



Participant Engagement and Motivation SAQ

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.

Public reporting burden for this collection of information is estimated to average 6 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.

This page intentionally left blank.

Participant Engagement and Motivation SAQ

TABLE OF CONTENTS

GENERAL PROGRAMMER INSTRUCTIONS:.....	1
STUDY HISTORY.....	3
PARTICIPANT ENGAGEMENT AND MOTIVATION.....	5
FOR OFFICE USE.....	26

This page intentionally left blank.

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	<ul style="list-style-type: none"> Limit text to 255 characters
FIRST NAME AND LAST NAME	30	CHARACTER	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	

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.*)

SOURCE
New

(LAST_CHILD_AGE) Child's age at last visit

--	--	--	--

(LAST_CHILD_AGE_UNIT)

Label	Code	Go To
Months	1	

Label	Code	Go To
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

SOURCE
New

SH05000/(NUM_PHONE_VISIT). How many telephone interviews with the NCS have you participated in?

Number of telephone visits

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	

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	

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	

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	

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	

Label	Code	Go To
9	9	
10 Very Important	10	

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	

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	

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	

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	

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	

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:

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

SOURCE

participation. *Ethnicity & Disease*, 16, 547-550. (modified)

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: _____

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.

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	

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	

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	

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	

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.

SOURCE
National Children's Study, Legacy Phase

PEM18000/(NCS_EXPERIENCE_POSITIVE). Overall, my experience in the NCS has been positive.

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

SOURCE
New

PEM19000/(NCS_MET_EXPECTATIONS). NCS Study visits have met my expectations.

Label	Code	Go To
Strongly Disagree	1	

Label	Code	Go To
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	

Label	Code	Go To
Strongly Agree	5	

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	

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	

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. <i>Accountability in Research</i> , 8, 27-47. (modified)

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

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

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	

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	

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	

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	

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 circle 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	

Label	Code	Go To
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	

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	

Label	Code	Go To
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	

Label	Code	Go To
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	

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	

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	

SOURCE
New

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

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: _____