

# Abbreviated Follow-up General History

A2. CKiD VISIT #:

\_\_\_\_\_

A3. FORM VERSION:

08/01/21

A4. DATE OF VISIT:

\_\_\_\_\_

Age at visit

\_\_\_\_\_

A5. SITE COORDINATOR'S INITIALS:

\_\_\_\_\_

A6. Is this study visit an irregular (accelerated) visit?

- Yes  
 No

A7. 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:

Thank you for participating in this study.

The following pages contain questions about your 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 you and the participant's background. If you have trouble understanding anything, please feel free to ask for further clarification.

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

- Mother
- Father
- Legal Guardian
- Self
- Other

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a. If OTHER, specify your relationship:

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**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 currently in the 12th grade, then enter "11", or if the participant is currently in the 6th grade, then enter "5". In addition, if the participant is in the 1st grade, kindergarten or pre-school/pre-K, then enter "0" or if participant is a sophomore in college, then enter "13". If Not Applicable/child less than 5 years old and does not attend pre-school/ pre-k choose -1.

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

\_\_\_\_\_  
(Grade)

C2. Does (name of participant) attend school (including pre-school and pre-K) outside of the home?

- Yes  
 No

C3. 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 unless this form is completed during the summertime when school is not in session. If this form is completed during the summer months, please refer to the service(s) the participant received during the past school year.

C4. 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

C5. 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 D: 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.**

D1. 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.

D2. 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)

D3. How many people live in the primary household at least half the time?

\_\_\_\_\_

(people)

D4. 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)

D5. Which of the following adults (18 years of age or older) live in the primary household at least half the time? Include the participant, if applicable. (Circle "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 \_\_\_\_\_
- \_\_\_\_\_

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D6. 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

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D9. 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

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D9a. 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

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

- Yes  
 No  
 Don't know

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D9b. 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

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

- Yes  
 No  
 Don't know

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D9c. 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 \_\_\_\_\_

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

- Yes
- No
- Don't know

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D10. What is the zip code where the participant currently lives at least half of the time?

\_\_\_\_\_

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D11. Has the participant lived at the current zip code for more than 1 year?

- Yes
- No
- Don't know

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

\_\_\_\_\_

(months)

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

\_\_\_\_\_

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

\_\_\_\_\_

(years)

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D12. Approximately, how many years has the participant lived at the current zip code?

\_\_\_\_\_

(years)

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D13. Is the participant's zip code and their parents/guardians' zip code the same?

- Yes
- No
- Don't know

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D14. 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)?

\_\_\_\_\_

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D15. Approximately, how long have the parent(s) lived at the current zip code?

\_\_\_\_ years \_\_\_\_ months

IRRB

**SECTION F: PARTICIPANT'S DEVELOPMENTAL HISTORY**

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

F1. At the last CKiD study visit, was (name of participant) older than 5 years of age?

- Yes  
 No

F2a. 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.)

( )

F3. 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)

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F4. 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
- 

F5. At the last CKiD study visit, was (name of participant) toilet trained?

- Yes  
 No  
 Don't know
- 

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

- Yes  
 No  
 Don't know
- 

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

\_\_\_\_\_  
(Age in years )

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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?

( )

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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)  
 Don't know (END)
- 

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)

( )

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

- Yes  
 No  
 Don't know
- 

Data Entry Person: \_\_\_\_\_

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TO BE COMPLETED BY CLINICAL SITE:

DATE: \_\_\_\_\_ INITIALS: \_\_\_\_\_  
ADMINISTRATION: \_\_\_\_\_