ABBREVIATED FOLLOW-UP GENERAL HISTORY (F13a)

Chronic Kidney Disease in Children (CKiD)
SECTION A: GENERAL INFORMATION

A1. PARTICIPANT ID: AFFIX ID LABEL OR ENTER NUMBER IF ID LABEL IS NOT AVAILABLE

|__| - |__|__| - |__|__|__|

A2. CKiD VISIT #: ___ ___

A3. FORM VERSION: _1_ _0_ / _0_ _1_ / _1_ _2_

A4. DATE OF VISIT: ___ ___/ ___ ___/ ___ ___ ___ ___
   M M D D Y Y Y Y

A5. INTERVIEWER'S INITIALS: ___ ___ ___

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

Yes**………………………** 1

No**………………………..** 2

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 child's family background and family medical history since their last study visit. I am going to ask you a series of questions. 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.

If at any point in the interview you want me to stop, let me know. As with all study information, your responses will be kept strictly confidential, and the responses you provide will in no way affect your child's clinical care. The first set of questions asks about you and your child's background. If you have trouble understanding anything I say, stop me and I will re-read the question.

Are you ready to begin?

SECTION B: INFORMATION ABOUT YOU

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

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

Mother**………………….………….....**	1	→ **(Skip to C1)**
Father**.………………………………….**	2	→ **(Skip to C1)**
Legal Guardian**.……………………….**	3	→ **(Skip to C1)**
Self	5	→ **(Skip to C1)**
Other**.……………………………….**	4	

a. If **OTHER,** specify your relationship: _____

(Such as: grandmother, stepfather, uncle, etc.)

SECTION C: CHILD'S EDUCATION

The following questions are about the child's education. Specifically, the next question asks about the highest grade the child has completed. For example, if the child is currently in the 12th grade, then enter "11", or if the child is currently in the 6th grade, then enter "5". In addition, if the child is in the 1st grade, kindergarten or not yet in school, then enter "0".

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

___ ___Grade

Don't Know**……………………………….**   -8

C2.   Does (*name of child*) attend school outside of the home?

Yes**………………………….....**   1

No**……………........................**   2   → **(Skip to D1)**

C3.   During the past school year, approximately how many days has (*name of child*) missed from school because of not feeling well?

___ ___ Days

Don't Know**……………………………….**   -8

The next two questions refer to service(s) the child 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 child received during the past school year.

C4.   Does (name of child) 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. REFER TO QXQ FOR DETAILED DESCRIPTION.)

Yes**………………………………..**   1

No**…………………………….....**   2

Don't Know**……………………………….**   -8

C5. Does (name of child) 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. REFER TO QXQ FOR DETAILED DESCRIPTION.)

Yes**…………………………………..** 1

No**…………………………….....** 2

Don't Know**…………………………….** -8

SECTION D: CHILD'S FAMILY AND PRIMARY HOUSEHOLD

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

D1. What is the current relationship between (*name of child*) **biological parents**?

Not married, living together**…..…………….** 1

Married, living together**…...........................** 2

Married, separated**…………………………** 3

Widowed**……………..…………………......** 4

Divorced**………………………………......** 5

Never married, not living together **…………** 6

Refuse to answer**…………………………..** -7

Don't Know**…………………………………** -8

The following questions ask about the child's <u>primary household</u>. The <u>primary household</u> is the home in which the child lives at least half of the time.

D2. How many days per week does (*name of child*) live in the primary household?
Indicate a number between 4 and 7.

____ days

Don't Know**………………………………….** -8

D3. How many people (including *name of child*), live in the primary household at least half the time?

___ ___ people

Don't Know**………………………………….** -8

D4. How many adults live in the primary household at least half the time? <u>An adult</u> 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

Don't Know**………………………………….** -8

D5.   Which of the following adults (18 years or older) live in the primary household at least half the time? **(Circle "Yes", "No" or "Don't Know" for EACH of the following.)**

		Yes	No	Don't Know
a.	Birth Mother**.............................**	1	2	-8
b.	Birth Father**.............................**	1	2	-8
c.	Step Mother/ Adoptive Mother**...............**	1	2	-8
d.	Step Father/ Adoptive Father**................**	1	2	-8
e.	Other**.....................................**	1	2 **(Skip to D5)**	-8 **(Skip to D5)**
	i. Specify: _____			

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**…………………………………...............**   1
No**……………………………………………**   2
Don't Know**……………………………………..**   -8

Deleted Questions D7 and D8.

> **For D9: ALLOW RESPONDENT TO CIRCLE THE NUMBER IN THE FAR RIGHT COLUMN THAT CORRESPONDS TO THEIR TOTAL INCOME.**

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 child*) primary household, by year, month, or week. Do **NOT** include social security, disability insurance, or other governmental assistance. **Circle** the number in the FAR RIGHT COLUMN that corresponds to the total income.

YEAR	MONTH	WEEK	
$6,000 OR LESS**.............**	$500 OR LESS**..................**	$115 OR LESS**...............**	1
$6,001 TO $12,000**.........**	$501 TO $1,000**..................**	$116 TO $231 **...............**	2
$12,001 TO $18,000**..........**	$1,001 TO $1,500**..............**	$232 TO $346 **.................**	3
$18,001 TO $24,000**..........**	$1,501 TO $2,000**..............**	$347 TO $461 **.................**	4
$24,001 TO $30,000**.........**	$2,001 TO $2,500**..............**	$462 TO $577 **.................**	5
$30,001 TO $36,000**..........**	$2,501 TO $3,000**..............**	$578 TO $692 **.................**	6
$36,001 TO $75,000**..........**	$3,001 TO $6,250**..............**	$693 TO $1442 **...............**	7
MORE THAN $75,000**.......**	MORE THAN $6,250**.........**	MORE THAN $1442**........**	8

D9a. What is the current employment status of (*name of child*) MOTHER (including birth, adoptive or stepmother) in the **primary household**?

Working full-time (35 hours or more per week)……	1	
Working part-time (less than 35 hours per week)…	2	
Unemployed but seeking work…….……………....	3	→ **Skip to D9b**
Unemployed not seeking work…….……………...	4	→ **Skip to D9b**
Student……………………………………………...	5	→ **Skip to D9b**
Retired……………………………………………....	6	→ **Skip to D9b**
Disability………………………………….…………	7	→ **Skip to D9b**
No such person in household/Not Applicable…….	-1	→ **Skip to D9b**
Don't Know……………………………….…………..	-8	→ **Skip to D9b**

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

Yes……………………………………..................	1
No……………………………………………………	2
Don't Know……………………………………..	-8

D9b. What is the current employment status of (*name of child*) FATHER (including birth, adoptive or stepfather) in the **primary household**?

Working full-time (35 hours or more per week)……	1	
Working part-time (less than 35 hours per week)…	2	
Unemployed but seeking work…….……………....	3	→ **Skip to D9c**
Unemployed not seeking work…….……………...	4	→ **Skip to D9c**
Student……………………………………………...	5	→ **Skip to D9c**
Retired……………………………………………....	6	→ **Skip to D9c**
Disability………………………………….…………	7	→ **Skip to D9c**
No such person in household/Not Applicable…….	-1	→ **Skip to D9c**
Don't Know……………………………….…………..	-8	→ **Skip to D9c**

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

Yes…………………………………….................…….	1
No………………………………………………………	2
Don't Know……………………………………..………	-8

D9c. What is the current employment status of (*name of child*)?

Working full-time (35 hours or more per week)......	1	
Working part-time (less than 35 hours per week)...	2	
Unemployed but seeking work.............................	3	→ **Skip to D10**
Unemployed not seeking work.............................	4	→ **Skip to D10**
Student...	5	→ **Skip to D10**
Retired...	6	→ **Skip to D10**
Disability..	7	→ **Skip to D10**
Not Applicable	-1	→ **Skip to D10**
Don't Know...	-8	→ **Skip to D10**

    i.   Is (*name of child*) self-employed?

Yes.. 1

No... 2

Don't Know.. -8

D10. What is the current zip code of the child's **primary household** (i.e., the home in which the child lives at least half of the time)?

___ ___ ___ ___ ___ ___

Don't Know... -8

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

Yes... 1 **(Skip to D12)**

No.. 2

Don't Know... -8 **(Skip to Section F)**

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

___ ___ months

Don't Know... -8

    b.   What was the zip code of the child's previous primary household?

___ ___ ___ ___ ___ ___

Don't Know... -8

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

___ ___ . ___ years **(Skip to Section F)**

Don't Know... -8 **(Skip to Section F)**

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

___ ___ . ___ years

Don't Know... -8

Deleted Section E.

SOME OF THE FOLLOWING QUESTIONS MAY BE EMBARASSING TO THE CHILD. ASK THIS SECTION OF QUESTIONS WHEN THE CHILD IS NOT IN THE ROOM .

SECTION F: CHILD'S DEVELOPMENTAL HISTORY

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

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

Yes**……………………………….............** 1 → **(Skip to F4)**
No**……………………………………………** 2

F2.   a. Is (*name of child*) currently older than 5 years of age?

Yes**……………………………….............** 1 → **(Skip to F2c)**
No**……………………………………………** 2

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

Yes**……………………………….............** 1 → **(Skip to F3)**
No**……………………………………………** 2
Don't Know**…………………………………** -8 → **(Skip to F3)**

c. Was (*name of child*) breast-fed?

Yes**……………………………….............** 1
No**……………………………………………** 2 → **(Skip to F3)**
Don't Know**…………………………………** -8 → **(Skip to F3)**

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

Age ___ ___   1 = years
                2 = months
                3 = weeks
                4 = days
Don't Know**……………………………………** -8

F3.   Is (*name of child*) currently bottle-fed?

Yes**……………………………….............** 1 → **(Skip to F4)**
No**……………………………………………** 2
Don't Know**……………………………….....** -8 → **(Skip to F4)**

a. Was (*name of child*) bottle-fed?

Yes**……………………………….............** 1
No**……………………………………………** 2 → **(Skip to F4)**
Don't Know**……………………………….....** -8 → **(Skip to F4)**

b. How old was (*name of child*) when he/she was weaned from bottle feeding?
(Please circle "1" for years, "2" for months, "3" for weeks or "4" for days)
Age ___ ___ 1 = years
2 = months
3 = weeks
4 = days
Don't Know **……………………………….....** -8

**FOR QUESTION F4 – F5, PLEASE PAY CLOSE ATTENTION TO THE SKIP PATTERNS.
FOLLOW EACH SKIP PATTERN CAREFULLY. IT IS IMPORTANT TO ANSWER EACH QUESTION
ACCORDING TO THE SKIP PATTERN.**

F4. In the past year, has *(name of child)* had any wetness or leakage of urine (accidents) during the day or night?

Yes**……………………………….................** 1
No**………………………………………** 2 → **(Skip to c)**
Don't Know**……………………………….....** -8 → **(Skip to c)**

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

Yes**……………………………….................** 1

No**………………………………………** 2

Don't Know**……………………………….....** -8

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

Yes**……………………………….................** 1

No**………………………………………** 2

Don't Know**……………………………….....** -8

c. In the past year, has *(name of child)* catheterized the bladder (i.e., put a tube in the bladder)?
Yes**……………………………….................** 1

No**………………………………………** 2 → **(Skip to F5)**

Don't Know**……………………………….....** -8 → **(Skip to F5)**

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

Yes**……………………………….......** 1

No**……………………………………..** 2

Don't Know**………………………………** -8

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

Yes**……………………………….......** 1

No**……………………………………..** 2

Don't Know**………………………………** -8

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

Yes**…………………………….............** 1 → **(END Form)**
No**………………………………………** 2
Don't Know**…………………………….....** -8 → **(END Form)**

  a. Is (*name of child*) currently toilet trained?

Yes**…………………………….............** 1
No**………………………………………** 2 → **(END Form)**
Don't Know**…………………………….....** -8 → **(END Form)**

  b. When was (*name of child*) toilet trained?
Age ___ ___ years

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

Yes**…………………………….............** 1
No**………………………………………** 2 → **(Skip to d)**
Don't Know**…………………………….....** -8 → **(Skip to d)**

    i. Does bed-wetting still occur?

Yes**…………………………….............** 1 → **(Skip to iii)**
No**…………………………….............** 2
Don't Know**………………………..** -8 → **(Skip to c)**

    ii. At what age did bed-wetting stop?
(Please circle "1" for years and "2" for months)
Age ___ ___   1 = years
            2 = months
Don't Know**……………………………..** -8

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

Yes**...** 1
No**...** 2
Don't Know**...** -8

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

Yes**………………………………………................** 1
No**………………………………………………** 2 → **(END Form)**
Don't Know**………………………………….....** -8 → **(END Form)**

   i. Does bed-soiling still occur?

     Yes**………………………………….......** 1 → **(Skip to iii)**
     No**…………………………………….....** 2
     Don't Know**……………………………..** -8 → **(END Form)**

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

     Don't Know**……………………………..** -8

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

     Yes**…………………………………….......** 1
     No**…………………………………………..** 2
     Don't Know**………………………………..** -8

Deleted Questions F6, F7, F8, F9 and Section G.

TO BE COMPLETED BY CLINICAL SITE:

DATE: ___ ___/ ___ ___/ ___ ___ ___ ___   **INITIALS:** ___ ___ ___
       M   M / D   D / Y   Y   Y   Y

ADMINISTRATION: **1 = Interviewer Assisted**
(Circle "1", "2" or "3")   **2 = Self-Administered**
                         3 = Both