

General History For Post-KRT (RF13)

Data entry person:

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 we 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.

What is the participant's date of birth?

_____ (MM-DD-YYYY)

Age at visit

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 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."

C1. What is the highest grade or level of school that
(name of participant) has COMPLETED?

_____ (Grade)

D1. 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.)

- a. Birth Mother _____
- b. Birth Father _____
- c. Step Mother/ Adoptive Mother _____
- d. Step Father/ Adoptive Father _____

- e. Participant _____
- f. Other _____
- _____

D2. 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. Select the number in the FAR RIGHT COLUMN that corresponds to the total income.

- \$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

D3. 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

D4. What is the zip code where the participant currently lives at least half of the time? _____

D5. 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)

D6. Approximately, how many years has the participant lived at the current zip code? _____

D7. Is the participant's zip code and their parents/guardians' zip code the same?

- Yes
- No
- Don't know

D8. 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)?

D9. Approximately, how long have the parent(s)/guardian(s) lived at the current zip code?

_____ year(s)

_____ month(s)

SECTION E: 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.

E1a. In the past year, have any of (name of participant) living or deceased 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?

1. Mother _____
2. Father _____
3. Sibling (full brother or sister) _____
4. Grandparent(s) _____
5. Aunt(s)/Uncle(s) _____
6. Cousin(s) _____

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

E2a. In the past year, have any of (name of participant) living or deceased 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.)

1. Mother _____
2. Father _____
3. Sibling (full brother or sister) _____
4. Grandparent(s) _____
5. Aunt(s)/Uncle(s) _____

6. Cousin(s) _____

E3a. In the past year, have any of (name of participant) living or deceased 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.)

- 1. Mother _____
- 2. Father _____
- 3. Sibling (full brother or sister) _____
- 4. Grandparent(s) _____
- 5. Aunt(s)/Uncle(s) _____
- 6. Cousin(s) _____

E4a. 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) _____

E5a. 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?

_____ 1. Mother _____

_____ yrs old

2. Father _____

_____ yrs old

3. Sibling _____

_____ yrs old

4. Grandparents _____

_____ yrs old

5. Aunts/Uncles _____

_____ yrs old

6. Cousins _____

_____ yrs old

E6a. 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 _____ yrs old

2. Father _____ yrs old

3. Sibling _____ yrs old

4. Grandparents _____ yrs old

5. Aunts/Uncles _____ yrs old

6. Cousins _____ yrs old

SECTION F: PARTICIPANT'S DEVELOPMENTAL HISTORY

The following questions are to learn more about the participant's development.

F1. Is (name of participant) currently on dialysis?

- Yes
 No

F2. In the past year, has (name of participant) had any wetness or leakage of urine (accidents) during the day or night?

- Yes
 No
 Don't know

a. In the past year, is (name of participant) wet during the day?

- Yes
 No
 Don't know

b. In the past year, is (name of participant) wet during the night?

- Yes
 No
 Don't know

c. In the past year, has (name of participant) catheterized the bladder (i.e., put a tube in the bladder)?

- Yes
 No
 Don't know

i. In the past year, has (name of participant) catheterized through the urethra?

- Yes
 No
 Don't know

ii. In the past year, has (name of participant) catheterized through a stoma?

- Yes
 No
 Don't know

F3. At the last CKiD study visit, was (name of participant) toilet trained?

- Yes (END FORM)
 No
 Don't know (END FORM)

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

- Yes
 No
 Don't know

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

(Age in years)

c. 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
-

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

- Yes
 - No (END FORM)
 - Don't know (END FORM)
-

i. Does bed-soiling still occur?

- Yes
 - No
 - Don't know (END FORM)
-

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
-

DATE: _____ INITIALS: _____
FORM ADMINISTRATION: _____