify: \_\_\_\_\_

**SOURCE**

National Children's Study Vanguard Phase

**NIR30000/(NIR\_FRIENDS\_FAMILY).** Do you think that you would be more likely to join or continue to participate in the National Children's Study if it was suggested by a friend or family member?

Label	Code	Go To
Yes	1	
No	2	

<b>SOURCE</b>
National Children's Study Vanguard Phase

**NIR31000/(NIR\_FINAL).** If you have any additional comments, feedback, or suggestions about the National Children's Study, please enter them in this box.

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<b>SOURCE</b>
National Children's Study Vanguard Phase (modified)

**NIR32000.** Thank you for taking the time to answer these questions.

**FOR OFFICE USE ONLY:**

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

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