FOLLOW-UP MEDICAL HISTORY (F14)

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 1 / 0 1 / 1 0

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:

Now, I am going to ask you questions about your child's health history. I will be asking you a series of questions about the current and past diseases that your child may have had in the past year. 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. Finally, I need to re-emphasize that all your answers are confidential, and the responses you provide will in no way affect your child's clinical care. The first set of questions asks about your child's kidney disease. Throughout the questionnaire, I am going to use the words "health care provider" to mean any doctor, nurse, physician assistant or nurse practitioner the child has ever seen. If you have trouble understanding anything I say, stop me and I will re-read the question.

SECTION B: KIDNEY DISEASE

B1. In the past year, has *(name of child)* been seen by a Urologist (adult or pediatric)?

Yes..... 1
No..... 2

PROMPT: IF ANY OF B2 – B3 = YES, THEN COMPLETE THE MEDICAL ABSTRACTION TRACKING FORM (MAT).

B2. In the past year, has (*name of child*) had a urologic procedure, including surgery to treat his or her kidney problems?

Yes ..... 1 **(Complete MAT)**
No 2
Don't Know ..... -8

B3. In the past year, has (*name of child*) had a genetic test (i.e., Podocin or Nephrin) performed to help diagnose his or her kidney disease?

Yes ..... 1 **(Complete MAT)**
No 2
Don't Know ..... -8

B4. In the past year, has a healthcare provider diagnosed (*name of child*) with a kidney infection with a fever?

Yes 1
No ..... 2 **(Skip to B5)**
Don't Know ..... -8 **(Skip to B5)**

a. In the past year, how many times did he/she have a kidney infection with a fever?

___ ___ times

Don't Know..... -8

B5. Is participant a female?

Yes..... 1
No..... 2 **(Skip to C1)**

B6. In the past year, has (*name of child*) started her menses (i.e. period)?

Yes..... 1
No..... 2 **(Skip to C1)**
Don't Know..... -8 **(Skip to C1)**

a. How old was she when she started her first period?

___ ___ years of age

Don't Know..... -8

SECTION C: GENERAL MEDICAL HISTORY

The next set of questions asks about diseases, other than kidney disease, that your child may currently have or that your child has had in the past year.

In the past year, has a doctor or any other healthcare professional told you that (*name of child*) has any of the following diseases?

PROMPT: IF ANY OF C1 – C4 = YES, THEN COMPLETE THE MEDICAL ABSTRACTION TRACKING FORM (MAT).

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

	Yes	No	Don't Know
C1. GENERAL / METABOLIC DISEASE			
a. Diabetes Mellitus (Sugar Diabetes, High Blood Sugar)	1	2	-8
b. Sickle Cell Disease	1	2	-8
c. Auto-immune Disease (Lupus, Rheumotid Arthritis)	1	2	-8
C2. CARDIOVASCULAR DISEASE			
a. Hypertension (High blood pressure)	1	2 **(Skip to C2b)**	-8 **(Skip to C2b)**
i. If hypertensive, what is the status?			
Continued problem…… 1			
Resolved problem…….... 2			
Controlled with medication…… 3			
b. Heart Failure (Congestive heart failure)	1	2	-8
c. Stroke	1	2	-8
C3. LUNG DISEASE			
a. Asthma	1	2	-8
b. Chronic Lung Disease	1	2	-8
c. Bronchopulmonary Dysplasia (BPD)	1	2	-8
C4. GENITOURINARY DISEASE			
a. Urinary Tract Infections	1	2	-8
b. Blood in urine	1	2	-8
c. Protein in urine	1	2	-8
d. Passage of kidney stones	1	2	-8
e. Recurrent pain on urinating	1	2	-8
C5. INFECTIOUS DISEASE			
a. Hepatitis	1	2 **(Skip to C5b)**	-8 **(Skip to C5b)**
1. If yes, has a doctor or any other healthcare professional told you in the past year that (name of child) has had any of the following types of hepatitis?			
i. Type A	1	2	-8
ii. Type B	1	2	-8
iii. Type C	1	2	-8
iv. Other Type(s)	1	2 **(Skip to C5b)**	-8 **(Skip to C5b)**
Specify:_____			
b. Other Infection(s)	1	2 **(Skip to C6)**	-8 **(Skip to C6)**

Specify:_____

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

		Yes	No	Don't Know
C6.	CANCER			
a.	Leukemia	1	2	-8
b.	Lymphoma	1	2	-8
c.	Bone Cancer	1	2	-8
d.	Liver Cancer	1	2	-8
e.	Soft Tissue Sarcoma	1	2	-8
f.	Other	1	2 **(Skip to C7)**	-8 **(Skip to C7)**
	Specify:_____			
C7.	NEUROPSYCHIATRIC DISEASE			
a.	Attention Deficit Disorder (ADD)	1	2	-8
b.	Attention Deficit Hyperactivity Disorder (ADHD)	1	2	-8
c.	Depression	1	2	-8
d.	Learning Disability other than ADD or ADHD	1	2	-8
e.	Anxiety Disorder	1	2	-8
f.	Other	1	2 **(Skip to C8)**	-8 **(Skip to C8)**
	Specify:_____			
C8.	CHILDHOOD ILLNESSES			
a.	Measles	1	2	-8
b.	German Measles	1	2	-8
c.	Mumps	1	2	-8
d.	Chickenpox	1	2	-8
e.	Tuberculosis	1	2	-8
f.	Whooping Cough	1	2	-8
g.	Scarlet Fever	1	2	-8
h.	Rheumatic Fever	1	2	-8
i.	Diphtheria	1	2	-8
j.	Meningitis	1	2	-8
k.	Encephalitis	1	2	-8
l.	Anemia	1	2	-8
m	Fever above 104° for greater than 2 days.	1	2	-8
n.	Head injury	1	2	-8
o.	Coma or loss of consciousness	1	2	-8

Please indicate whether (*name of child*) has or has had any of the following problems in the past year.

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

		Yes	No	Don't Know
C9.	NEUROLOGICAL			
	a. Seizures/Convulsions	1	2	-8
	b. Speech Defects	1	2	-8
	c. Accident Prone	1	2	-8
	d. Bites Nails	1	2	-8
	e. Sucks Thumb	1	2	-8
	f. Grinds Teeth	1	2	-8
	g. Twitches/Tics	1	2	-8
	h. Bangs Head	1	2	-8
	i. Rocks Back and Forth	1	2	-8
	j. Bowel Movements in Bed/Pants	1	2	-8
C10.	HEARING			
	a. Ear Infections	1	2	-8
	b. Hearing Problems	1	2	-8
	c. Ear Tubes	1	2	-8
C11.	VISION			
	a. Vision Problems	1	2	-8
	b. Wears Glasses/Contacts	1	2	-8
	c. Color Blind	1	2	-8

SECTION D: ORTHOPEDIC HISTORY

The next set of questions asks about any orthopedic injuries your child may currently have or that your child has had in the past year. Orthopedic injuries are injuries to the bones.

		Yes	No	Don't Know
D1.	In the past year, has a doctor or any other health professional told you that (name of child) has had any broken bones?	1	2 **(Skip to D2)**	-8 **(Skip to D2)**

a. Please indicate which of the following bones (name of child) has broken.

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

		Yes	No	Don't Know
1.	Skull	1	2	-8
2.	Neck	1	2	-8
3.	Back	1	2	-8
4.	Shoulder	1	2	-8
5.	Arm/Elbow	1	2	-8
6.	Wrist/Hand	1	2	-8
7.	Hip	1	2	-8
8.	Knee	1	2	-8
9.	Ankle	1	2	-8
10.	Foot	1	2	-8
11.	Leg	1	2	-8
12.	Fingers	1	2	-8
13.	Toes	1	2	-8
14.	Ribs	1	2	-8
15.	Collar Bone	1	2	-8

D2. Does (*name of child*) have any bone disease in the hips?

Yes ..... 1 **(Complete MAT)**
No ..... 2 **(Skip to F1)**
Don't Know ..... -8 **(Skip to F1)**

a. Was the bone disease diagnosed within the past year?
Yes ..... 1 **(Complete MAT)**
No 2
Don't Know ..... -8

SECTION F: HEALTHCARE UTILIZATION

Now, I am going to ask you about all the places your child may have received care in the past year.

F1. In the past year, where has (*name of child*) gone to receive medical care? **(Please circle "Yes" or "No" for EACH of the following places.)**

Did (name of child) go to…

		Yes	No
a.	A clinic or health care center	1	2
b.	A private doctor's office	1	2
c.	Hospital Outpatient Department	1	2
d.	The emergency room in a hospital	1	2 **(Skip to e)**
	1. How many times has (name of child) received care at the emergency room in the past year? ___ ___		
e.	Some other place	1	2 **(Skip to F2)**
	1. Please specify: _____		

At this time, I am going to ask you some questions about your child's use of health care. In this set of questions, I am going to use the words "health care provider" to mean any doctor, nurse practitioner, or physician assistant you may go to for medical care.

F2. In the past year, how many times did (*name of child*) see a health care provider, not including this CKiD study visit or the visit at which you were screened for eligibility into the study? Include well child visits, sick visits and ER visits. **Do not include** times when (name of child) was hospitalized overnight.

___ ___ times

Don't Know..... -8

F3. In the past year, when you or (*name of child*) went for medical care, did he/she usually (more than half of the time) see the same health care provider or group of providers for his/her medical appointments?

Yes 1
No 2

Don't Know..... -8

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The next questions ask about hospitalizations. Being hospitalized includes staying overnight or being admitted for a procedure that was done in one day. Please include all medical and psychiatric hospitalizations in the past year. This does not include being treated in the emergency room and then released the same day.

F4. In the past year, has (*name of child*) been hospitalized (apart from when he or she was born)? Do not include overnight stays in the emergency room.

Yes	1	**(Complete MAT)**
No	2	**(Skip to F5)**
Don't Know	-8	**(Skip to F5)**

a. How many different times was (*name of child*) hospitalized in the past year?
___ ___ times

Don't Know ..... -8

Now, I am going to ask you some questions about care or social services that your child may have received in the past year.

F5. In the past year, has (*name of child*) been seen by a social worker or a case manager to help him/her obtain services?

Yes	1
No	2

F6. In the past year, has (*name of child*) received care or services from a psychologist, psychiatrist, psychiatric nurse, counselor, or other mental health professional?

Yes	1
No	2

F7. In the past year, has an agency assisted (*name of child*) with food, such as food stamps or WIC, meals on wheels, food pantries, or arranged to have groceries delivered to your child's primary household (i.e., the home in which the child lives at least half of the time)?

Yes	1
No	2

F8. In the past year, has a social service agency helped you or (*name of child*) find a place to live?

Yes	1
No	2

F9. In the past year, has (*name of child*) received care from a dentist or dental hygienist?

Yes	1
No	2

F10. In the past year, has (*name of child*) seen a nutritionist or a dietician?

Yes	1
No	2

SECTION G: HEALTH INSURANCE

Now I am going to ask you questions about your child's health care coverage.

G1. Does (*name of child*) currently have any kind of health insurance or health care coverage? This includes both private and public insurance programs (e.g., Medicaid, SCHIP or MCHIP), dental insurance, and programs that help pay for medications.

Yes **…….....** 1 **(Skip to G1b)**
No **…….....** 2

G1a. How long has it been since (name of child) last had ANY health insurance or coverage?

6 months or less **…….....** 1 **(skip to G14)**
More than 6 months, but now more than 1 yr ago**……** 2 **(skip to G14)**
More than 1 year, but no more than 3 years ago**……..** 3 **(skip to G14)**
More than 3 years**……** 4 **(skip to G14)**
Never had health insurance or coverage**……** 5 **(skip to G14)**
Don't know**……** -8 **(skip to G14)**

G1b. In the past year, was there any time when (name of child) was not covered by ANY health insurance or coverage?

Yes **…….....** 1
No **…….....** 2 **(skip to G2)**

G1c. In the past year, about how long was (name of child) without ANY health insurance or coverage?

__ __ 1 = months 2 = weeks 3 = days

G1d. In the past year, was (name of child) not covered by ANY insurance or coverage due to medical cost?

Yes **…….....** 1
No **…….....** 2

INSTRUCTIONS:	**ASK QUESTIONS G2 - G15. IF THE RESPONSE IS YES, CIRCLE "1" AND ASK QUESTION "A" (FAR RIGHT COLUMN) UNLESS THE BOX IS SHADED.**			
Does (*name of child*) currently have...	YES	NO	**NA**	**A.** Do you or your family members pay for any of the insurance premium? YES NO
G2. *CALIFORNIA ONLY: Medi-CAL?	1	2	**99**	
G3. *MARYLAND ONLY: Medical Assistance?	1	2	**99**	
G4. ALL STATES EXCEPT CALIFORNIA and MARYLAND: Medicaid?	1	2	**99**	
G5. Private Health Insurance plan from employer or workplace?	1	2 **(Skip to G6)**		1 2
G6. Private Health Insurance plan purchased directly?	1	2 **(Skip to G7)**		1 2
G7. Private Health Insurance plan through a state or local government program or community program?	1	2 **(Skip to G8)**		1 2
G8. CHIP (Children's Health Insurance Program)?	1	2 **(Skip to G9)**		1 2
G9. Military Health Care/VA?	1	2 **(Skip to G10)**		1 2
G10. CHAMPUS or other veteran's health insurance?	1	2 **(Skip to G11)**		1 2
G11. Student Health Coverage?	1	2 **(Skip to G12)**		1 2
G12. State-Sponsored Health Plan?	1	2 **(Skip to G13)**		1 2
G13. Dental Insurance?	1	2		
G14. Vision Insurance?	1	2		
G15. Other types of health insurance? a. Specify _____ _____ _____	1	2 **(Skip to G16)**		

G16. Do any of these plans assist with prescriptions/medications?

Yes 1
No 2

G17. In the past year, has (name of child) been without needed prescription medication due to cost?

Yes	1
No	2
Don't Know	-8

G18. Do any of these health insurance plan(s) pay for both doctor visits and hospital stays?

Yes	1
No	2
Don't Know	-8

G19. In the past year, have you had difficulty filing claims and/or getting reimbursed for medical care?

Yes	1
No	2
Did not file any claims	-1
Don't Know	-8

G20. In the past year, how much of a problem, if any, was it to get care for (name of child) that you or a doctor believed necessary?

A big problem	1
A small problem	2
No problem	3
My child had not visits in the last year	-1
Don't Know	-8

G21. In the past year, how often did (name of child) doctors or other health providers **listen carefully to you**?

Never	1
Sometimes	2
Usually	3
Always	4
My child had not visits in the last year	-1
Don't Know	-8

G22. In the past year, how often did (name of child) doctors or other health providers **explain things** in a way you could understand?

Never	1
Sometimes	2
Usually	3
Always	4
My child had not visits in the last year	-1
Don't Know	-8

G23. In the past year, how often did (name of child) doctors or other health providers show **respect for what you had to say**?

Never	1
Sometimes	2
Usually	3
Always	4
My child had not visits in the last year	-1
Don't Know	-8

G24. In the past year, how often did doctors or other health providers **spend enough time** with you and (name of child)?

Never	1
Sometimes	2
Usually	3
Always	4
My child had not visits in the last year	-1
Don't Know	-8

We want to know your rating of all of (name of child) health care in the last year from all **doctors and other health providers**. Use **any number from 0 to 10** where 0 is the worst health care possible, and 10 is the best health care possible.

G25. How would you rate all (name of child) health care?

0 Worst health care possible	0
1	1
2	2
3	3
4	4
5	5
6	6
7	7
8	8
9	9
10	10
My child had not visits in the last year	-1
Don't Know	-8

SECTION H: RENAL REPLACEMENT THERAPY

H1. Have you ever discussed renal replacement therapy (i.e., dialysis or transplantation) with your nephrologist or health care provider?

Yes	1	
No	2	**(END)**
Don't know.....	-8	**(END)**

H2. In the past year, have you discussed renal replacement therapy with your nephrologist or health care provider?

Yes	1	
No	2	

H3. Was dialysis discussed?

Yes	1	
No	2	**(skip to H5)**

H4. Which modality is preferred?

Hemodialysis	1
Peritoneal dialysis.....	2
No Preference.....	3

H5. Was transplantation discussed?

Yes	1	
No	2	**(END)**

H6. Which donor option(s) has/have been discussed?

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

	Yes	No	Don't Know
Living Donor.....	1	2	-8
Deceased Donor.....	1	2	-8

H7. Has child been listed for deceased donor transplantation?

Yes	1	
No	2	**(END)**

a. Date listed: ___ ___/ ___ ___/ ___ ___ ___ ___ ← **SITE SHOULD CONFIRM DATE**

M M / D D / Y Y Y Y

TO BE COMPLETED BY CLINICAL SITE:

DATE: ___ ___/ ___ ___/ ___ ___ ___ ___
M M / D D / Y Y Y Y

INITIALS: ___ ___ ___

ADMINISTRATION:
(Circle "1", "2" or "3")

1 = Interviewer Assisted
2 = Self-Administered
3 = Both

Was the date listed on DECEASE DONOR LIST CONFIRMED by site:
1 = YES
2 = NO

Chronic Kidney Disease in Children