OMB #: 0925-0593 OMB Expiration Date: 8/31/2014 Participant Satisfaction SAQ, Phase 2g OMB Specification



Participant Satisfaction SAQ

| Event Category: | Time-Based |
|---------------------------------------|--|
| Event: | 6M, 42M |
| 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: | 2 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 2 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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Participant Satisfaction SAQ

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Participant Satisfaction 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 CHARACTE RS 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 DESIGNATI ON | 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 $\mathbf{R}_{-}\mathbf{P}_{-}\mathbf{ID}$ (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.**

PARTICIPANT SATISFACTION

PS01000. 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 2 minutes to complete. Your responses will be used to help us understand more about what it is like to be a reserch 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.

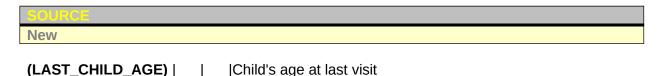
PS02000. Please enter today's DATE:

| (PSS_DATE_MM) |
|-----------------|
| M M |
| (PSS_DATE_DD) |
| _ D D |
| (PSS_DATE_YYYY) |
| |

Y Y Y Y

PS03000. 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).



(LAST_CHILD_AGE_UNIT)

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

| PS04000/(NUM_INPERSON_VISITS). How many times has NCS staff conducted face-to-face visits (interviews or sample collection) with you or your child <u>at your home, a clinic or other location?</u> |
|--|
| Number of face-to-face visits conducted |
| SOURCE |
| PS05000/(NUM_PHONE_VISIT). How many telephone visits (interviews) with the NCS have you participated in? |
| Number of telephone visits completed |
| SOURCE |
| New |
| PS06000/(CURRENT_PART_REASON). From the list below, please rank the top three reasons for your current participation in the National Children's Study. Rank your reasons using: |
| 1 = most important 2 = second most important 3 = third most important |
| I am curious about children's health |
| The Study visits are interesting |
| I feel I have to participate |
| My participation will help other children and families |
| I am contributing to science |
| Participating is fun |
| I participate for the cash incentives |
| I think my participation may improve my child's health |
| Other |
| 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>Acountability in Research</i> , 8, 27-47. (modified) |

PROGRAMMER INSTRUCTIONS

- LOOP THROUGH CURRENT_PART_REASON THREE TIMES TO SELECT MOST IMPORTANT = 1, SECOND MOST IMPORTANT = 2, AND THIRD MOST IMPORTANT = 3 REPSONSES.
- IF PARTICIPANT SELECTS "OTHER," GO TO **PS07000**.
- OTHERWISE, IF "OTHER" IS NOT SELECTED, GO TO CURRENT PART REASON OTH.

| PS06100/(CURRENT_PART_REASON_OTH). | |
|------------------------------------|--|
| Specify | |

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. Acountability in Research, 8, 27-47. (modified)

PS07000. 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 only one response per statement.

SOURCE

National Children's Study, Legacy Phase (Satisfaction survey) (modified)

PS08000/(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

National Children's Study, Legacy Phase (Satisfaction survey)

PS09000/(PREFER_INPERSON). I prefer to talk with NCS staff in-person instead of by telephone

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

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

PS10000/(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' expectations for health care: a review and psychometric testing of a measure of pateints' expectations. *Health Technology Assessment*, 16(30). (modified)

PS11000/(PART_NOT_CONVENIENT). 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. *Acountability in Research*, 8, 27-4. (modified)

PS12000/(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 | |

PS13000/(NCS_BORING). I find participating boring

| Label | Code | Go To |
|-----------------------------------|------|-------|
| Strongly Disagree | 1 | |
| Diagree | 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. *Acountability in Research*, 8, 27-4. (modified)

PS14000/(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. *Acountability in Research*, 8, 27-4. (modified)

PS15000/(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

PS16000/(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. *Acountability in Research*, 8, 27-4. (modified)

PS17000. On a scale of 1-10 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.

SOURC

New

PS18000/(CONTRIB_GEN_SCIENCE). Contributing to general science and health information

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

SOURCE

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

PS19000/(LEARN_MORE). Learning more about child health

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

SOURCE

Gantry, 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)

PS20000/(ENJOY_PART). The enjoyment of participation

| Label | Code | Go To |
|----------------------|------|-------|
| Not at All Important | 1 | |
| | 2 | |
| | 3 | |
| | 4 | |
| | 5 | |
| | 6 | |

| Label | Code | Go To |
|----------------|------|-------|
| | 7 | |
| | 8 | |
| | 9 | |
| Very Important | 10 | |

SOURCE

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

PS21000/(PART_HEALTH). To get information about my health and my child's health from Study testing

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

SOURCE

Gantry, 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)

PS22000/(PART_INCENTIVE). Receiving incentives (money,gift cards, etc.)

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

SOURCE

Gantry, 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)

PS23000/(PART_NEXT_GENERATION). Wanting to help the next generation of children

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

SOURCE

Gantry, 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)

| PS24000/(SHARE_EXPERIENCES_NCS). Is there anything about your experince National Children's Study you would like to share? | es in | the |
|---|-------|-----|
| | | |
| | | |

SOURCE

New

PS25000. Thank you for participating in the National Children's Study and for taking the time to complete this survey.

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| FOU01000/(P_ID). Participant ID: | _ |
|-----------------------------------|---|
| FOU02000/(R_P_ID). Respondent ID: | |