

General History

Thank you for participating in the CKiD study.

The following pages contain a series of questionnaires for you to complete. Please reach out to your study coordinator if you have any questions or need further clarification.

Data entry person:

Date of data entry:

A2. CKiD VISIT #:

A3. FORM VERSION:

08/01/21

A4. DATE OF VISIT:

A5. SITE COORDINATOR'S INITIALS:

A6. INDICATE PERSON COMPLETING THE FORM

- Child/young adult
- Parent or other adult
- Both (Parent and Child/young adult)

For each question, fill in the answer or circle the number that best matches the respondent's answer. Circle -8 for "Don't Know" responses. If a participant declines to answer a question, document -7 to the right of the response choice(s). For missing data, document -9 to the right of the response choice(s). Please document the reason for missing data (i.e., the question was accidentally skipped.)

Read each question and follow skip patterns as they appear on the form. Review the QxQ for detailed descriptions of questions.

INTRODUCTION TO PARTICIPANT/PARENT OR OTHER ADULT:

Thank you for participating in this study.

The following pages contain questions about the participant's family background and family medical history since their last study visit. Some of the questions may be difficult for you to answer and exact dates may be hard to remember. Please take as much time as you need, so I can gather information that is as accurate as possible.

As with all study information, your responses will be kept strictly confidential, and the responses you provide will in no way affect the participant's clinical care. The first set of questions asks about the person completing the form and the participant's background. If you have trouble understanding anything please feel free to ask for further clarification.

SECTION B: INFORMATION ABOUT YOU

The following questions are about your relationship to the participant who is participating in the study.

B1. What is your relationship to (name of participant)?

- Mother
- Father
- Legal Guardian
- Self
- Other

a. If OTHER, specify your relationship:
(Such as: grandmother, stepfather, uncle, etc.)



SECTION C: PARTICIPANT'S BACKGROUND

The next questions are about the participant's background.

C1. What is (name of participant) date of birth?

(MM-DD-YYYY)

Age at visit _____

C2. What is (name of participant) gender at birth?

- Male
- Female

C3. Was (name of participant) born in the United States of America (USA)?

- Yes
- No

a. Was (name of participant) born in Canada?

- Yes
- No

b. In what country was he or she born?

c. When did (name of participant) move to the U.S. or Canada?

((year))

C4a. Is (name of participant) of Hispanic or Latino/a origin?

- Yes, Mexican-American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, other Hispanic/Latino/a
- No, not of Hispanic or Latino/a origin
- Don't know

b. Which language does the participant speak most frequently?

- English
- Spanish
- Both (participant is bilingual)

C5. Which of the following describe the race of (name of participant)? (Circle "Yes", "No", or "Don't Know" for EACH of the following. You may select "Yes" for more than one race.)

- a. White _____
- b. Black / African American _____
- c. American Indian / Alaskan Native _____
- d. Asian _____
- e. Native Hawaiian/Pacific Islander _____
- f. Other _____

SECTION D: PARTICIPANT'S BIRTH

The next questions are about the birth of the participant who is participating in the study. The following questions also ask about the participant's biological parents. Biological parents are defined as the participant's birth or blood-related father or mother.

D1. Was (name of participant)'s birth weight in pound (lbs) or kilograms (kg)?

- lbs
- kg
- don't know

a. What was (name of the participant)'s birth weight in lbs and ounces?

_____ lbs _____ oz

b. What was (name of participant)'s birth weight in kilograms?

(kg)

D2. What was (name of participant) length at birth? (Round off to the nearest inch or centimeter. If 1/2 or greater round up.) (Please select "1" for inches or "2" for centimeters.)

()

D3. Was (name of participant) born in a hospital?

- Yes
- No
- Don't know

D4. How was (name of participant) delivered?

- Vaginal birth (natural)
- Cesarean section (c-section)
- Don't know

D5. Was (name of participant) born BEFORE due date?

- Yes
- No
- Don't know

a. How many weeks BEFORE due date was (name of participant) born?

(weeks)

b. Was (name of participant) considered "pre-mature" at the time of his/her birth?

- Yes
- No
- Don't know

D6. Was (name of participant) a part of a multiple birth (e.g. a twin, triplet, etc.)?

- Yes
- No

D7. Immediately after birth, did (name of participant) spend time in the intensive care unit (ICU or NICU) before being allowed to go home?

- Yes
- No
- Don't know

D8. Immediately after birth, did (name of participant) have any kidney problems?

- Yes
- No
- Don't know

D9. How long was (name of participant) birth mother in the hospital after the delivery?

()

D10. How long was (name of participant) in the hospital after the delivery?

()

D11. What was the age of (name of participant) biological mother when the participant was born?

(years)

D12. Is (name of participant) biological mother of Hispanic or Latina Origin?

- Yes, Mexican-American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, other Hispanic/Latina
- No, not of Hispanic or Latina origin
- Don't know

D13. Which of the following describe the race of (name of participant) biological mother? (Select "Yes", "No" or "Don't Know" for EACH of the following. You may select "Yes" for more than one race.)

White _____

Black / African American _____

American Indian / Alaskan Native _____

Asian _____

Native Hawaiian / Pacific Islander _____

Other _____

D14. What was the age of (name of participant) biological father when the participant was born?

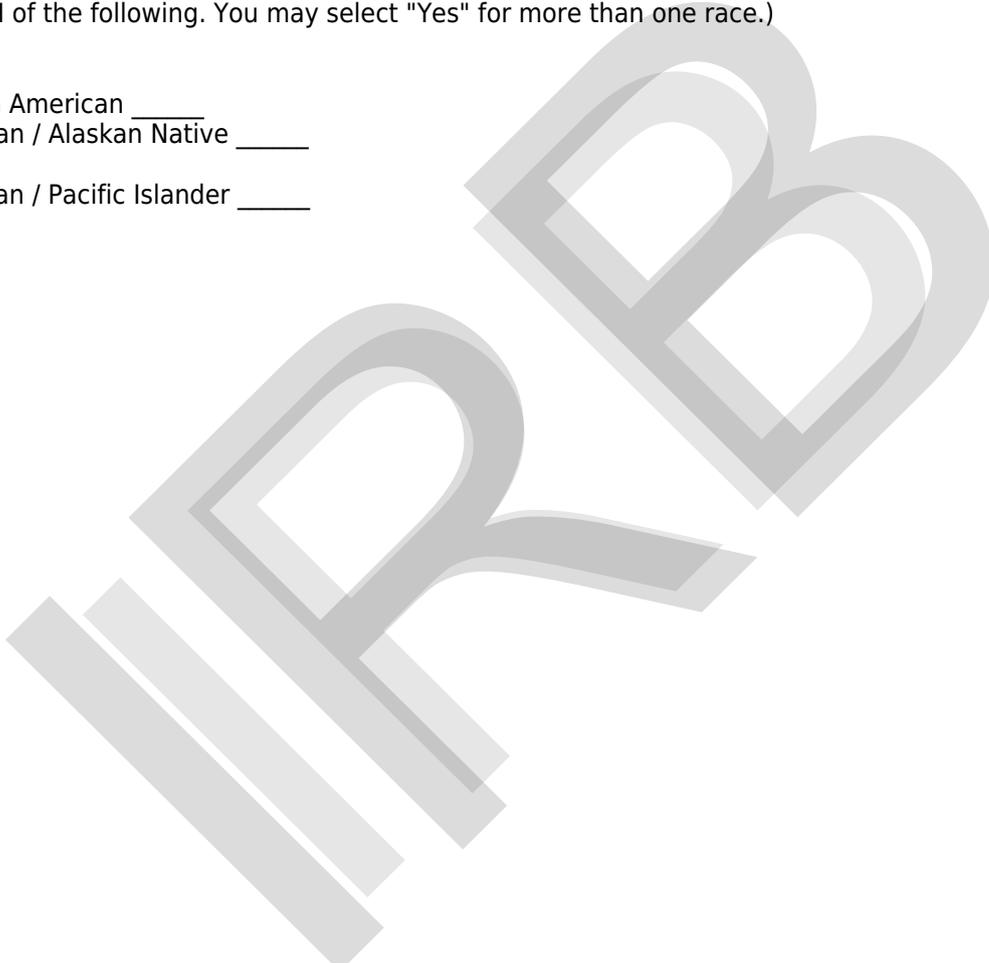
(years)

D15. Is (name of participant) biological father of Hispanic or Latino Origin?

- Yes, Mexican-American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, other Hispanic/Latina
- No, not of Hispanic or Latina origin
- Don't know

D16. Which of the following describe the race of (name of participant) biological father? (Select "Yes", "No" or "Don't Know" for EACH of the following. You may select "Yes" for more than one race.)

- White _____
- Black / African American _____
- American Indian / Alaskan Native _____
- Asian _____
- Native Hawaiian / Pacific Islander _____
- Other _____
- _____



SECTION E: PARTICIPANT'S EDUCATION

The following questions are about the participant's education. Specifically, the next question asks about the highest grade or level of school the participant has completed. For example, if the participant is in the 1st grade, kindergarten or pre-school/pre-K, then enter "0". If the child is less than 5 years old and does not attend pre-school/pre-k then choose Not Applicable (-1). If the participant is currently in the 12th grade, then enter "11", if participant is a sophomore in college, then enter "13" or if the participant is currently in the 6th grade, then enter "5". In addition, if completed high school enter "12 years", if completed 4-year college degree enter "16 years", and if completed a 4-year doctoral degree enter "20 years."

E1. What is the highest grade or level of school that (name of participant) has COMPLETED?

(Grade)

E2. Does (name of participant) attend school (including pre-school and pre-K) outside of the home?

- Yes
 No

E3. During the past school year, approximately how many days has (name of participant) missed from school because of not feeling well?

(Days)

The next two questions refer to service(s) the participant is currently receiving. If this form is completed during the summer months, please refer to the service(s) the participant received during the past school year.

E4. Does (name of participant) have an individualized educational plan (IEP)? (An individualized educational plan includes special education and related services designed to address specific educational needs of children with disabilities.)

- Yes
 No
 Don't know
 Not Applicable/child less than 5 years old

E5. Does (name of participant) have a 504 plan at school (or equivalent for Canadian sites)? (A 504 plan is a program designed to assist students with physical or emotional disabilities or other special needs in a regular school environment.)

- Yes
 No
 Don't know

SECTION F: PARTICIPANT'S FAMILY AND PRIMARY HOUSEHOLD

The following questions are to learn more about the participant's home and with whom he or she lives.

F1. What is the current relationship between (name of participant) biological parents?

- Not married, living together
- Married, living together
- Married, separated
- Widowed
- Divorced
- Never married, not living together
- Refuse to answer
- Don't Know

The following questions ask about the participant's primary household. The primary household is the parent/guardian's home in which the participant lives at least half of the time. If the participant does not live with a parent/guardian (living independently, attending college or boarding school, emancipated, etc.), then the primary household is the parent/guardian's home where the participant used to live at least half the time prior to living independently.

F2. How many days per week does (name of participant) live in the primary household? Indicate a number between 4 and 7. (For participants who do not live with a parent/guardian, indicate the number of days the participant lived in parent/guardian's home prior to living independently.)

(days)

F3. How many people live in the primary household at least half the time?

(people)

F4. How many adults live in the primary household at least half the time? An adult is a person at least 18 years of age. Include all persons at least 18 years of age, including siblings and non-relatives. Include participant if 18 years of age.

(adults)

F5. Which of the following adults (18 years of age and older) live in the primary household at least half the time? Include the participant, if applicable. (Select "Yes", "No" or "Don't Know" for EACH of the following.)

- Birth Mother _____
- Birth Father _____
- Step Mother/ Adoptive Mother _____
- Step Father/ Adoptive Father _____

Participant _____

Other _____

F6. Do any of the people, adults or children, living in the primary household at least half the time routinely smoke cigarettes, cigars, cigarillos or little cigars?

- Yes
 No
 Don't know

The following questions are about the education level of the participant's parent(s)/guardian(s) in the primary household. Remember, primary household is defined as the home in which the participant lives at least half of the time or lived prior to living independently.

F7. What is the highest grade or level of school that (name of participant) MOTHER (including birth, adoptive or stepmother) in the primary household has COMPLETED? For example, if completed high school enter "12 years", if completed 4-year college degree enter "16 years", and if completed a 4-year doctoral degree enter "20 years."

([Years]; if No such person, choose Not applicable (-1))

F8. What is the highest grade or level of school that (name of participant) FATHER (including birth, adoptive or stepfather) in the primary household has COMPLETED? For example, if completed high school enter "12 years", if completed 4-year college degree enter "16 years", and if completed a 4-year doctoral degree enter "20 years."

([Years]; if No such person then choose Not applicable (-1))

F9. Please estimate the total income (before taxes) of all members of the primary household. Include total income from wages, business, or investments for all members of (name of participant) primary household, by year, month, or week. Do NOT include social security, disability insurance, or other governmental assistance.

- \$6,000 OR LESS/yr \$500 OR LESS/mo \$115 OR LESS/wk
 \$6,001 TO \$12,000/yr \$501 TO \$1,000/mo \$116 TO \$231/wk
 \$12,001 TO \$18,000/yr \$1,001 TO \$1,500/mo \$232 TO \$346/wk
 \$18,001 TO \$24,000/yr \$1,501 TO \$2,000/mo \$347 TO \$461/wk
 \$24,001 TO \$30,000/yr \$2,001 TO \$2,500/mo \$462 TO \$577/wk
 \$30,001 TO \$36,000/yr \$2,501 TO \$3,000/mo \$578 TO \$692/wk
 \$36,001 TO \$75,000/yr \$3,001 TO \$6,250/mo \$693 TO \$1442/wk
 MORE THAN \$75,000/yr MORE THAN \$6,250/mo MORE THAN \$1442/wk
 Don't know

F9a. What is the current employment status of (name of participant) MOTHER (including birth, adoptive or stepmother) in the primary household?

- Working full-time (35 hours or more per week)
 Working part-time (less than 35 hours per week)
 Unemployed but seeking work
 Unemployed not seeking work
 Student
 Retired
 Disability
 No such person in household/Not Applicable
 Don't Know

i. Is (name of participant) MOTHER in the primary household self-employed?

- Yes
 No
 Don't know

F9b. What is the current employment status of (name of participant) FATHER (including birth, adoptive or stepfather) in the primary household?

- Working full-time (35 hours or more per week)
 Working part-time (less than 35 hours per week)
 Unemployed but seeking work
 Unemployed not seeking work
 Student
 Retired
 Disability
 No such person in household/Not Applicable
 Don't Know
-

i. Is (name of participant)'s FATHER in the primary household self-employed?

- Yes
 No
 Don't know
-

F9c. What is the current employment status of (name of participant)?

Working full-time (35 hours or more per week) _____
 Working part-time (less than 35 hours per week) _____
 Disability income _____
 Student _____
 Unemployed but seeking work _____
 Unemployed not seeking work _____

i. Is (name of participant) self-employed?

- Yes
 No
 Don't know
-

F10. What is the zip code where the participant currently lives at least half of the time?

F11. Has the participant lived at the current zip code for more than 1 year?

- Yes
 No
 Don't know
-

a. Approximately how many months has the participant lived at the current zip code?

(months)

b. What was the zip code where the participant previously lived?

c. Approximately, how many years did the participant live at the previous zip code?

(years)

F12. Approximately, how many years has the participant lived at the current zip code?

F13. Is the participant's zip code and their parents/guardians' zip code the same?

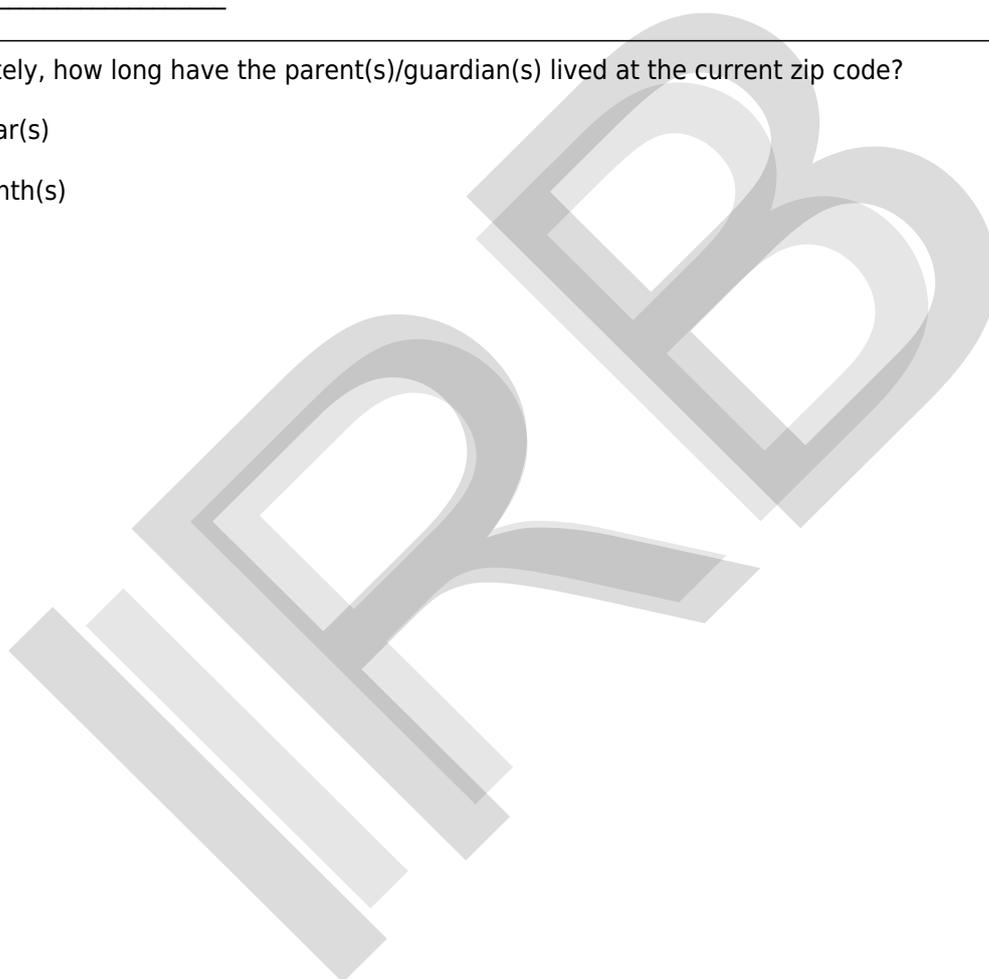
- Yes
 No
 Don't know

F14. What is the current zip code of the parent(s)/guardian(s) (i.e., the parent(s)/guardian(s) home where the participant used to live at least half the time prior to living independently)?

15. Approximately, how long have the parent(s)/guardian(s) lived at the current zip code?

_____ year(s)

_____ month(s)



SECTION G: PARTICIPANT'S FAMILY HISTORY

The health conditions and illnesses experienced by close family members can provide important information about the participant's health. The following questions ask about the medical history of the participant's biological family. The participant's biological family includes his or her birth mother, birth father, grandparents, aunts, uncles, full brothers, full sisters and first cousins. (This does not include great aunts, great uncles and great grandparents.) Full brothers and full sisters are defined as siblings who have the same birth mother and birth father as the participant.

Some people who lost their parents at an early age, or who were adopted, may not have information on their birth family. If you are familiar with the health history of any of the members of the participant's biological or birth family, please answer the following questions about these relatives' health to the extent that you are able. If you are uncertain of the answer to any question, please select "Don't Know." If you have trouble understanding anything, please feel free to ask for further clarification. If more than one parent, sibling, grandparent, aunt, uncle, or cousin has kidney disease or other health issues indicated below, ask your site coordinator for further instructions.

G1. Do you have knowledge of the health history of any members of (name of participant) birth family (i.e. parents, grandparents, aunts, uncles, siblings and cousins)?

- Yes
 No

G2a. How many living half siblings does (name of participant) have (Half siblings are defined as brothers and sisters, who have only one parent, either mother or birth father in common. Do not include deceased siblings.)?

b. Does (name of participant) have any living half siblings in the study?

- Yes
 No

i. How many living half siblings does (name of participant) have participating in the study?

(living half siblings)

G3a. How many full siblings does (name of participant) have? (Full siblings are defined as brothers and sisters, who have the same birth mother and birth father as the participant. Include deceased siblings.)

_____)

(full (living and deceased) siblings)

b. How many living full siblings does (name of participant) have?

(full (living) siblings)

c. Does (name of participant) have any living full siblings in the study?

- Yes
 No
-

i. How many living full siblings does (name of participant) have participating in the study?

_____ (living full siblings)

G5a. Including living or deceased, has (name of participant) biological family members been told by a health care professional that they had kidney disease in the past year?

- Yes
 No
 Don't know
-

b. Which family members? c. What type of kidney disease?

Mother _____
 Father _____
 Sibling (full brother or sister) _____

Grandparent(s) _____
 Aunt(s)/Uncle(s) _____
 Cousin(s) _____

Next, the following questions ask about (name of participant) biological family members.

G6a. Including living and deceased, have any of (name of participant) biological family members been told by a health care professional that they had the SAME kidney disease as (name of participant)?

- Yes
 No
 Don't know
-

b. Which biological family members?

(Select "Yes" or "No" for EACH of the following.)

Mother _____
 Father _____
 Sibling (full brother or sister) _____
 Grandparent(s) _____
 Aunt(s)/Uncle(s) _____
 Cousin(s) _____

G7a. Including living and deceased, have any of (name of participant) biological family members had a kidney biopsy?

- Yes
 No
 Don't know
-

b. Which biological family members?

(Select "Yes" or "No" for EACH of the following.)

Mother _____
 Father _____
 Sibling (full brother or sister) _____
 Grandparent(s) _____
 Aunt(s)/Uncle(s) _____
 Cousin(s) _____

G8a. In the past year, have any of (name of participant) living or deceased biological family members been told by a health care professional (any doctor, nurse, physician assistant or nurse practitioner) that they had... b. Which biological family members? (Circle "Yes", "No", or "Don't Know" for EACH of the following)

1. High Blood Pressure or Hypertension _____ Mother _____

Father _____

Sibling _____

Grandparent(s) _____

Aunt(s)/Uncle(s) _____

Cousin(s) _____

2. High Cholesterol _____ Mother _____

Father _____

Sibling _____

Grandparent(s) _____

Aunt(s)/Uncle(s) _____

Cousin(s) _____

3. Diabetes (high blood sugar or sugar diabetes) _____ Mother _____

Father _____

Sibling _____

Grandparent(s) _____

Aunt(s)/Uncle(s) _____

Cousin(s) _____

4. Stroke before the age of 50 _____ Mother _____

Father _____

Sibling _____

Grandparent(s) _____

Aunt(s)/Uncle(s) _____

Cousin(s) _____

5. Heart Attack before the age of 50 _____ Mother _____

Father _____

Sibling _____

Grandparent(s) _____

Aunt(s)/Uncle(s) _____

Cousin(s) _____

G9a. In the past year, have any of (name of participant) living or deceased biological family members had dialysis as treatment for kidney disease? b. Which biological family members?

(Select "Yes", "No", or "Don't Know" for EACH of the following)

c. At what age was treatment started?

_____ Mother _____

_____ Father _____

_____ Sibling _____

_____ Grandparents _____

_____ Aunts/Uncles _____

_____ Cousins _____

G10a. In the past year, have any of (name of participant) living or deceased biological family members had a kidney transplant as treatment for kidney disease? b. Which biological family members? (Select "Yes", "No", or "Don't Know" for EACH of the following) c. At what age was transplant performed?

_____ 1. Mother _____

2. Father _____

3. Sibling _____

4. Grandparents _____

5. Aunts/Uncles _____

6. Cousins _____

G11. In the past year, have any of the birth mother's pregnancies resulted in the following?

(Select "Yes", "No" or "Don't Know" for EACH of the following)

Stillbirth (fetus died at birth) _____

Miscarriage _____

G12. What is the current height of (name of participant) birth mother? _____ feet _____ inches

G13. What is the current weight of (name of participant) birth mother?

_____ (lbs)

G14. Has (name of participant) birth mother had recurrent Urinary Tract Infections (UTI)?

- Yes
 No
 Don't know
-

G15. What is the current height of (name of participant) birth father?

_____ feet _____ inches

G16. What is the current weight of (name of participant) birth father?

_____ lbs

G17. Has (name of participant) birth father had recurrent Urinary Tract Infections (UTI)?

- Yes
 No
 Don't know
-

G18. Have any of (name of participant) siblings had recurrent Urinary Tract Infections (UTI)?

- Yes
 No
 Don't know
 N/A, participant does not have any siblings
-

H1. At what age did (name of participant) first perform the following activities?

Age
a. Turn over _____
months

b. Sit alone _____
months

c. Crawl _____
months

d. Stand alone _____
months

e. Walk alone _____
months

f. Walk upstairs _____
months

g. Walk downstairs _____
months

h. Show interest in or attraction to sound (i.e., showed interest in shaking keys) _____

i. Understand first words _____

months

j. Speak first words _____

months

k. Speak in sentences (3 or more words)

months

H2a. Is (name of participant) currently older than 5 years of age?

- Yes
 No

b. Is (name of participant) currently breast-fed?

- Yes
 No
 Don't know

c. Was (name of participant) breast-fed?

- Yes
 No
 Don't know

d. How old was (name of participant) when he/she was weaned from breast feeding?
(Please select "1" for years, "2" for months, "3" for weeks or "4" for days.)

(_____)

H3. Is (name of participant) currently bottle-fed?

- Yes
 No
 Don't know

a. Was (name of participant) bottle-fed?

- Yes
 No
 Don't know

b. How old was (name of participant) when he/she was weaned from bottle feeding?
(Please select "1" for years, "2" for months, "3" for weeks or "4" for days)

(_____)

H4. Does (name of participant) have any wetness or leakage of urine (accidents) during the day or night?

- Yes
 No
 Don't know

a. Is (name of participant) wet during the day?

- Yes
 No
 Don't know

b. Is (name of participant) wet during the night?

- Yes
 No
 Don't know

c. Does (name of participant) catheterize the bladder (i.e., put a tube in the bladder)?

- Yes
 No
 Don't know

i. Does (name of participant) catheterized through the urethra?

- Yes
 No
 Don't know

ii. Does (name of participant) catheterized through a stoma?

- Yes
 No
 Don't know

H5. Is (name of participant) currently toilet trained?

- Yes
 No
 Don't know

a. When was (name of participant) toilet trained?

_____ (years)

b. After toilet training, did bed-wetting occur?

- Yes
 No
 Don't know

i. Does bed-wetting still occur?

- Yes
 No
 Don't know

ii. At what age did bed-wetting stop?

_____ ()

iii. Were medical reasons the cause of bed-wetting?

- Yes
 No
 Don't know

c. After toilet training, did bed-soiling occur?

- Yes
 No
 Don't know

i. Does bed-soiling still occur?

- Yes
 No
 Don't know

ii. At what age did bed-soiling stop?
(Please select "1" for years and "2" for months)

_____ ()

iii. Were medical reasons the cause of bed-soiling?

- Yes
 No
 Don't know

H6. Is (name of participant) 4 years of age or older?

- Yes
 No

H7. During (name of participant) first 4 years, were any problems noted in the areas listed below? (Circle "Yes", "No" or "Don't Know" for EACH of the following.)

- a. Eating _____
- b. Excessive crying _____
- c. Failure to thrive _____
- d. Motor skills _____
- e. Separating from parents _____
- f. Sleeping too little _____
- g. Sleeping too much _____
- h. Temper tantrums _____

H8. Which hand does (name of participant) primarily use to write?

- Primarily right
- Primarily left
- Ambidextrous (writes equally with both left and right hands)

If the participant is under 4 years old, please answer the next question based on whether a doctor or health care professional has told you that the participant has had any of the following problems.

H9. Is (name of participant) currently under 4 years old?

- Yes
- No (END FORM)

H10. Has (name of participant) experienced any of the following problems?

(Select "Yes", "No" or "Don't Know" for EACH of the following.)

- a. Feeding problem _____
- b. Eating disorder _____
- c. Underweight problem _____
- d. Overweight problem _____
- e. Walking difficulty (per healthcare professional) _____
- f. Unclear speech (per healthcare professional) _____
- g. Sleep problem _____
- h. Colic _____

Date:

INITIALS:

ADMINISTRATION:

- Interviewer Assisted
- Self-Administered
- Both