Medical History

Chronic Kidney Disease in Children (CKiD)

SECTION A: GENERAL INFORMATION

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, select the number that best matches the respondent's answer. Select -8 for "Don't Know" responses. If a participant declines to answer a question, choose -7 to the right of the response choice(s). For missing data, choose -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:

The following questions are about the participant's health history, including information about the current and past diseases that the participant 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.

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 participant's kidney disease. Whenever the term "health care provider" is used, it means any doctor, nurse, physician assistant or nurse practitioner the participant has ever seen. If you have trouble understanding anything, please feel free to ask for further clarification.

SECTION B: KIDNEY DISEASE

B1. When did the mother or another family member first become aware of (name of participant) kidney problem?

◯ During Pregnancy
◯ After Pregnancy
◯ Don't know

B3. How old was (name of participant) when you or another family member first became aware of his/her kidney problem?

_____
(_____)

B4. How old was (name of participant) when he or she was first seen by a pediatric nephrologist?
(Please select "1" for years, "2" for months, "3" for weeks or "4" for days.)

_____
(_____)

B5. Has (name of participant) been seen by a Urologist (adult or pediatric)?

◯ Yes
◯ No

a. How old was (name of participant) when he or she was first seen by a Urologist (adult or pediatric)? (Select circle "1" for years, "2" for months, "3" for weeks or "4" for days.)

_____
(_____)

B6. What were the methods/procedures performed to determine the primary diagnosis of (name of participant) with chronic kidney disease?

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

Kidney Biopsy _____
Ultrasound/sonogram _____
Voiding Cystourethrogram (VCUG) _____
Nuclear Medicine Study (i.e., DMSA, DTPA, MAG3) _____
Intravenous Pyelogram (IVP) _____
Magnetic Resonance Imaging (MRI) _____
Computed Tomography Scan (Cat/CT Scan) _____
Genetic Testing _____
Other _____
_____

PROMPT: IF ANY OF B7 - B8 = YES, THEN COMPLETE THE MEDICAL ABSTRACTION TRACKING FORM (MAT).

B7. Has (name of participant) had a urologic procedure, including surgery to treat his or her kidney problems?

◯ Yes
◯ No
◯ Don't know

B8. Has (name of participant) had a genetic test (i.e., Podocin or Nephrin) performed to help diagnose his or her kidney disease?

◯ Yes
◯ No
◯ Don't know

B9. Has a healthcare provider ever diagnosed (name of participant) with a kidney infection with a fever?

◯ Yes
◯ No
◯ Don't know

a. How many times did he/she have a kidney infection with a fever in his/her first year of life?

_____
(times)

b. How many times did he/she have a kidney infection with a fever during the last year?

_____
(times)

B10. Is participant a female?

◯ Yes
◯ No

B11. Has (name of participant) started her menses (i.e. period)?

◯ Yes
◯ No
◯ Don't know

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

_____
(years of age)

Has a doctor or any other healthcare professional told you that (name of participant) had or has developed any of the following diseases/illnesses?

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

C1.

GENERAL / METABOLIC DISEASE:

a.

Diabetes Mellitus

(Sugar Diabetes, High Blood Sugar)

_____
b.

Sickle Cell Disease

_____
c.

Auto-immune Disease
(Lupus, Rheumatoid Arthritis)

_____
C2.

CARDIOVASCULAR DISEASE:

a.

Heart Failure (Congestive heart failure)

_____
b.

Stroke

_____
c.

Left Ventricular Hypertrophy (LVH)/

Thickened Heart Muscle

_____
C3.

LUNG DISEASE:

a.

Asthma

_____
b.

Chronic Lung Disease

_____
c.

Bronchopulmonary Dysplasia (BPD)

_____
C4.

GENITOURINARY DISEASE:

a.

Urinary Tract Infections

_____
b.

Blood in urine

_____
c.

Protein in urine

_____
d.

Passage of kidney stones

_____

e.

Recurrent pain on urinating

_____

C5.

GASTROINTESTINAL DISEASE:

a.

Gastroenteritis (stomach flu, food poisoning)

_____

b.

Gastroesophageal Reflux (GERD)

_____

c.

Gastrointestinal Ulcer

_____

d.

Gastrointestinal Bleeding

_____

e.

Liver Inflammation Non-Infectious

_____

f.

Fatty Liver

_____

g.

Irritable Bowel

_____

h.

Encopresis (constipation)

_____

C6. Has a doctor or healthcare professional told you that (name of participant) has hypertension (high blood pressure) or that (name of participant) should take medicine to lower blood pressure?

◯ Yes
◯ No
◯ Don't know

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a. What is the status of (name of participant's) high blood pressure (i.e., hypertension)?

◯ Taking medicine but BP still high (Continued problem)
◯ No longer has high blood pressure (Resolved problem)
◯ Taking medicine and BP no longer high (Controlled w/ meds)

b. Was the hypertension diagnosed within the past year?

◯ Yes
◯ No
◯ Don't know

C7. Has a doctor or healthcare professional told you that (name of participant) has hepatitis?

◯ Yes
◯ No
◯ Don't know

a. Which of the following types of hepatitis does (name of participant) have?

Type A _____
Type B _____
Type C _____
Other type _____
_____

b. Was the hepatitis diagnosed within the past year?

◯ Yes
◯ No
◯ Don't know

C8. Has a doctor or healthcare professional told you that (name of participant) has any other infection(s)?

◯ Yes
◯ No
◯ Don't know

Specify Other Infection:

_____

a. Was the infection diagnosed within the past year?

◯ Yes
◯ No
◯ Don't know

Please indicate whether (name of participant) has or has had any of the following problems.

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

C9. CANCER

a.

Leukemia

_____

b.

Lymphoma

_____

c.

Bone Cancer

d.

Liver Cancer

_____

e.

Skin Cancer

_____

f.

Soft Tissue Sarcoma

_____

g.

Other

_____

_____

C10. NEUROPSYCHIATRIC DISEASE

a.

Attention Deficit Disorder (ADD)

_____

b.

Attention Deficit Hyperactivity Disorder (ADHD)

_____

c.

Depression

_____

d.

Learning Disability other than ADD or ADHD

_____

e.

Anxiety Disorder

_____

f.

Other

_____

_____

C11. CHILDHOOD ILLNESSES

a.

Measles

_____

b.

German Measles

_____

c.

Mumps

_____
d.

Chickenpox

_____
e.

Tuberculosis

_____
f.

Whooping Cough

_____
g.

Scarlet Fever

_____
h.

Rheumatic Fever

_____
i.

Diphtheria

_____
j.

Meningitis

_____
k.

Encephalitis

_____
l.

Anemia

_____
m.

Fever above 104° for greater than 2 days

_____
n.

Head injury including brain bleed

_____
o.

Coma or loss of consciousness

_____
p.

Other

_____
_____

C12. NEUROLOGICAL

a.

Seizures/Convulsions

_____
b.

Speech Defects

_____
c.

Accident Prone

_____
d.

Bites Nails

_____
e.

Sucks Thumb

_____
f.

Grinds Teeth

_____
g.

Twitches/Tics

_____
h.

Bangs Head

_____
i.

Rocks Back and Forth

_____
j.

Bowel Movements in Bed/Pants

_____
C13. HEARING

a.

Ear Infections

_____
b.

Hearing Problems

_____
c.

Ear Tubes

_____
C14. VISION

a.

Vision Problems

_____

b.

Wears Glasses/Contacts

_____

c.

Color Blindness

_____

SECTION D: ORTHOPEDIC HISTORY

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

D1. Has a doctor or any other health professional told you that (name of participant) has had any broken bones?

◯ Yes ◯ No ◯ Don't know

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

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

1. Back _____
2. Shoulder _____
3. Arm/Elbow _____
4. Wrist/Hand _____
5. Hip _____
6. Knee _____
7. Ankle _____
8. Foot _____
9. Leg _____
10 Fingers _____
11. Toes _____
12. Ribs _____
13. Collar Bone _____

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

◯ Yes
◯ No
◯ Don't know

a. Was the bone disease diagnosed within the past year?

◯ Yes
◯ No
◯ Don't know

F1. In the past year, where has (name of participant) gone to receive medical care?

(Please select "Yes" or "No" for EACH of the following places.)

Did (name of participant) go to...

a.

A clinic or health care center (not a part of a hospital building)

_____

b.

A private doctor's office (not a part of a clinic or hospital)

_____

c.

Hospital Outpatient Department

_____

d.

The emergency room

_____
_____
e.

Some other place

_____
_____

These questions ask about the participant's use of health care. In this set of questions, the term "health care provider" means any doctor, nurse practitioner, or physician's assistant you may go to for medical care.

F2. In the past year, how many times did (name of participant) 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 participant) was hospitalized overnight.

_____
(times)

F3. In the past year, when you or (name of participant) 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
◯ No
◯ Don't know

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. This does not include being treated in the emergency room and then released the same day.

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

◯ Yes
◯ No
◯ Don't know

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

_____
(times)

These questions ask some questions about care or social services that the participant may have received in the last year.

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

◯ Yes
◯ No

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

◯ Yes
◯ No

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

◯ Yes
◯ No

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

◯ Yes
◯ No

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

◯ Yes
◯ No

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

◯ Yes
◯ No

SECTION G: HEALTH INSURANCE

These questions ask about the participant's health care coverage.

G1. Does (name of participant) 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
◯ No

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

◯ 6 months or less
◯ More than 6 months, but no more than 1 year ago
◯ More than 1 year, but no more than 3 years ago
◯ More than 3 years
◯ Never had health insurance or coverage
◯ Don't know

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

◯ Yes
◯ No

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

_____
(_____)

G1d. In the past year, was (name of participant) not covered by ANY insurance or coverage?

◯ Yes
◯ No

INSTRUCTIONS: ASK QUESTIONS G2 - G15. IF THE RESPONSE IS YES, SELECT "1" AND ASK QUESTION "A" (FAR RIGHT COLUMN) UNLESS THE BOX IS SHADED.

Does (name of participant) currently have... A. Do you or your family members pay for any of the insurance premium?

G2. *CALIFORNIA ONLY:

Medi-CAL? _____

G3. *MARYLAND ONLY:

Medical Assistance?

_____

G4. ALL STATES EXCEPT CALIFORNIA and MARYLAND: Medicaid? _____
G5. Private Health Insurance plan from employer or workplace? _____ _____
G6. Private Health Insurance plan purchased directly? _____ _____
G7. Private Health Insurance plan through a state or local government program or community program? _____ _____
G8. CHIP (Children's Health Insurance Program)? _____ _____
G9. Military Health Care/VA? _____ _____
G10. CHAMPUS or other veteran's health insurance? _____ _____
G11. Student Health Coverage? _____ _____
G12. State-Sponsored Health Plan? _____ _____
G13. Dental Insurance? _____
G14. Vision Insurance? _____
G15. Other types of health insurance? _____
_____

G16. Do any of these plans help pay for prescriptions/medications?

◯ Yes
◯ No
◯ Not applicable / No Insurance

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

◯ Yes
◯ No
◯ Not applicable / No Insurance
◯ Don't know

G18. Does the participant's health insurance plan(s) help pay for both doctor visits and hospital stays?

◯ Yes
◯ No
◯ Don't know

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

◯ Yes
◯ No
◯ Did not file any claims / No insurance
◯ Don't know

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

◯ A big problem
◯ A small problem
◯ No problem
◯ My child had not visits in the last year
◯ Don't know

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

◯ Never
◯ Sometimes
◯ Usually
◯ Always
◯ My child had no visits in the last year
◯ Don't know

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

◯ Never
◯ Sometimes
◯ Usually
◯ Always
◯ My child had no visits in the last year
◯ Don't know

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

◯ Never
◯ Sometimes
◯ Usually
◯ Always
◯ My child had no visits in the last year
◯ Don't know

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

◯ Never
◯ Sometimes
◯ Usually
◯ Always
◯ My child had no visits in the last year
◯ Don't know

G25. We want to know your rating of all of (name of participant) 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.
How would you rate all (name of participant) health care?

◯ 0 Worst healthcare possible
◯ 1
◯ 2
◯ 3
◯ 4
◯ 5
◯ 6
◯ 7
◯ 8
◯ 9
◯ 10
◯ My child had no visits in the last year
◯ Don't Know

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
◯ No
◯ Don't know

H2. In the past year, have you discussed dialysis or kidney transplant with your nephrologist or health care provider?

◯ Yes
◯ No

a. Did you discuss the type of dialysis (hemodialysis or peritoneal) or who would donate a kidney (living or deceased donor) with your nephrologist?

◯ Yes
◯ No

H3. Was dialysis discussed?

◯ Yes
◯ No

H4. Which modality is preferred?

◯ Hemodialysis
◯ Peritoneal dialysis
◯ No preference

H5. Was kidney transplantation discussed?

◯ Yes
◯ No

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

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

Living Donor _____
Deceased Donor _____

H7. Has child been listed for deceased donor transplantation?

◯ Yes
◯ No

a. Date listed:

_____

Data Entry person:

_____

TO BE COMPLETED BY CLINICAL SITE:

Date: _____ INITIALS: _____
ADMINISTRATION: _____